"Making my own path": Journeys of emerging adults with cerebral palsy

Nicole Louise Sharp
University of Wollongong

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“Making my own path”: Journeys of emerging adults with cerebral palsy

Nicole Louise Sharp

Supervisors:
Professor Anne Cusick
Doctor Rosalind Bye
Professor Iona Novak

This thesis is presented as part of the requirement for the conferral of the degree Doctor of Philosophy

This research has been conducted with the support of the Australian Government Research Training Program Scholarship

From
The University of Wollongong
School of Health and Society
Faculty of Social Sciences

August 2018
Abstract

Emerging adulthood has been identified as a unique developmental stage within developed countries. Generally associated with ages 18-25, emerging adulthood is seen as a time of: identity exploration; instability; self-focus; a sense of feeling in-between; and possibilities. It is a time of profound change when people develop, review and update their plan for the future. While emerging adulthood is a journey of significant change and transition for all young people, it may be even more challenging for young people with a lifelong disability such as cerebral palsy (CP). This research aimed to address significant gaps in knowledge around the individual stories of emerging adults with CP from their own perspective, and their collective experiences. It also aimed to critically examine the relevance of both developmental and disability frameworks to the experiences of emerging adults with CP. To achieve this aim, the theory of emerging adulthood (Arnett, 2000) and the International Classification of Functioning, Disability and Health (ICF, World Health Organisation, 2001) underpinned this study.

A qualitative, narrative inquiry guided by the methodological approaches of Donald Polkinghorne (1988; 1995) was undertaken with eighteen participants with CP aged 18-25 years who lived in New South Wales, Australia (mean age 21 years; 11 male, 7 female; 11 metropolitan, 5 regional, 2 rural). Severity and type of CP varied. Multiple in-depth unstructured interviews were conducted with each person to explore their experience of emerging adulthood. Interviews continued until participants each felt they had ‘told their story’.

Narrative analysis provided valuable insights into the lives of the eighteen emerging adults: what was important to them, their experiences, activities, life roles and goals, and the impact of a range of environmental and personal factors on their experience. In this study step, each person’s narrative was constructed in detail to present their story of emerging adulthood. Variation across these individual stories highlighted the uniqueness of personal journeys of emerging adulthood, reinforcing the methodological appropriateness and conceptual importance of capturing individual narratives.

Insights from the collective experience of participants were gleaned using inductive, paradigmatic analysis of narratives. This study step identified fifteen themes presenting concepts existing within and across the stories. These themes provided detail regarding the journey of emerging adulthood for these young people with CP. This stage of analysis revealed that participants viewed this time of life as a path or road they were travelling to the valued destination of adulthood.
In addition, deductive *analysis of narratives* was utilised to explore whether the theoretical constructs of the theory of emerging adulthood (Arnett, 2000) and the ICF were reflected within the experiences of participants.

In terms of the theory of emerging adulthood, participants’ stories aligned with key features of this developmental theory, revealing that young people with CP strive for many of the goals proposed as normative for other 18-25 year old peers. Many participants were experiencing some of the five key features of emerging adulthood, with “identity exploration” in particular apparent in most stories. There were however, participant stories characterised by the absence of one or more of the defining features of emerging adulthood. Where “instability” for example could be expected, participants had stability; where “self-focus” could be expected for peers, fewer opportunities to be self-focused, or restricted life possibilities due to factors often out of participants’ control occurred for these young people with CP.

In terms of the ICF, the stories of emerging adults with CP featured descriptions of experiences, perceived as positive and negative by participants, across the ICF domains of activities and participation, with a particular emphasis on study, work, and social and civic life. The impact of personal factors including resilience, coping style, and financial status on activity and participation was apparent with stories describing these factors. Story content relating to body structure and body function was notable for its absence. For all participants story content was dominated by discussions of environmental factors; identifying what they were and how some acted as facilitators, but how most were barriers. Environmental factors acting as barriers included: negative assumptions by other people; pre-judgement by other people; discrimination; inaccessible environments; and inflexible services.

This study is the first time that the stories of emerging adults with CP have been documented using narrative methodology. The findings provide lived-experience evidence to help inform policy, planning of services and support. Interventions and resources should be directed to provide greater opportunities for young people with CP to experience a journey of emerging adulthood that reflects *their* goals and concerns at this time of life. Recommendations for theory, research, policy, and service provision are made in the thesis, with the hope that emerging adults with CP in the future will have increased opportunities to ‘make their own path’ at this critical time of life.
Dedication

“If you want to know me, then you must know my story, for my story defines who I am”

Dan P. McAdams, 1993, p. 11

This work is dedicated to the eighteen young people with cerebral palsy who let me into their lives. Thank you for the privilege.

And to Cooper - I cannot wait to see how your journey turns out.
Acknowledgements

It is hard to know where to start when I think about all of the people that have contributed to the long and challenging, but equally rewarding journey that has been my PhD. The process of telling the stories of others, along with all that has happened in my own life during that process, has led to immense changes in my own story; to my goals, priorities, and view of the world. I am forever indebted, first and foremost, to the eighteen young people with CP who so willingly opened their lives to me. It was a privilege to spend time with each of you and to learn from you.

This PhD would not have happened without the support, guidance, incredible knowledge and, especially, patience of my amazing supervisors. To Anne, thank you for your generosity, wisdom, experience and unwavering belief in my ability to complete this work. With every new challenge, every new life crisis I faced during the course of this research, you never once questioned that I would finish. Being believed in by you made it much easier, to believe in myself. To Ros, you were the one who first ignited my passion for research, and especially for taking the time to hear the stories of others. I also watched you research while raising a young family, and I learnt much from you about the importance of perspective. Your support in the final stages particularly has meant everything to me. Thank you so much. To Iona, I would never have found my amazing participants without your support, guidance and renowned presence within the field. Thank you for believing in this research and in the power of stories, for helping me learn everything I know about cerebral palsy, and so much of what I know about research.

This thesis would not have come to fruition without the support of a number of close friends and colleagues; the people in my life who truly understand how challenging it is, because they have been there. Some started before me, some together, and some after. They have mostly finished before me, but we all share this journey. To Bree, Sarah, Nerida, Katie, and Nikki I am so grateful for your friendship, support and the opportunities to talk with people who really ‘get it’. Bree and Sarah, the final stage would never have ended without your help, support, encouragement and “intervention”, thank you so much.

Lastly, to my amazing family. To mum and dad, who have always believed in me, I don’t know what I would do without you. Thank you for the endless support, the meals, the childcare, the proof-reading, the mowing so I didn’t have to, and everything else you do without a second thought. You have supported and encouraged my learning throughout my life and I would never have come this far without you backing me every step of the way. To Matt, for all of your love and support throughout the last most difficult stages of this journey, for bringing me wine and chocolate, and most importantly for believing in me. And to Cooper, my beautiful, clever, funny, inquisitive, challenging and amazing 7 year old boy who arrived during this PhD, I love you with all my heart. I cannot imagine life without you; you are the reason for everything I do. I promise I will turn the computer off more often now.

This research has been conducted with the support of the Australian Government Research Training Program Scholarship, for which I am very grateful.
Certification

I, Nicole Louise Sharp, declare that this thesis submitted in fulfilment of the requirements for the conferral of the degree Doctor of Philosophy, from the University of Wollongong, is wholly my own work unless otherwise referenced or acknowledged. This document has not been submitted for qualifications at any other academic institution.

Nicole Louise Sharp

Date: 30th August 2018
# List of Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full text</th>
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<tbody>
<tr>
<td>ACT</td>
<td>Australian Capital Territory</td>
</tr>
<tr>
<td>COAG</td>
<td>Council of Australian Governments</td>
</tr>
<tr>
<td>CP</td>
<td>Cerebral palsy</td>
</tr>
<tr>
<td>DDA</td>
<td>Disability Discrimination Act</td>
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<tr>
<td>DES</td>
<td>Disability Employment Service</td>
</tr>
<tr>
<td>DSP</td>
<td>Disability Support Pension</td>
</tr>
<tr>
<td>EA</td>
<td>Emerging adulthood</td>
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<tr>
<td>FTFI</td>
<td>Face-to-face interview</td>
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<tr>
<td>GMFCS</td>
<td>Gross Motor Function Classification System</td>
</tr>
<tr>
<td>HSC</td>
<td>Higher School Certificate</td>
</tr>
<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
</tr>
<tr>
<td>MACS</td>
<td>Mobile Attendant Care Service</td>
</tr>
<tr>
<td>NDIS</td>
<td>National Disability Insurance Scheme</td>
</tr>
<tr>
<td>NSW</td>
<td>New South Wales</td>
</tr>
<tr>
<td>OECD</td>
<td>Organisation for Economic Cooperation and Development</td>
</tr>
<tr>
<td>OH&amp;S</td>
<td>Occupational Health and Safety</td>
</tr>
<tr>
<td>TAFE</td>
<td>Technical and Further Education</td>
</tr>
<tr>
<td>TPC</td>
<td>Tertiary Preparation Certificate</td>
</tr>
<tr>
<td>UK</td>
<td>United Kingdom</td>
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<tr>
<td>UN</td>
<td>United Nations</td>
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<tr>
<td>USA</td>
<td>United States of America</td>
</tr>
</tbody>
</table>
# Table of Contents

Abstract ............................................................................................................................... ii  
Dedication ............................................................................................................................. iv  
Acknowledgements .............................................................................................................. v  
Certification .......................................................................................................................... vi  
List of Abbreviations .......................................................................................................... vii  
Table of Contents ............................................................................................................... viii  
List of Figures .................................................................................................................... xiv  
List of Tables ...................................................................................................................... xiv  

## Chapter 1. The story begins: Introduction ................................................................. 1  
1.1 Background to the problem ....................................................................................... 1  
1.2 Introducing emerging adulthood ............................................................................. 2  
1.3 Approaches to understanding disability ................................................................. 4  
1.4 Introducing cerebral palsy ....................................................................................... 6  
1.5 Emerging adults with CP: What we know ............................................................... 8  
1.6 The research problem: Where is their voice? ......................................................... 12  
1.7 Narrative approaches to giving voice: Hearing their stories .................................. 13  
1.8 Scope of the research ............................................................................................. 14  
1.9 Synopsis and overview of the thesis ....................................................................... 15  

## Chapter 2. The story so far: Literature review ......................................................... 17  
2.1 Introduction ............................................................................................................... 17  
2.2 A developmental perspective: Emerging adulthood .............................................. 18  
   2.2.1 Emerging adulthood: Developmental context and critique ............................. 18  
   2.2.2 What is emerging adulthood? .......................................................................... 22  
   2.2.3 What does positive emerging adulthood look like? ...................................... 30  
   2.2.4 When does emerging adulthood end: What is adulthood? ........................... 32  
   2.2.5 Emerging adulthood in vulnerable populations .......................................... 35
Chapter 2. A perspective on health and disability: The ICF

2.3 A perspective on health and disability: The ICF

2.3.1 Constructs and key values of the ICF

2.3.2 Utilisation and critique of the ICF

2.3.3 The ICF as a conceptual framework

2.4 Cerebral palsy

2.4.1 Definition

2.4.2 Aetiology

2.4.3 Incidence

2.4.4 Characteristics of CP: Body functions and structures

2.4.5 Medical and health management of body structures and function

2.5 Emerging adults with CP: Activities and participation

2.5.1 Communication, mobility, self-care and domestic life

2.5.2 Relationships, social and civic life

2.5.3 Major life areas: Education, training and employment

2.6 Emerging adults with CP and the environment

2.6.1 Support, relationships, and attitudes

2.6.2 Services, systems and policies

2.6.3 Physical environment, products and technology

2.7 Personal factors influencing experiences of emerging adults with CP

2.7.1 Character and coping styles

2.7.2 Social background

2.8 What we don’t know: The research problem

2.9 Synopsis

Chapter 3. Storytelling: Research Design and Methods

3.1 Introduction

3.2 A constructivist research perspective

3.3 Methodological focus: Narrative inquiry

3.3.1 Narrative analysis and analysis of narratives

3.3.2 Approach to narrative inquiry in the present study

3.3.3 Narrative inquiry to reveal experiences of disability

3.4 Participant recruitment and selection
Chapter 5. Journeys of emerging adults with CP: Story themes and theoretical connections

5.1 Introduction

5.2 Summary presentation of themes and theoretical connections

5.3 Detailed presentation and discussion of themes and theoretical connections

5.3.1 The journey to find myself: Identity exploration

5.3.2 Dealing with roadblocks: Resilience

5.3.3 Supporting others’ journeys: Altruism

5.3.4 It’s a hard road: Mental health problems

5.3.5 Telling others about my journey: Disclosure

5.3.6 Finding my place: Friendships

5.3.7 My journey is limited: Romantic relationships

5.3.8 Changing direction and help with navigation: Education pathways

5.3.9 A bumpy road: Finding the right job

5.3.10 Controlling my journey: Negotiating an adult relationship with parents

5.3.11 My crew: Personal care and health services
5.3.12 The open road or a traffic jam: Transport options .........................282
5.3.13 Funding my journey: Opportunity costs ...........................................285
5.3.14 Off the beaten track: The limits of a rural location .........................287
5.3.15 Are we there yet?: Clarifying what it means to be adult .................289
5.4 Synopsis ....................................................................................................291

Chapter 6. The point of the story: Discussion and conclusion .....................293

6.1 Introduction ...............................................................................................293
6.2 Summary of findings ..................................................................................294
  6.2.1 Research question 1 ............................................................................294
  6.2.2 Research question 2 ............................................................................297
  6.2.3 Research question 3 ............................................................................300
6.3 Bringing the findings together ....................................................................301
6.4 Discussion of key contributions .................................................................304
  6.4.1 A unique journey towards adulthood: “Making my own path” ........304
  6.4.2 Collective stories of emerging adults with CP reveal 15 themes, offering new insights into diverse experiences .................................................306
  6.4.3 Extending the theory of emerging adulthood in relation to people with CP .................................................................................................307
  6.4.4 The ICF helps facilitate a detailed understanding of factors influencing the journeys of emerging adults with CP ........................................311
  6.4.5 Understanding the lives of vulnerable people through narrative inquiry methods ..........................................................................................313
6.5 Implications and recommendations ............................................................315
  6.5.1 Implications for the theory of emerging adulthood .........................315
  6.5.2 Implications for research with people with disability .......................316
  6.5.3 Methodological implications for research with people with disability316
  6.5.4 Implications for disability policy and related research ....................317
  6.5.5 Implications for service provision .......................................................319
6.6 Strengths and limitations ..........................................................................320
  6.6.1 Limitations of the sample ....................................................................321
  6.6.2 Limitations in data collection ...............................................................322
6.6.3 Limitations in design ................................................................. 323
6.7 The story ends for now: Conclusion ........................................... 323

References ................................................................. 325

Appendix A: Recruitment advertisement ........................................ 364
Appendix B: Participant information statement .............................. 365
Appendix C: Participant consent form ............................................. 368
Appendix D: Interview guide ......................................................... 370
Appendix E: Published manuscript .................................................. 371
Appendix F: Example of analysis of narratives ................................. 382
Appendix G: Ethics approval: Western Sydney University ............... 383
Appendix H: Ethics approval: Cerebral Palsy Alliance .................... 384
Appendix I: Ethics approval: University of Wollongong ................. 385
Appendix J: Mapping of themes against theoretical constructs ......... 387
Appendix K: List of publications and conference presentations related to PhD Candidature ................................................................. 395
List of Figures

Figure 1: ICF Framework........................................................................................................................40
Figure 2: Themes within emerging adults’ collective stories.........................................................243
Figure 3: Key research finding: “Making my own path”.................................................................303

List of Tables

Table 1: Definition of key ICF concepts...............................................................................................41
Table 2: Gross Motor Function Classification System – description and incidence of GMFCS Levels........................................................................................................................50
Table 3: Objects of the Disability Discrimination Act.......................................................................88
Table 4: Convention on the Rights of Persons with Disabilities – general principles.........................89
Table 5: Demographic details of participants.....................................................................................119
Table 6: Number, time period and format of interviews..................................................................130
Table 7: Summary of theoretical constructs reflected within themes..............................................244-247
Table 8: Superscript codes used to identify theoretical constructs within themes.248
Chapter 1. The story begins: Introduction

1.1 Background to the problem

When I started initial planning for this research as a naive new graduate occupational therapist, my idea was to study the transition of young people with cerebral palsy (CP) from paediatric to adult healthcare services. As a health professional I thought this was very important and healthcare transition was a “buzz word” in the literature – researchers and clinicians alike were focusing on the importance of ensuring a smooth transition. I realised no one had taken the time to ask young people with CP themselves how they experienced this transition, and this became the gap my research was to fill. I spent so much time focusing on this narrow topic that what I later realised was almost a surprise. On reflection, and through spending more time with people with disabilities in both my personal and work lives, I realised that most likely they would not want to talk about healthcare much at all! Did I, as an emerging adult myself, want to talk about trips to the doctor or other health professionals? Of course not...so why such a focus for young people with disabilities? Was it not more important to find out their stories of emerging adulthood as a whole? Whether they experienced this life stage in a similar way to young people without disabilities? Should they not be the ones to tell us what was important to them? And with this reality check, a totally different research study was born.

This research is all about stories; stories of emerging adulthood; stories of CP; stories of growing up and moving towards adulthood as a person who happens to have CP. Through this research we hear the participants’ stories from their own perspectives, learn about their experiences and their goals, and start to understand a fuller picture of their lives. Access to healthcare and healthcare transition does come into their stories, but it is definitely not the whole story. This research has emerged into something very different to what I first imagined...just as my own
emerging adulthood turned out very differently to how I anticipated it. I have learnt so much from the young people who opened their lives to me – about CP, about what it means to be an emerging adult who happens to have a disability – about life. I feel blessed that they told me what they really thought – what was really important to them - and I am glad that I took the time to listen.

The story begins in this chapter with an introduction to emerging adulthood, a contemporary life-stage as described in a growing body of research. It moves on to consider different approaches to the exploration of disability and stories of CP. What we know about emerging adults with CP is detailed and the paucity of their own voices and stories within current literature is explored as the key research problem. A narrative approach to overcoming the omission of young people’s voices is described, along with the scope of the research. Lastly, an overview of the thesis is presented.

1.2 Introducing emerging adulthood

Emerging adulthood has been identified as a unique developmental period marking the transition from adolescence to young adulthood in the 21st century. This is particularly the case for young people in developed countries (Arnett, 2000a) such as Australia, where this study took place. When Jeffrey Arnett first provided evidence of this new life stage in 1997, he defined it as roughly the period between the ages of 18 and 25 (Arnett, 1997). More recent research provides evidence that it may extend as far as age 29 (Arnett & Schwab, 2012; Arnett, Zukauskiene, & Sugimura, 2014; Tanner, 2011), although in the current study participants were aged 18-25, in line with current thinking at the time of data collection.

Emerging adulthood is a time of frequent change, when young people explore possible ways of living. Emerging adulthood is a time when the making of long-term choices and decisions is delayed in favour of exploration in the areas of work, residence, love and world views (Arnett, 2000a). Emerging adults are in the process of developing the skills, knowledge and qualities socially constructed by their
culture as signifying the arrival of adulthood (Arnett, 1997, 1998). Emerging adulthood is a time when young people strive to accept responsibility, make independent decisions, become financially independent, decide on their own personal beliefs, and develop an equal relationship with their parents. That is, they strive to become self-sufficient (Arnett, 1994, 1998; Arnett & Galambos, 2003; Nelson & McNamara Barry, 2005).

Arnett has articulated five key features of the period of emerging adulthood. It is seen as a time of identity exploration, when young people explore various options in terms of “what kind of person to be and what kind of life to live, specifically in the areas of love relationships, work, and ideology” (Arnett et al., 2014, p. 570). It is a time of instability, when young people make frequent changes, particularly in relationships, love, work and living arrangements (Arnett, 2014). Emerging adulthood is also seen to be a self-focused age, whereby young people have fewer commitments and obligations to others, in comparison to childhood, adolescence and adulthood. There are few rules, and freedom for emerging adults to make their own decisions, build their independence and self-sufficiency, prior to making enduring commitments to others during adulthood (Arnett, 2011, 2014, 2015; Arnett et al., 2014). The fourth feature of emerging adulthood is that it is a time of feeling in-between, when most young people feel they are on the way to adulthood, but not there yet. It is a gradual process that has been described as “long and winding” (Arnett, 2014, p. 159). Lastly, emerging adulthood is a time of possibilities and optimism, when most young people have high hopes and expectations for their life as they recognise many different futures are open to them (Arnett, 2004).

Evidence now exists to support the relevance of emerging adulthood to broad population groups in a range of countries, including Australia (Griffin, Cusick, & Sharp, 2007; Johnstone & Lee, 2012; Sharp, Cusick, & Griffin, 2017; Weier & Lee, 2015). There is however, recognition in literature that understandings need to be developed regarding how vulnerable groups of young people experience this life stage (Cote, 2006). Hinton and Meyer (2014) specifically highlighted the gap in
knowledge around how individuals with disability experience emerging adulthood, while Cote (2006) identified the need to understand the experience of people with disabilities, disadvantaged and socially marginalised young people, immigrants and people from cultural minorities, and young people in developing countries. He highlighted that identifying what can be done to ameliorate negative experiences, and enhance positive ones, during emerging adulthood for these vulnerable young people should be a priority (Cote, 2006). Arnett reflected on this in the context of young people aging out of foster care; he identified that it is likely most of this group do experience emerging adulthood, but that the way they experience it may be different and more difficult than for other emerging adults (Arnett, 2007a).

The current study employs Arnett’s conceptualisation of emerging adulthood to reflect upon the experiences of young people from another vulnerable group, those with disability, specifically cerebral palsy. In doing so this study contributes to addressing the gap in knowledge highlighted by both Cote (2006) and Hinton and Meyer (2014). More detailed information about emerging adulthood is presented in Chapter Two. The following section introduces various approaches to understanding the experience of disability.

1.3 Approaches to understanding disability

Over recent decades, there have been significant shifts in approaches to service delivery, research and policy in disability. Throughout much of the twentieth century, the emphasis was on a medical model. The medical model views disability as the result of some physiological impairment which requires the treatment of the individual. The overall view of the medical model is that the person can be “altered” while the environment is “unalterable” (Llewellyn & Hogan, 2000, p. 158). Services based on the medical model rarely involved people with disabilities as active participants (Cott, 2004), and research based on the medical model was traditionally carried out on people, reinforcing disability as a problem within the individual (Bricher, 2000). The medical model has been criticised as not sufficiently encompassing all aspects of disability (Colyer, 2004; Llewellyn & Hogan, 2000).
In contrast to the medical model of disability, the social model defines disability as a construct of society, and views problems as being located in the practices of society, rather than in the impairment of the individual (Bickenbach, Chatterji, Badley, & Ustun, 1999; Oliver, 1996). The earliest description of the social model was by a small group of people with disabilities in 1976 who interpreted disability as a socio-political issue resulting from social oppression and discrimination (Barnes & Mercer, 1996). Their view was that “it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society” (The Union of the Physically Impaired Against Segregation, 1976, p. 3-4).

Later developments of the social model of disability accept that there is a medical element of disability, but reinforce that the impact of society on creating disadvantages for people with disabilities is more salient (Craddock, 1996a, 1996b; Marks, 1997). While the social model has received criticism based on a perceived inadequate recognition of the realities of impairment, proponents explain that this is due to a conceptual misunderstanding, as follows. Oliver (2004) states that the model does recognise the negative influence of impairment on a person’s function and participation, but emphasises “the social model is not about the personal experience of impairment, but rather about the collective experience of disablement” (Oliver, 2004, p. 22). He clarifies that:

In the broadest sense, the social model of disability is about nothing more complicated than a clear focus on the economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of impairment - whether physical, sensory or intellectual. The barriers disabled people encounter include inaccessible education systems, working environments, inadequate disability benefits, discriminatory health and social support services, inaccessible transport, houses and public buildings and amenities, and the devaluing of disabled people through negative images in the media (Oliver, 2004, p. 21).
It has now been recognised that it is possible to integrate the key concepts of both medical and social models and that they need not be mutually exclusive. This is referred to as a biopsychosocial approach and it aims to capture a synthesis of both perspectives (World Health Organisation, 2001). The International Classification of Functioning, Disability and Health (ICF) is one such conceptual framework adopting a biopsychosocial approach (http://www.who.int/classifications/icf/en/).

Unlike previous frameworks of disability and classifications, the ICF focuses on health and functioning, rather than on disability. In doing so, it avoids segregating people with disabilities from those people without disabilities, and recognises that all people may experience some level of disability (World Health Organisation, 2002). The ICF framework recognises the multidimensional nature of disability and the multidirectional interactions between body structures and functions, activities, and participation. Additionally, it reflects the social construction of health and disability by recognising environmental and personal contexts that may affect a person’s health and wellbeing (Bertoti & Moyers, 2004; Stewart & Rosenbaum, 2003). Disability is therefore seen as the outcome of not just a health condition and personal factors, but also external factors and circumstances in which a person lives. The ICF has been adopted internationally as the authoritative framework representing “our best understanding of the complex phenomena of functioning and of disability” (Cerniauskaite et al., 2011, p. 282), and for this reason has been adopted in the current study as a framework to assist in understanding the stories of emerging adults with cerebral palsy. More detailed information is presented about the ICF in Chapter Two.

The following sections introduce cerebral palsy, and what we know of experiences of emerging adults who have CP.

1.4 Introducing cerebral palsy

Cerebral palsy is not a single condition, but rather a group of disorders. It is very diverse, in relation to both its aetiology, and types and levels of severity
(Rosenbaum, Paneth, Levinton, Goldstein, & Bax, 2007). CP excludes conditions that are transient, but secondary impairments may lead to changes in function over time. It occurs at a time when motor development is not yet well established; before, during or in the first two years after birth. CP affects gross and fine motor functioning and organisation, and arises from a causal pathway of events which are no longer active at the time of diagnosis (Rosenbaum et al., 2007).

Cerebral palsy is the most common physical disability in childhood. The birth prevalence internationally is 2.1 cases per 1000 live births (Oskoui, Coutinho, Dykeman, Jetté, & Pringsheim, 2013). In relation to aetiology, there is rarely one risk factor, but rather an interaction between a range of risk factors resulting in the development of CP (Nelson & Chang, 2008). These risk factors include pre-conception factors (e.g. maternal seizures, history of miscarriage, low socio-economic status, older maternal age); antenatal risk factors (e.g. birth defects, perinatal infection, pre-eclampsia); intrapartum risk factors (e.g. breech presentation, hypoxic events); and neonatal factors (e.g. seizures, infections) (Blair & Stanley, 2002; McIntyre et al., 2012).

In relation to body functions and structures, CP is generally classified in three different ways: by motor type, by distribution and by severity of motor impairments and other associated impairments (Blair & Watson, 2006). While neuro-muscular and movement related impairments are central to CP, there is also a high incidence of associated impairments. These include intellectual disability, speech impairment, sleep disorders, pain, epilepsy, excessive drooling, behaviour problems, bladder control problems, displaced hips, and sensory impairments (Novak, Hines, Goldsmith, & Barclay, 2012). Not surprisingly, these health problems continue to affect people with CP into emerging adulthood and beyond, and a significant proportion will also experience deterioration in their gross motor function over time (Usuba, Oddson, Gauthier, & Young, 2014). What we know about the way in which the presence of CP impacts the activities and participation of emerging adults is now introduced, along with the environmental and personal factors contributing to their experience.
新兴成人与CP：我们所知道

虽然新兴成人与CP被认为是经历相同的发展过程，与没有残疾的同龄人共享许多相同的挑战，希望和抱负（Ansari, Sheikh, Akhdar, & Moutaery, 2001），很明显，与CP相关的额外问题和困难使得成年过渡成为一个具有挑战性的过程。虽然没有研究在澳大利亚或国外能够以特定的目的是了解年轻CP在成年时的第一手故事和经验，一般研究在这一领域确实提供了一些关于他们的结果、体验和可能挑战的认识。与日常活动和参与相关的。

文献表明，新兴成人与CP可能在移动性、自我照顾和家务方面遇到挑战。在澳大利亚一项针对20-30岁人群的研究中，有一半可以独立行走，但只有35.5%独立进行自我照顾。参与者也更加可能与父母同住，而不是与一个基于人口的对照组（80%对21%）（Reddihough et al., 2013）。沟通困难是CP较严重人群的特定挑战，如果没有有效的沟通手段，年轻人就减少了“说出自己的想法”能力来做出关于他们生活重要决定的能力（Morris, 2001, p. 19）。

有限的现有研究关于人际关系、社会和公民生活同样识别了许多新兴成人与CP的挑战。他们参加的社交活动较少，社交接触减少，亲密关系较少，并且由于与CP相比，他们提供了较少的重要话题信息，如人际关系和性（Blum, Resnick, Nelson, & St Germaine, 1991; East & Orchard, 2014; Stevenson, Pharoah, & Stevenson, 1997; Wiegerink, Roebroeck, Donkervoort, Stam, & Cohen-Kettenis, 2006; Wiegerink, Roebroeck, et al., 2010）。严重或多重残疾的人，以及那些具有认知障碍的人，面临特别高的不利条件（Bottos, Feliciangeli,
Young people with CP are also more likely than their peers to have higher levels of dependence, lower levels of responsibility, less opportunities for decision making, and to be overprotected by parents (Blum et al., 1991). Many experience challenges finding and maintaining friendships and relationships. Teasing and bullying are commonly experienced, and the reduced capacity to be spontaneous in social activities has been found to be frustrating (Bjorquist, Nordmark, & Hallstrom, 2014). In one Australian case-control study only 20% of 20-30 year old participants with CP have ever been married or partnered, compared to 70% of a population control group (Reddihough et al., 2013). Few have participated in sexual activities, despite research showing they have the same level of sexual interest as their peers without disabilities (East & Orchard, 2014; McCabe, 1999; McCabe, Cummins, & Deeks, 2000; Wiegerink, Stam, et al., 2010).

With regard to the major life areas of education, training and employment, emerging adults with CP have significantly lower levels of educational attainment, and are much more likely to be unemployed (Reddihough et al., 2013). Barriers to employment identified by young people with disabilities in one qualitative study included a “hostile” labour market, discriminatory employers, limited support for personal assistance and difficulty earning enough to cover the additional support costs required (Hendey & Pascall, 2001, p. 14). Improving outcomes in this area is imperative because of the role employment plays in improving social inclusion, mental health, self-esteem, and quality of life (Cocks, Thoresen, & Lee, 2015; Merton & Bateman, 2007). Conversely, unemployment increases risk of poverty, distress, social exclusion and anxiety (Australian Council of Social Service, 2014).

It is now widely recognised that a person’s impairment is only one of a number of factors influencing the activities and participation of people with disability. Environmental and personal factors must also be addressed in order to facilitate
improved participation and inclusion of emerging adults with CP (Stewart, Gorter, & Freeman, 2013). Relevant environmental and personal factors are now introduced.

Literature indicates that it is environmental barriers that often impact on the capacity of emerging adults with CP to achieve their social, educational and employment goals. Environmental barriers including bullying, negative attitudes, discrimination, and a lack of physical access and transport options are all commonly experienced. Many young people rely on family for all social engagement, due to difficulties making friends (Morris, 2001). Many young people with disabilities report that the low expectation others hold of them can also be a barrier and that with limited opportunities to participate in mainstream community activities, there are few opportunities to challenge negative attitudes and misperceptions (Stewart et al., 2014).

Other environmental barriers include inadequate provision of information about resources and services which makes it difficult for young people to know what is available in the community (Darrah, Magill-Evans, & Adkins, 2002). This is reflected in a significant decrease in access to healthcare and other services after young people with CP leave school (Cathels & Reddihough, 1993; Ng, Dinesh, Tay, & Lee, 2003; Stevenson et al., 1997) and may be worsened by inadequate transition planning and support, a lack of coordination, and inadequate communication between service systems in the areas of health, education and employment (Betz, 2004; Brumfield & Lansbury, 2004; Meadows, Davies, & Beamish, 2014; Morris, 1999; Parker & Hirst, 1987; Stewart, 2006; Stewart, Law, Rosenbaum, & Willms, 2001). The lack of flexibility of community services has also been identified as a barrier to participation for people with disability (Hendey & Pascall, 2001), as has a lack of suitable accessible and flexible transport options (Darrah, Magill-Evans, & Galambos, 2010; Stewart et al., 2012), and poor accessibility of built environments (Law, Petrenchik, King, & Hurley, 2007).

Along with environmental factors, there is some limited evidence within the literature of personal factors influencing the experiences of emerging adults with
CP. In particular, traits, including self-confidence, self-esteem, self-concept, self-awareness and self-advocacy, are all seen to facilitate positive outcomes (Gannotti, Minter, Chambers, Smith, & Tylkowski, 2011; Magill-Evans & Restall, 1991; Stewart et al., 2014). Resilience is also identified as a valuable personal characteristic (Mannino, 2015; Stewart et al., 2014). Resilience has been defined as:

*an individual's tendency to cope with adversity better than expected; the process of becoming proactive rather than reactive in dealing with adversity; and having a positive outcome through the use of individual and environmental attributes also known as protective factors* (Mannino, 2015, p. e132)

Protective factors include such traits as assertiveness, enthusiasm, drive, and a positive attitude (Mannino, 2015). There is evidence that many young people with CP cope with barriers they face through sheer determination and perseverance to overcome them and prove their doubters wrong (King, Cathers, Polgar, MacKinnon, & Havens, 2000).

Another personal trait demonstrated by many emerging adults with disability, including CP, is a strong sense of altruism. Other research has identified that a desire to share knowledge with others with disabilities is common for young people with disability as they moved towards adulthood. Having overcome many barriers, and learning from their past experiences, many young people with disability want to share their learnings with others (Mannino, 2015). Lastly, socio-economic status and income levels also have the potential to influence the experiences and opportunities of emerging adults with CP. One Australian study with 20-30 year olds with CP found that this group have significantly lower personal income than their peers without disability, and that 83% received the disability support pension. For three quarters of these, the pension was their sole source of income (Reddihough et al., 2013).
1.6 The research problem: Where is their voice?

The current state of knowledge in relation to emerging adults with CP briefly introduced above was composed from a myriad of research papers, each contributing, but none providing, an overall picture and understanding of the stories of 18-25 year olds with CP from their own perspective. The current study aims to address this research gap. An understanding of the experiences of emerging adults aged 18-25 years with CP, from their own perspective, is well overdue. Individual stories need to be shared for the unique insights they offer, and key themes existing across stories need to be identified. The understanding of emerging adulthood from the perspective of 18-25 year olds with CP will illuminate an as yet neglected aspect of lifespan development theory and evidence. Stories of these young people will also provide data to show how the ICF, as a universal framework of health and health related domains, is evidenced in the context of everyday life of participants.

Through listening to the stories of emerging adults with CP, original findings will provide new perspectives that could help inform future service and system development with insights of lived experience. There is likely to be little benefit in continuing to attempt to improve health and disability service provision and address barriers to participation without first understanding the experiences, needs, goals and priorities of this group. The idea that young people should be directly involved in the development of services and systems that are designed to support them is not new. It has been said that “adult providers cannot assume full understanding of the problems confronting youths….thus, the search for effective interventions and solutions requires collaborative development and evaluation processes” (Ginsburg, Menapace, & Slap, 1997, pp. 929-930). We need to come to an understanding of young people’s self-perceptions of the impact of their condition on all aspects of their life, and the support and/or services they identify as important to helping them achieve their goals (Telfair, Alleman-Velez, Dickens, & Loosier, 2005).
It has been established that understanding experiences is a vital first step if we can hope to improve the relevance and effectiveness of services provided to emerging adults with CP in the future. So how, then, do we come to such an understanding? Polkinghorne (1988) argues that the only way to do so is by paying attention to the stories that people tell. These stories demonstrate the way that people make sense of, and create meaning in, their lives. If research fails to understand people’s lives then Polkinghorne (1988) argues it will also likely fail to address the real problems and needs people face. For this reason, a narrative approach was adopted for this research.

### 1.7 Narrative approaches to giving voice: Hearing their stories

A narrative approach involves the integration of events and human actions into a goal-directed story which is organised in terms of time (Polkinghorne, 1988, 1995). A thematic thread, or plot, is used to allow individual events and happenings to take on a “narrative meaning” (Polkinghorne, 1995, p. 5). Events and happenings are then “understood from the perspective of their contribution and influence on a specific outcome” (Polkinghorne, 1995, p. 5). In this way a complex range of events are woven together to make a single story which reveals greater meaning than when the individual events are viewed in isolation (Polkinghorne, 1988).

Narrative inquiry has been seen as a particularly useful method for understanding the lives of people whose experiences may be different from ‘normative’ expectations (Bruner, 1990; Mishler, 1991; Reissman, 1990, 1993). Thus, narrative inquiry was identified as the most appropriate method for use in this study, because of its ability to reveal the stories of emerging adults with CP, stories which may be different to the ‘normative’ experiences of emerging adults without a disability.
1.8 Scope of the research

This research contributes a new understanding of the experience of emerging adults aged 18-25 years with CP by eliciting and constructing their unique stories. In addition, it highlights the essence of these stories at the group level, through the development of themes within and across individual stories. Lastly, this research explores the extent to which the theoretical constructs of the theory of emerging adulthood and the ICF are reflected within these themes.

These aims were achieved through in-depth interviews and data analysis using multiple narrative inquiry approaches. Narrative analysis was used to construct individual stories. Inductive and deductive paradigmatic analysis of narratives were also used to develop themes, and explore the presence of theoretical constructs within themes, respectively. The stories of eighteen people aged between 18 and 25 years with CP from New South Wales (NSW) or the Australian Capital Territory (ACT), Australia were constructed and analysed. Results of this study provide new knowledge relevant to the development of services, policies and future research informed by the actual experiences and views of emerging adults with CP. The study findings provide an important starting point for future collaboration between emerging adults with CP and service providers, policy makers and researchers in the development and evaluation of new services and systems targeting the priorities of young people themselves.

This study cannot claim to represent the stories of all emerging adults with CP. The stories are those of eighteen young people collected over a two year period between late 2005 and late 2007. These young people were all emerging adults around the same point in time and in the same state, in the same country. The stories of emerging adults moving towards adulthood in a different state or country, with different systems and cultures, may be very different. Even within NSW and the ACT, there has been much change in policy and service approaches since the mid-2000s, along with huge advancements in technology. If these narratives were collected from emerging adults today they too may be quite different. Regardless,
this study represents the first to understand the stories of emerging adults with CP from their own perspective, and so contributes new knowledge to both developmental and disability literature.

Due to the constraints of collecting data for a defined doctoral research project, long-term follow-up with participants was not possible. It would have been highly informative to revisit each participant when they reached age 25, or even 30, to gain a perspective of their full story of emerging adulthood. This was not feasible within this study, however, the research did provide participants with the opportunity to be involved in multiple interviews over time, and so for many their stories do reflect some level of longitude. Participants were able to take the lead in deciding when they felt their story was complete. For some this was after the first interview, but for others multiple interviews took place over a period up to 20 months. They were able to provide updates and new interpretations based on their growing experiences.

1.9 Synopsis and overview of the thesis

This chapter has provided a background to and rationale for the study. This research tells the stories of emerging adults with CP from their own perspective, using a narrative inquiry approach that is informed, but not defined, by the theory of emerging adulthood and the ICF. Chapter Two provides a more detailed review of literature relevant to this study, including research on emerging adulthood, CP, what is known about the experiences of emerging adults with CP, and the contextual factors influencing those experiences. Through this critical analysis, a case is made for a greater understanding of the first-hand stories of emerging adults with CP, and the themes within and across these stories. The specific research questions to be answered by this study are presented.

The research design and methods used to gather, recount and analyse the stories of participants are explored in Chapter Three. Details are provided of narrative inquiry as the methodological focus, and of recruitment strategies. A profile of participants
is presented, along with an introduction to the researcher. The data collection method, in-depth interviews, and the procedures used during data collection and analysis are explained. Techniques utilised to ensure trustworthiness and ethics considerations are outlined.

Chapters Four and Five present the results of this research. Chapter Four presents the individual narratives of each of the 18 participants; told separately for the unique insights they offer. Chapter Five details the themes developed from these stories, and explores how the theoretical constructs of the theory of emerging adulthood and the ICF are reflected in these themes, and concurrently discusses these findings by comparing and contrasting them with existing literature.

Lastly, Chapter Six highlights the key findings and significance of the study in terms of its key contributions to knowledge. Discussion of prior research and scholarship highlights the impact of this research in addressing prior research gaps. Chapter Six also identifies the strengths and limitations of the research, and discusses implications for theory, research, policy, service provision, and education.
Chapter 2. The story so far: Literature review

2.1 Introduction

A life-span view of human development has been widely accepted for much of the second half of the twentieth century and beyond. Back as far as 1978 it was noted that “the pervasiveness of change throughout the life span has been empirically demonstrated” (Lerner & Ryff, 1978, p. 3). The view that humans continue to develop throughout their lives was initiated by the seminal work of Erik Erikson, whose psychosocial stages of human development encompassed eight sequential crises to be resolved during the entire life cycle (Erikson, 1950b). Significant theoretical work has continued since this time, including the work underpinning the current study; the theory of emerging adulthood (Arnett, 2000a). Emerging adulthood is a life stage now widely recognised as existing between adolescence and young adulthood for young people in developed countries, and is a time of major change and transition. Emerging adults who have a lifelong disability such as CP also face these significant changes. However, they may also face additional challenges at this time of life associated with their disability.

This chapter explores the current literature relevant to emerging adults with CP. Emerging adulthood is discussed in the context of human development, and the ICF introduced as a framework for exploring experiences of health and disability. Cerebral palsy is introduced, and what we know of the experience of emerging adults with CP analysed, framed by the ICF domains of body functions and structures, activities and participation, and environmental and personal factors. Finally, the research problem is detailed, and the research aims and questions introduced.
2.2 A developmental perspective: Emerging adulthood

Arnett, through his research of college students’ conceptions of the transition to adulthood (Arnett, 1994), is widely recognised as being the first to coin the term ‘emerging adulthood’. Since his seminal works, emerging adulthood has become widely accepted as a unique and distinct period of development existing between adolescence and young adulthood, particularly for young people in developed countries. The veracity of the concept is illustrated by the following: Arnett formally articulated his theory of a new life stage in the year 2000 (Arnett, 2000a), by August 2018 this article had been cited 11,099 times according to Google Scholar; the Society for the Study of Emerging Adulthood (http://ssea.org/) was established in 2007, and a journal *Emerging Adulthood* was established with the renowned international academic publishers Sage in 2013.

This section of the thesis introduces emerging adulthood in the context of human development, explains why emerging adulthood is seen to be different to adolescence and young adulthood, explores the five key features of this life stage, and analyses the defining characteristics which are an indication that a young person has reached adulthood.

2.2.1 Emerging adulthood: Developmental context and critique

Historically, research on the transition to adulthood has been based on an assumption that reaching adulthood could be defined by a series of events, including leaving home, finishing education, getting married, and having children (Arnett, 2014; Howard & Galambos, 2011). Interestingly, Arnett identified that researchers had not actually asked people how they think about adulthood, or what being an adult meant to them, so he decided to do so (Arnett, 2014). Through extensive interview-based and survey research he identified that people consistently believed it was not discrete events that marked entry into adulthood, but instead such outcomes as accepting responsibility for your actions and becoming financially independent (Arnett, 2014; Arnett & Schwab, 2012). Using a developmental systems perspective, another emerging adulthood researcher,
Tanner (2006), identified that the key processes undertaken during emerging adulthood can be described as “recentering”. Three key sequential processes are undertaken by individuals during this time: renegotiation of relationships with parents and others who they depended on during childhood and adolescence; exploring a range of opportunities and potential pathways; and committing to adult roles and responsibilities (Tanner, 2006). Arnett and Fishel (2013) later described these three processes as launching, exploring and landing. Successful recentering has been linked with the presence of resilience, social supports, self-determination and coping skills (Hinton & Meyer, 2014).

Arnett has identified a range of factors which he believes have contributed to the rise of a new life stage of emerging adulthood, particularly in developed countries. A key contributor has been the shift from a manufacturing-based economy to a services-based economy reliant on the use of information and technology. This has significantly increased enrolments in tertiary education, extending the time before people join the workforce (Arnett & Fishel, 2013; Arnett et al., 2014). Others have concurred with the significant increases in demand for education and training over recent decades (Furstenberg, Rumbaut, & Settersten, 2005; Fussell & Furstenberg, 2005). Other identified factors contributing to the rise of emerging adulthood include the sexual revolution, including the rise of sex outside of marriage and access to reliable contraception, broader opportunities for women, and people getting married and having children later in life (Arnett, 2007c, 2015; Arnett & Fishel, 2013; Arnett & Schwab, 2012). Australian Census data has confirmed the existence of these trends within Australian society. Between 1981 and 2001, such trends included people partnering and becoming parents later in life, and increasing labour force and post-secondary education participation of women (Martin, 2007).

The theory of emerging adulthood has not been without criticism. Indeed some have the opinion that the whole idea of aged-based life stages is obsolete and that research should instead focus on developmental processes across the whole life span (Baltes, Lindenberger, & Staudinger, 2006; Bynner, 2005; Hendry & Kloep,
Others have specifically criticised the theory of emerging adulthood, arguing that it is only relevant to certain groups of young people, in particular “affluent middle classes in Western societies” (Hendry & Kloep, 2007a, p. 76). In addition, authors have raised concerns that the theory does not sufficiently capture the variations existing between individuals and across cultures, is likely to become outdated, and has the potential to marginalise young people who do not experience emerging adulthood as a result of a lack of personal or familial resources (Cote, 2014; Hendry & Kloep, 2007a, 2010; Kloep & Hendry, 2014).

Hendry and Kloep (2010), in their qualitative research with 38 Welsh young people aged 17-20, identified that while some participants were experiencing emerging adulthood as Arnett describes it, others were better labelled ‘prevented adults’ as a result of disadvantage caused by a lack of resources, skills or opportunities. A third group were labelled ‘adults’ even at this young age, because they had experienced non-normative challenges that forced them to mature quickly, such as having to care for ill parents or early parenting. They conclude that while emerging adulthood is a relevant description of the experience of many young people, there are others whose pathways vary significantly and that the various economic, social and individual factors that influence experiences need to be further considered (Hendry & Kloep, 2010). Others have reported similar evidence of the influence of such factors as social class, poverty status, gender, ethnicity, immigration status, geographical location, and disability on experiences during the transition to adulthood (Jones, 2002; Konstam, 2007; Lee & Waithaka, 2017).

Arnett, however, is clear that emerging adulthood was never meant to be interpreted as a theory suggesting that everyone experiences this life stage in the same way. He states:

*think of emerging adulthood as one stage with many possible paths within it...most young people in developed countries experience emerging adulthood...but they experience it in a wide variety of ways depending on their culture, social class, gender, personality, individual life events, and other circumstances (Arnett, 2015, p. 26)*
Arnett argues that life stages still provide a useful framework for understanding development as long as it is understood that they depend on historical and cultural context and therefore are not “universal”, nor “uniform”; not everyone, everywhere, will experience a life stage in the same way (Arnett, 2014, p. 157). Although the majority of emerging adulthood research has been undertaken in the United States of America (USA), other research indicates its relevance in Australia (Griffin et al., 2007; Johnstone & Lee, 2012; Weier & Lee, 2015), a range of European countries (Buhl & Lanz, 2007; Vleioras & Mantziou, 2017), Argentina (Facio & Micocci, 2003), and Israel (Mayseless & Scharf, 2003). A recent review of the trends in empirical research about emerging adulthood found that the concept is now being explored in over 55 countries, indicating that emerging adulthood is now a global concept. However, much of this international research is in its early stages and much more research is needed to confirm its relevance across cultures and in other underrepresented groups (Swanson, 2016).

In relation to underrepresented groups, Arnett has found consistent evidence of the five features of emerging adulthood, and consistent views of the criteria for adulthood, across socio-economic groups, providing some evidence that emerging adulthood is not only relevant to the middle and upper class (Arnett, 2006a). Arnett does however recognise that in time the theory may become outdated, as have developmental theories of the 20th century, including those of Freud, Erikson and Piaget (Arnett, 2014). He asserts, however, that in the present time, “emerging adulthood is a normative period of development in industrialised societies that are moving rapidly toward a post-industrial, information and technology-based economy” (Arnett, 2007b, p. 81). He reinforces that the theory of emerging adulthood provides a useful guide for thinking and research on this age period, but emphasises that the heterogeneity of experiences needs also to be explored (Arnett, 2006b).

The terms older adolescence, emerging adulthood, and young adulthood, continue to be used somewhat interchangeably within literature. However, the term emerging adulthood is becoming more and more widely adopted. Arnett argues
that there are distinct differences between adolescence, emerging adulthood and young adulthood, worthy of emerging adulthood being recognised as a distinct phase of life. In comparison to emerging adulthood, adolescence is a time when young people are likely to still be in school, be minors under the law, and still going through puberty. In contrast to young adults in their thirties, most emerging adults have not yet made stable, long-term commitments in love relationships and work, instead they are still experiencing significant instability and frequent changes (Arnett et al., 2014). Developmentally too, there are specific changes that occur during emerging adulthood. These include cognitive maturation within the prefrontal lobe resulting in advances in executive functioning and behavioural and emotional maturation (Arnett & Taber, 1994; Tanner, 2006). This is reflected by emerging adults demonstrating, in comparison to adolescents, increased impulse control, increased emotional intelligence, reduced inappropriate behaviour, and an increased ability to prioritise, make decisions, resolve conflict and empathise (Arnett & Taber, 1994; Tanner, 2006).

In sum, despite the presence of critique, a significant and growing evidence base supports the existence of the period of emerging adulthood. It was therefore an obvious decision to explore this concept further in the current research with 18-25 year olds with CP. The theory of emerging adulthood is now explored in more detail.

2.2.2 What is emerging adulthood?

Emerging adulthood refers roughly to the period between the ages of 18 and 25. Research has shown that the majority of young people in this age group do not consider themselves as adults or adolescents, but rather as having reached adulthood in some respects while not in others (Arnett, 1997, 1998, 2000a, 2001; Arnett & Taber, 1994). More recent literature and research has demonstrated that the period of emerging adulthood may actually extend as far as age 29 (Arnett & Schwab, 2012; Arnett et al., 2014; Tanner, 2011), although in the current study participants were aged 18-25, in line with thinking at the time of data collection.
Arnett has identified five “features” of emerging adulthood; identity explorations, instability, self-focus, feeling in-between, and possibilities/optimism (Arnett, 2004, p. 8). The existence of five overarching features of emerging adulthood is not to say that all emerging adults experience these five features in the same way. In fact, evidence suggests wide variability in experiences and responses of young people to the emerging adulthood life stage (Nelson & Padilla-Walker, 2013; Osgood, Ruth, Eccles, Jacobs, & Barber, 2005; Shulman, Feldman, Blatt, Cohen, & Mahler, 2005).

2.2.2.1 A time of identity explorations

Identity exploration has historically been viewed as taking place in adolescence. Erikson’s (1950a) life span psychosocial theory identified the key challenge of adolescence as being the task of achieving identity synthesis as compared to identity confusion. Arnett argues that although identity exploration may start during adolescence, in modern times it is most intense during emerging adulthood, as this is when people “move toward making enduring choices in love, work, and ideology” (Arnett, 2014, p. 158). A National Survey of 1,009 18-29 years olds in the USA found that 77% agreed, somewhat or strongly, that “this is a time of life for finding out who I really am” (Arnett & Schwab, 2012). Identity explorations refers to the process of trying out and reviewing various options in terms of “what kind of person to be and what kind of life to live, specifically in the areas of love relationships, work, and ideology” (Arnett et al., 2014, p. 570).

While identity explorations in adolescence are often “transient and tentative”, in emerging adulthood they become more “serious and focused” (Arnett, 2000a, p. 473). Relationships tend to involve greater intimacy and are considered in terms of whether they could potentially represent a lifetime partnership. Explorations around work in emerging adulthood are more likely to involve consideration of whether a job could become a satisfying long-term career. Emerging adults also explore a variety of worldviews and may question the worldview of their childhood and adolescence, before committing themselves to an ideology, albeit with an expectation that their ideology will continue to evolve (Arnett, 2000a).
Marcia’s (1966) identity status model, which further operationalised the work of Erikson, has also received attention in recent times as remaining relevant to the period of emerging adulthood (Schwartz, Zamboanga, Luyckx, Meca, & Ritchie, 2013). Indeed, Marcia’s research was with 18-22 year olds, a group he termed at that time as “late adolescents” (Marcia, 1994), but who are now commonly referred to as emerging adults. Marcia’s model details four identity statuses: achievement, commitments made following exploration; moratorium, active exploration with an absence of achievement; foreclosure, commitments made without prior exploration; and diffusion, an absence of commitments along with little interest in exploration (Marcia, 1966). More recently, some of the barriers which may contribute to young people failing to reach identity achievement have been articulated. These include socio-economic status, educational opportunities, parental domination, geographic isolation, ethnicity, age, religion, gender, and the presence of physical limitations (Yoder, 2000). Conversely, research by Arnett and colleagues has identified that agency is one factor which positively influences identity development. Young people with higher levels of agency demonstrate positive identity exploration and flexible commitment (Schwartz, Côté, & Arnett, 2005).

Recent research in the area of identity formation has also identified that although the exploration of identity is exciting, it can be associated with confusion and symptoms of anxiety and depression (Arnett & Schwab, 2012; Twenge, 2013b). This is particularly the case for young people who find it hard to make choices or feel that their goals in love and work are unattainable (Arnett et al., 2014). Emerging adults with low levels of social support from family and friends are also more likely to experience reduced well-being during the transitions of emerging adulthood (Galambos, Barker, & Krahn, 2006; Murphy, Blustein, Bohlig, & Platt, 2010). Anxiety and depression are both common during emerging adulthood (Arnett & Schwab, 2012; Twenge, 2013b). In Australia, 26.4% of 16-24 year olds have a mental disorder, with anxiety and depression being the most common. This percentage is higher than in any other age group, and females fare particularly poorly (Slade et al., 2009). A national survey of 1029 emerging adults in the USA also identified that
anxiety and depression are more common in females, as well as in younger emerging adults, and people from lower socio-economic backgrounds (Arnett & Schwab, 2012). Others have reported related findings in relation to the influence of higher socio-economic status on increased well-being. It is reasonable to suggest that emerging adults from middle class backgrounds are more likely to be assisted financially by their parents to make a successful transition to adulthood, for example through support with education, housing, and transport (Galambos et al., 2006).

Evidence also suggests that mental health problems are more likely for emerging adults who do not have clear study or work roles, or who experience disruption to these roles, for example those experiencing long periods of unemployment (Aseltine & Gore, 2005; Galambos et al., 2006). Australian research with 8,749 emerging adult women (Bell & Lee, 2008) specifically explored stress during emerging adult transitions and identified similar findings; that high levels of stress are more likely when people do not make normative transitions, make them earlier than is normative, or revert to more “adolescent” statuses, such as moving back home (Bell & Lee, 2008). Qualitative research from the United Kingdom (UK) highlighted that unemployed emerging adults with mental illness felt suspended between adolescence and adulthood, “stagnated”, or even that they were “moving backward”. Participants also reported “feeling left behind” and excluded from their peer group (Cockshott, Kiemle, Byrne, & Gabbay, 2018, p. 5). Although the process of identity exploration can be anxiety-provoking, once a person is able to commit to a meaningful life purpose they are likely to experience increased well-being, self-esteem and life satisfaction (Luyckx, Schwartz, Goossens, & Pollock, 2008; Sumner, Burrow, & Hill, 2015).

In recent years research has specifically started to explore the effects of identity processes on the health-related behaviours of emerging adults with chronic health problems (Luyckx, Seiffge-Krenke, et al., 2008; Schwartz et al., 2013). For example emerging adults with diabetes who have not yet made identity commitments are more likely to report problems following their recommended diet (Luyckx, Seiffge-
Krenke, et al., 2008). The limited research in this area indicates that a well-established sense of identity may facilitate coping with the presence of a chronic health condition, help to provide a sense of meaning and purpose in life, and protect against emotional problems (Schwartz et al., 2013). Research is needed to identify whether this is the case for emerging adults with physical disabilities such as cerebral palsy. Exploration of identity through the study of life narratives has been identified as one useful approach to this work (Schwartz et al., 2013), and the current study contributes to this exploration. Exploring the narratives of emerging adults with CP also allows an understanding to be developed of the range of contextual factors that influence identity development. These may include environments, events, significant others, historical, cultural and social factors (Goosens & Phinney, 1996).

2.2.2.2 A time of instability

Emerging adulthood is characterised as a time of instability, when young people make frequent changes, particularly in relationships, love, work and living arrangements. In a National USA survey, 83% of respondents agreed with the statement “this time of my life is full of changes” (Arnett, 2014). Emerging adults know they should have a “Plan with a capital ‘P’” (Arnett, 2015, p. 11); an idea about the path they want to take toward adulthood. However, for most young people, this Plan is subject to numerous revisions during the period of emerging adulthood. For example, they may choose a tertiary course only to discover it is not what they hoped, end a relationship they thought was secure, change jobs or move house numerous times for study or work or to live with romantic partners. This instability plays a role in helping young people clarify who they are and the kind of future they want, but can also be a source of worry, stress and confusion (Arnett, 2015). This is particularly the case when changes are involuntary, for example when a partner ends a relationship or when an employer lays them off (Arnett et al., 2014).
2.2.2.3 A time of self-focus

Emerging adulthood is seen to be a self-focused age in that young people have fewer commitments and obligations to others, in comparison to childhood, adolescence and adulthood (Arnett, 2011, 2014, 2015). Even if still living in the family home, emerging adults are generally free to come and go as they please, without having to justify their whereabouts or be home at a certain time. They may have obligations to an employer, but given the often transient nature of employment during emerging adulthood, young people are likely to feel less obligated to their employer than they will in adulthood after having settled into a long-term occupation. There are few rules and much freedom for emerging adults to make their own decisions. They build their independence and self-sufficiency during emerging adulthood, prior to making enduring commitments to others – children, partners, long-term employers – during adulthood (Arnett, 2011, 2014, 2015; Arnett et al., 2014).

In a recent USA National Survey of 1009 emerging adults, 71% agreed that “this is a time of life for focusing on myself” (Arnett, 2014). This level of self-focus is in contrast to childhood and adolescence, when young people must still respond to the demands of parents and schools (Arnett et al., 2014), although 30% of emerging adults still believe their parents are more involved in their lives than they would like. Regardless, emerging adults still generally feel close to their parents, and 76% believe they get along a lot better than they did as adolescents (Arnett & Schwab, 2012). Often this improved relationship is attributed to an increase in distance, with emerging adults moving out of home to study or work (Lefkowitz, 2005). Parents and emerging adult children seem to value their time together more when effort is required to maintain contact. In emerging adulthood, young people are more able to understand the point of view of their parents, and parents are more likely to take their child’s point of view seriously (Arnett, 2015). Relationships are also seen to improve once young people commence full-time work, as financial dependence is reduced and their roles become more similar to those of their parents (Buhl, 2007).
Arnett is quick to reinforce that the self-focus of emerging adulthood is not a synonym for selfishness, although other researchers have suggested that emerging adults are, in fact, selfish (eg: Twenge, 2013a). Arnett believes that it is wise for emerging adults to explore various options before making independent and enduring decisions as they move into adulthood. He also reinforces that emerging adults place a high value on community, that they are more likely than previous young people to participate in community service and volunteering, and that in one USA survey, 86% agreed that they wanted to have a job that “does some good in the world” (Arnett, 2014). Relevant to the current study, recent research has highlighted that emerging adults with disabilities are a group who are more likely to demonstrate higher levels of other-focus than their peers without disability (Nario-Redmond & Oleson, 2016). Qualitative research with emerging adults with varying disabilities similarly established that demonstrating an “altruistic sense of duty” toward others living with disabilities was a goal of many of the 31 participants. Participants reported the desire to use their other-focus to help other young people in future by sharing learnings from their own experience (Mannino, 2015, p. e137).

2.2.2.4 A time of feeling in-between

Emerging adulthood is a time when most young people feel they are on the way to adulthood, but not there yet. It is a gradual process that has been described as “long and winding” (Arnett, 2014, p. 159). Research in this area has consistently showed that when emerging adults are asked whether they feel they have reached adulthood, the most common response is “in some ways yes, in some ways no”. An Australian study of 247 emerging adults aged 18-25 found 50.2% answered this way, with 45.3% answering “yes” and 4.5% “no” (Griffin et al., 2007). In a National USA survey of 1009 people, 45% identified “in some ways yes, in some ways no” as their response. This increased to 62% of those aged 18-21, and decreased to 30% of those aged 26-29. By ages 26-29, 68% of young people felt they had reached adulthood (Arnett & Schwab, 2012). Other research has found similar trends, with people gradually more likely to describe themselves as an adult with increasing age (Weier & Lee, 2015). In one American study, only 19% of 13-19 year olds felt they were adult, compared to 46% of 20-29 year olds and 86% of 30-55 year olds (Arnett,
2001). Often the sense of feeling in-between during emerging adulthood relates to an ongoing reliance in some ways on parents (Arnett, 2014).

### 2.2.2.5 A time of possibilities and optimism

Emerging adulthood is seen to be “the age of possibilities, when many different futures remain open, when little about a person’s direction in life has been decided for certain. It tends to be an age of high hopes and great expectations” (Arnett, 2004, p. 16). It is also a time of struggle and stress for many young people; one National USA survey found that 72% of respondents agreed that emerging adulthood is stressful. Regardless, it is a time of high optimism, with 89% of emerging adults agreeing that “I am confident that someday I will get what I want out of life” and 77% believing “overall, my life will be better than my parents’ lives have been” (Arnett, 2014). Many believe their lives will be better in a number of ways: financially, in relation to career achievement, and in relation to personal relationships (Arnett, 2000b). Arnett states that a significant contributing factor to this optimism about the future is that many have received more education than their parents did, and that they correctly perceive a strong correlation between education level and occupational and financial success (Arnett, 2014).

Other authors have labelled these high hopes as being narcissistic (Twenge, 2013a), a claim that Arnett refutes and believes promotes an unwarranted negative view of emerging adults (Arnett, 2007d, 2010). He says “rather than scoffing at their naïveté, perhaps it would be wiser to see their optimism as a psychological resource that they can draw upon” during times of challenge (Arnett & Schwab, 2012, p. 19). Although emerging adults may be more self-confident and assertive than in the past, Arnett cites reduced impulsive risk-taking behaviour, increased volunteering, and greater tolerance and acceptance of difference as evidence that today’s emerging adults are not, as a group, narcissistic and egocentric (Arnett, 2013). Others have reflected that emerging adults’ capacity to demonstrate optimism in relation to their future, even in spite of difficult previous or current experiences, is a sign of a high level of resilience within this group (Murphy et al., 2010). Protective factors contributing to resilience include intelligence, the presence of at least one
loving relationship with a parent or other adult, religious faith, and personality characteristics including optimism and determination (Arnett, 2015). Arnett believes however, there are additional factors that are distinct to the period of emerging adulthood. These include the ability to leave home, particularly when the situation at home is difficult or destructive, growing cognitive development, particularly a growing understanding of abilities and an appreciation of capacity to change, and an ability to incorporate negative past events into a positive identity (Arnett, 2015).

2.2.3 What does positive emerging adulthood look like?

Arnett has proposed that there are four key cultural beliefs that underlie the period of emerging adulthood in developed countries. These are:

*the belief that independence and self-sufficiency should be attained before entering into adult commitments; the belief that romantic love should be the basis of marriage; the belief that work should be an expression of one’s identity; and the belief that the years from the late teens through at least the mid-twenties should be a time of self-focused leisure and fun* (Arnett, 2011, p. 266).

Arnett expands his proposal by explaining that young people today want to feel that they are capable of being independent and managing their own life, and they want to find their soul mate, not just any partner. They do not want to settle with work that is boring and laborious; instead they want to use their abilities to participate in work that is an expression of their identity, enjoyable and self-fulfilling. They also want this time of life to be a time of great fun, a chance to do things they could not do when they were younger, and will not be able to do when they are older with more responsibilities. Arnett’s research suggests that these are the factors which emerging adults themselves believe are indicators of a positive outcome of this life stage (Arnett, 2011, 2015).

Limited theoretical literature and research has explored what positive development in emerging adulthood actually looks like. Although consensus is yet to be reached, it is possible to identify factors which are considered to be indicative of positive development. Some of the most comprehensive research to date has been
conducted in Australia utilising confirmatory factor analysis (Hawkins, Letcher, Sanson, Smart, & Toumbourou, 2009). This research included a large cohort of 1,158 young Australians aged 19-20 who completed a self-report questionnaire adapted from a range of standardised instruments. The authors noted that the cohort represented a wide range of family backgrounds and circumstances, although there was a slight underrepresentation of participants from lower sociodemographic backgrounds or with a parent born outside of Australia (Hawkins et al., 2009). Analysis revealed a robust model that identified five domains of positive development during emerging adulthood:

- “social competence”, referring to being responsible and displaying self-control and empathy;
- “life satisfaction”, referring to satisfaction with achievements, life direction, social and personal life;
- “trust and tolerance of others” and “trust in authorities and institutions”, reflecting an individual’s attachment to their community and acceptance of difference;
- and to a lesser extent “civic action and engagement”, referring to involvement in community and social groups, and civic action (Hawkins et al., 2009, p. 96).

An earlier literature review undertaken in the USA on successful young adult development identified fairly similar constructs, while also detailing some more specific examples of indicators including physical health, avoidance of risk-taking, ethical behaviour, financial responsibility, and completing post-secondary education (Benson, Scales, Hawkins, Oesterle, & Hill, 2004). More recently, Australian research from the same research team as the Hawkins et al. (2009) study, has identified that higher socio-economic status, academic achievement, and having a strong relationship with parents and peers can also influence positive development during emerging adulthood (O’Connor et al., 2011).

The impact of the relationship with parents has been a focus of existing literature around positive development during emerging adulthood. A positive relationship with parents is one supportive of independence and autonomy whilst maintaining a
high level of emotional support, involvement, open communication, acceptance, mutual respect and empathy (Aquilino, 2006). The relationship an emerging adult has with their parents can influence, positively or negatively, emerging adults’ psychological adjustment and well-being, identity formation, health and risk-taking, living situations, educational attainment, and capacity for healthy relationships (Aquilino, 2006). Positive development is reflective of emerging adults being provided opportunities to build their autonomy while continuing to feel supported by their parents. This is often referred to as an authoritative approach (Koepke & Denissen, 2012; Nelson, Padilla-Walker, Christiensen, Evans, & Carroll, 2011). Existing research has identified that emerging adults and their parents have different views of the criteria for adulthood, and has hypothesised that positive parental relationships during emerging adulthood may be more likely for those families with higher levels of agreement in relation to what it means to be an adult (Nelson et al., 2007).

It is important to note that this description of positive development during emerging adulthood is based on research conducted with broad populations of emerging adults, none of which were groups of emerging adults with identified disabilities. Further research is needed to explore whether the views of emerging adults with disabilities in relation to positive emerging adulthood are consistent.

2.2.4 When does emerging adulthood end: What is adulthood?

While markers of the entry to adulthood which have typically been described in the literature include such things as the establishment of a stable residence independent of parents, school completion, career selection, marriage and having children (Arnett, 1997; Cohen, Kasen, Chen, Hartmark, & Gordon, 2003; Morrow & Richards, 1996), these are not the characteristics that have been found to matter most to young people. Instead, attributes that young people themselves feel represent the transition to adulthood are not events, such as marriage or leaving home, but rather cognitive attributes, such as independence in decision making, and social participation in the community (Arnett, 1997, 1998, 2001; Arnett & Taber, 1994; Scheer, Unger, & Brown, 1996). In a USA survey study of 486 college
students aged between 18 and 28, 93% felt that accepting “responsibility for the consequences of your actions” was a criteria for adulthood, followed by developing “personal beliefs and values independently of parents or other influences” (79%), and establishing “a relationship with parents as an equal” (71%) (Arnett, 1997, p. 10). A 2003 study exploring conceptions of adulthood across American ethnic groups showed consensus between groups that criteria for adulthood included accepting responsibility, financial independence, deciding on personal beliefs and values, establishing an equal relationship with parents, and developing greater consideration for others (Arnett, 2003). Similar findings around conceptualisation of adulthood have been reported in other international studies (Arnett, 1994, 1998, 2001; Scheer et al., 1996).

More recent research has started to identify some cultural variations, although accepting “responsibility for the consequences of your actions” has consistently been rated highly. An Italian study explored the views of 1,513 young people aged 19-30. Respondents considered an adult as a person who takes responsibility, has finished education, obtained a licence, is employed in a stable job, takes care of his/her family, and respects the law (Tagliabue, Crocetti, & Lanz, 2016). A Danish study of 400, 17-29 year olds identified that the most endorsed criteria were accepting responsibility for one’s self, making independent decisions, and becoming financially independent (Arnett & Padilla-Walker, 2015).

The first exploration of emerging adults’ perceptions of adulthood in Australia was undertaken by the current author and colleagues in 2007 (Griffin et al., 2007). Two hundred and forty seven participants with a mean age of 21.5 completed the standardised Criteria for Adulthood Questionnaire (Arnett, 2003). The large majority (80.1%) were enrolled in tertiary study. Results showed similar conceptualisations of adulthood as reported above. The most endorsed criteria were “accept responsibility for the consequences of your actions” (96.2%), “decide on personal beliefs and values independently of parents or other influences” (86.9%), become “financially independent from parents” (80.2%), and “become less self-oriented, develop greater consideration for others” (76.8%) (Griffin et al.,
2007). More recent Australian research with 365 university students aged 16-30, using the same standardised questionnaire, reported similar criteria endorsements: accept responsibility (95%), financial independence (88%), decide on personal beliefs independently (78%) and “established a relationship with parents as an equal adult” (77%) (Weier & Lee, 2015). Australian emerging adults were also more likely to endorse family capacity items such as a man or woman being able to care for a family financially, and norm compliance items such as avoiding petty crime, avoiding drunk driving, avoiding illegal drugs and driving safely, in comparison to Arnett’s 2001 USA study (Weier & Lee, 2015).

In all of the above studies, role transitions such as marriage, leaving school and parenthood ranked much lower in importance than cognitive attributes (Arnett, 1997, 1998, 2001; Scheer et al., 1996). Indeed, Arnett’s research has identified that in most areas, less than one quarter of participants indicated that achieving any of the traditional milestones was necessary for a person to be considered an adult (Arnett, 1997). Australian research also found very low levels of endorsement that traditional role transitions represent criteria for adulthood, including finishing education (28.2%), marriage (6.5%) and having children (1.3%) (Griffin et al., 2007).

When the above findings are collectively considered it is apparent that, although some cultural variations are beginning to emerge, most young people today believe that they have reached adulthood when they are autonomous and self-sufficient and no longer have to rely on others, especially their parents (Arnett, 1994; Arnett & Schwab, 2012).

This perspective of young people experiencing emerging adulthood is, however, at times at odds with the views of researchers who write about them. Of concern is the “deep disparity between the way the transition is conceptualised by researchers and theorists in the area and the way it is conceptualised by the people who are undertaking the transition” (Arnett, 1997, p. 17). This disparity highlights the need for further research exploring the transition experiences of young people from their own perspective (Furstenberg et al., 2005; Weier & Lee, 2015). Although the
research presented in this section provides a useful understanding of how emerging adults respond to standardised instruments about the criteria for adulthood, detailed explorations of their experiences of emerging adulthood are very limited.

A small number of books on emerging adulthood have presented the narratives of young people. Arnett presents four narrative profiles of emerging adulthood in his foundation text on emerging adulthood (Arnett, 2004). Konstam’s text titled “Emerging and young adulthood: Multiple perspectives, diverse narratives” presents fifteen (Konstam, 2007). Most recently, 29 narrative essays written by emerging adults from diverse backgrounds are presented in Padilla-Walker and Nelson’s edited text “Flourishing in emerging adulthood” (Padilla-Walker & Nelson, 2017). These few qualitative inquiries present the sum of scant evidence exploring the “richness and complexities of emerging adulthood life” (Schwab & Syed, 2015, p. 388). Qualitative research has been highlighted as particularly suited to understanding the experiences of emerging adults because of its capacity to explore the “intricacies of the human experience” (Schwab & Syed, 2015, p. 397). In addition, it is identified as the most appropriate means of understanding the experiences of marginalised young people (Schwab & Syed, 2015). This study adds to current limited knowledge in both of these areas, by exploring the narratives of a particularly vulnerable group of emerging adults; those with disability. What is currently known about the experiences of young people experiencing additional vulnerabilities is now explored.

2.2.5 Emerging adulthood in vulnerable populations

The change in conceptualisation of what it means to be an adult that has taken place over recent years and the rise of research on emerging adulthood also has significant implications for vulnerable emerging adults. Groups who have been identified within literature as being vulnerable include people with disabilities and mental health problems, those aging out of care, the homeless, people from low socio-economic backgrounds, and those coming out of the criminal justice system (Foster & Gifford, 2005; Osgood, Foster, & Courtney, 2010). These groups are recognised to face additional barriers over and above those experienced by all
emerging adults. These may include such factors as a history of trauma, specific challenges due to disability, a lack of familial support, or constraints within the service systems designed to support them (Osgood et al., 2010). Emerging adulthood presents challenges for vulnerable young people, which are now briefly discussed. However, opportunities and factors indicative of a positive outcome have also been identified, and these too are introduced.

2.2.5.1 Challenges for vulnerable emerging adults

While research indicates that emerging adulthood is a positive period for most young people, leading to increases in self-esteem and well-being, there is evidence that this is less likely the case for people from vulnerable populations (Arnett, 2007c). Evidence of outcomes, albeit limited, suggest that youth from vulnerable populations fare poorly during the transition to adulthood in comparison to their peers. They are less likely to have completed education, more likely to be unemployed and rely on income support, and less likely to have achieved residential stability (Foster & Gifford, 2005). Implications of disability may make it harder for young people to acquire the skills needed to achieve a level of independence and make a successful transition to adulthood. These challenges can also be compounded by concurrent loss of access to paediatric services (Osgood et al., 2010).

Evidence suggests that parents’ education level and income play a significant role in the transition to adulthood of their children. Young people from more advantaged families are more likely to have a successful transition, more likely to participate in higher education and receive significantly more material assistance from their parents (Schoeni & Ross, 2005). People experiencing social, personal or family problems during adolescence and emerging adulthood, in contrast, may have reduced family support at the same time as they age out of services they may have been accessing during adolescence (Marcotte, 2008). They may be less likely to successfully complete education, and more likely to experience unemployment. These factors can put vulnerable young people at greater risk of mental health
problems, antisocial behaviour, drug and alcohol use, and unsatisfactory relationships (Marcotte, 2008).

2.2.5.2 Positive indicators and opportunities for vulnerable emerging adults

It is known that some vulnerable young people do manage to make a successful transition regardless of the barriers they faced. Those who succeed demonstrate such personality traits as persistence, confidence and resilience (Osgood et al., 2010). Many factors contribute to a young person’s level of resilience, or ability to overcome difficulties and bounce back quickly from adversity. These include their own skills and personality type, motivation, perseverance and patience, social support from family, friends, and the broader community, and active involvement in the community (Hinton & Meyer, 2014; Mannino, 2015; Osgood et al., 2010). Relationships with others are particularly salient during the period of emerging adulthood, as young people’s relationship with their parents evolves. Those who are able to maintain effective connections with their parents, build new adult friendships and romantic relationships, and have supportive relationships with teachers, colleagues and other adults, are likely to experience positive transitions (Burt & Paysnick, 2012). Higher levels of autonomy, self-determination, future-motivation, and well-developed coping skills are also indicators of better outcomes in the transition to adulthood. However, factors out of young people’s control are also seen to play a role in transition outcomes. These include intellectual capacity, parenting quality and socio-economic status during childhood (Masten, 2004).

The expanded conceptualisation of what it means to be an adult within the theory of emerging adulthood also offers opportunities for vulnerable groups. The traditional view of key milestones being indicators of adult status had the potential to exclude people who may never reach some or any of these milestones, including people with disabilities like CP (Priestley, 2000). For example, research with 635 young people aged 21-25 (including n=18 with CP) found that young people with disability were significantly less likely than their peers without disability to have
acquired a social role such as participating in competitive employment or being a caregiver. People with little independence in their daily lives and activities were particularly at risk (Van Naarden Braun, Yeagin-Allsopp, & Lollar, 2005). The contemporary view that personal characteristics, rather than specific milestones, are the key to attainment of adult status, is more inclusive of people with lifelong disabilities. For example, many people with CP can take responsibility and make independent decisions even if they then require assistance to carry out activities and participate in society (Galambos, Darrah, & Magill-Evans, 2007). Similarly, recognition that ongoing identity exploration, frequent changes of direction, and extended periods of living with parents are common to many during emerging adulthood, has been identified as “normalising” common experiences of emerging adults with disability (Hinton & Meyer, 2014, p. 149).

It has been noted that particular attention should be given to learning about the experiences of disadvantaged groups during emerging adulthood, and to identifying what can be done to ameliorate negative experiences and enhance positive ones during this important life stage for vulnerable young people (Cote, 2006). Hinton and Meyer (2014) focus particularly on the need to explore emerging adulthood for those living with disability. They emphasise that the theory of emerging adulthood provides “a new vantage point and foundation on which to build successful services for young adults with disabilities, but empirical research is needed to guide our understanding and development of appropriate services for this population” (Hinton & Meyer, 2014, p. 154). Yi, Tian and Kim (2017) highlight the importance of such research focusing not only on the challenges of living with disability or chronic illness during emerging adulthood. They emphasise the need to also explore opportunities, and the strengths that emerging adults may develop in spite of, or even because of, their disability (Yi, Tian, & Kim, 2017). The current study contributes to this gap in research knowledge through exploring the first-hand experiences of emerging adults with cerebral palsy.

It is clear from the above discussion that a person’s capacity to engage and participate in all aspects of their life is an important influence on their experiences
and outcomes during emerging adulthood. To comprehensively explore the experiences of emerging adults with CP, an additional framework is required to guide the research to ensure consideration of the wide range of factors which influence a person’s participation in meaningful activities and their communities. A highly accepted 21st Century framework detailing such factors in the areas of health and disability is the World Health Organisation’s ICF. The following section introduces this framework.

2.3 A perspective on health and disability: The ICF

The ICF provides “a framework for the conceptualisation, classification and measurement of disability” (Australian Institute of Health and Welfare, 2003, p. 1). It aims to provide a universal language and framework to assist in the description of health and health-related states (World Health Organisation, 2001). Unlike previous conceptual frameworks of disability and classification systems, the ICF focuses on health and functioning, rather than on disability. In doing so, it avoids segregating people with disabilities from people without and recognises that all people may experience some level of disability (Bakas et al., 2012; World Health Organisation, 2002). The ICF framework recognises the multidimensional nature of disability and the multidirectional interactions between body structures and functions, activities, and participation. Additionally, it reflects the social construction of health and disability by recognising environmental and personal contexts that may affect a person’s health and wellbeing (Bertoti & Moyers, 2004; Stewart & Rosenbaum, 2003). Disability is therefore seen as the outcome of not just a health condition and personal factors, but also external factors and circumstances in which a person lives. The ICF Framework is presented in Figure 1.
2.3.1 Constructs and key values of the ICF

The ICF consists of two main parts: 1. Functioning and disability; and 2. Contextual factors (World Health Organisation, 2001). Functioning and disability includes the domains of body functions and structures, and activities and participation. These domains are characterised by ratings (positive or negative) that indicate severity of impairment in body systems and structures, and as well as limitations in a person’s capacity and performance in activities (the ability to engage in or complete tasks). The ability of a person to engage in activities in a life situation is conceptualised as participation and this can be rated according to the level of restriction (if any). Contextual factors refer to both environmental and personal factors. Environmental factors can be rated regarding whether they facilitate or hinder other framework dimensions. Personal factors do not as yet have codified ratings and their appraisal of contribution to functioning, disability and health is more subjective. In this way, the ICF can be used to catalogue and characterise not only impairments, activity limitations and participation restrictions (disability), but also to express functional and structural integrity, activity performance and participation (functioning). For this reason, the ICF is seen to have universal human application (World Health Organisation, 2002).
Organisation, 2001), acknowledging that every human being at some time is likely
to experience a reduction in health and some level of disability (Kostanjsek, 2011).
Table 1 defines the key ICF concepts.

<table>
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<th>Definitions of key concepts in the ICF in the context of health:</th>
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<tr>
<td><strong>Body Functions</strong></td>
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<td><strong>Participation restrictions</strong></td>
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<td><strong>Environmental factors</strong></td>
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Table 1: Definition of key ICF concepts (Copyright World Health Organisation, 2002, p. 10, reproduced with permission)

The ICF has been credited for enhancing understanding of “the nature of disablement” (Baylies, 2002, p. 729), and is respected for its ability to facilitate implementation of rights-based policies and rules, including the United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (Baylies, 2002) and the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006) which was ratified by Australia on 17 July 2008. It is also highly valued for its emphasis on what people can do, rather than on whether they can do them “normally”. It accepts variation and recognises that a goal accomplished is something to be celebrated, regardless of how it is achieved. It expands thinking beyond “fixing” body structures, and places equal value on promoting functional activity and participation in life. For example, the conceptual framework reminds us that being able to effectively communicate is more important than being able to talk (Rosenbaum & Stewart, 2004, p. 8). Using this framework, it is unsurprising to conclude that all people may experience some degree of disability during their lifetime, whether it be permanent or temporary (World Health Organisation, 2001).
2.3.2 Utilisation and critique of the ICF

The ICF is both a broad conceptual framework and a specific, detailed hierarchical classification system with numerous components, constructs, domains and categories (World Health Organisation, 2001, 2002). As such it has multiple purposes and potential uses within a wide range of sectors, including education, research, health care service delivery, policy development and advocacy. It can be used to collect and record data, measure outcomes, in treatment planning and assessment, for economic analyses, in social policy development and in education and awareness raising activities (World Health Organisation, 2001, 2002).

Regarding the use of the ICF as a classification system, a person with a particular condition (classified in the International Classification of Diseases) can have their biopsychosocial health characterised using alpha-numerical codes. An initial letter represents the component of the ICF being classified, for example d represents activities and participation, and e represents environmental factors. Numbers are added to the prefix letter to qualify the particular domain of the ICF being classified, for example e4 represents attitudes, while the more specific e460 refers to societal attitudes. Additional qualifiers are selected to highlight the extent of functioning or disability in each domain, or the extent to which an environmental factor is a facilitator or a barrier. Thus the ICF codes can be utilised to record both domains of relevance to an individual, and how these interact with each other part of the framework structure. As noted above, the only ICF domain currently unable to be classified is ‘personal factors’ which to date are yet to be codified due to their vast cultural and contextual diversity (World Health Organisation, 2013).

In relation to some health conditions and health care contexts, ICF Core Sets are available that extract and profile the essential domains and categories of most relevance to that condition or context (https://www.icf-research-branch.org/icf-core-sets-projects2). Developed through a rigorous standardised process through partnerships with the ICF Research Branch, Core Sets can provide clinicians and researchers with a common way to approach the description, through classification,
of functioning, disability and health for people with a particular condition. To date no Core Set exists for adults with CP. A project to develop a CP core set launches data collection in October 2018 by the Erasmus University Medical Center and Rijndam Rehabilitation in the Netherlands, with the support of the ICF Research Branch (https://www.icf-research-branch.org/). Because there is currently no core set for adults with CP, and in line with the qualitative nature of the research, the use of ICF terminology and the exploration of ICF domains, factors and interrelationships in this thesis is done from the author’s perspective using literature and participant experience to inform presentation of material.

The ICF, particularly as a classification system, but also as a conceptual framework, has not been without critique. Criticisms include a lack of emphasis on determinants of health, unclear distinctions between the activity and participation domains, a lack of specificity around personal factors, insufficient attention to the concepts of quality of life and human development, and whether classifying people holds any value or instead contributes to further marginalisation, or even worse to human rights abuses (for example Bakas et al., 2012; Hammell, 2004; Hemmingsson & Jonsson, 2005; Imrie, 2004; Nordenfelt, 2003; Wade & Halligan, 2003). Nonetheless, the ICF has been adopted internationally as the authoritative framework representing “our best understanding of the complex phenomena of functioning and of disability (Cerniauskaite et al., 2011, p. 282). The ICF has also been recognised as a positive, rights-based framework, even by people within the disability rights movement (Hurst, 2003). More recent research conducted in Sweden with representatives of disability organisations identified positive views of the ICF (Lundalv, Tornbom, Larsson, & Sunnerhagen, 2015). These included its capacity to encourage recognition of the broad range of elements influencing experience, and the identification of contextual factors which were forgotten in past conceptual frameworks. Similar criticisms to those noted above around the use of the ICF as a classification system were, however, also noted (Lundalv et al., 2015). In the current study, as highlighted above, the ICF was not used as a classification system, but rather as a broad conceptual framework for understanding experiences of functioning and disability.
2.3.3 The ICF as a conceptual framework

The ICF’s use as a framework for the development of a broad common understanding of both functioning and disability has been recommended in Australia (Australian Institute of Health and Welfare, 2003; Cusick, 2001; Fortune, 2004). The Australian Institute of Health and Welfare promotes the usefulness of the ICF for “organising thoughts and ensuring that major factors of interest are not omitted from a plan, explanation, argument or set of information” (Australian Institute of Health and Welfare, 2003, p. 28). The ICF has also been described as a useful framework for research specifically in the area of CP. Rosenbaum (2004) states that “studies of children and youth with cerebral palsy should include dimensions of activity and participation, as well as environmental factors, to capture the complex interactional nature of life experiences” (p. 9). Additionally, the value of the ICF in framing research around transition planning and service delivery for youth with chronic health conditions and disabilities has been highlighted (Nguyen, Stewart, Rosenbaum, et al., 2018).

A recent systematic review identified the ICF as a useful guide for comprehensively exploring the experiences and needs of people with chronic conditions from a person-centred approach (Alford et al., 2015). This review identified a limited but growing volume of published literature utilising the ICF to elicit personal narratives. A total of 37 articles covering a wide range of chronic health conditions met the inclusion criteria for the systematic review, of these 16 were qualitative papers, and the remainder used mixed methods (Alford et al., 2015). The papers used the ICF in a variety of ways; some utilised ICF constructs to develop open-ended questions for use during data collection, while others inductively or deductively linked participant’s responses to the ICF during data analysis. The review concluded that the ICF has the capacity to encourage consideration of the full multitude of factors which influence people’s experience, can enhance interdisciplinary communication and collaboration, and provide opportunities to identify unmet needs (Alford et al., 2015).
Only one paper included in the above systematic review utilised the ICF as a framework for exploring the experiences of participants with CP (Nieuwenhuijzen et al., 2009). The ICF was also utilised in a recent qualitative systematic review as a framework for classifying themes within 33 research papers with 2-25 year olds with CP (Lindsay, 2016a). The current study adds to this very limited evidence base of research about CP framed by the ICF. Within the current study, as in Lindsay (2016), and in many of the studies included in Alford and colleagues (2015) systematic review, the ICF was not utilised as a classification system, but rather a broad conceptual framework to help frame the literature, data collection and analysis. It was utilised in addition to the theory of emerging adulthood to specifically focus the exploration of the participants’ experience of disability. For example, interview questions and probes for further detail tried to capture experiences across all of the ICF domains, and data was interpreted to identify whether certain areas of the ICF are emphasised within the stories of emerging adults with CP, and therefore should form priorities for future service and policy development. Its use is explored further in the following chapter.

So far this chapter has introduced the theoretical frameworks guiding this research, including emerging adulthood as a developmental framework covering the life stage under study (18-25 years), and the ICF as a framework for exploring experience of functioning and disability. Considering concepts of human development alongside the ICF has previously been recommended (McDougall, Wright, & Rosenbaum, 2010), and this study makes clear efforts to do so. The following section introduces cerebral palsy as the particular disability explored in this research, and details the existing state of knowledge around the experiences of emerging adults with CP.

2.4 Cerebral palsy

This section provides an introduction to CP and in particular to the experiences of emerging adults with CP. This discussion is framed by the effects of CP on the ICF domains of body functions and structures, activities and participation, and on the environmental and personal factors influencing experience. Utilisation of the ICF as
a framework for exploring the experiences of adults with CP has been recommended (Haak, Lenski, Hidecker, Li, & Paneth, 2009). It is important to note that the literature that forms the basis of this review uses varying terms to describe this group of young people aged 18-25, including older adolescents, youth, and young adults. However, to enhance ease of reading and for consistency with current thinking around lifespan development, throughout this literature review young people aged 18-25 with CP, are referred to as emerging adults. In addition, because of the overall paucity of research specifically with emerging adults with CP, research is also reviewed that includes emerging adults within its sample along with youth and/or adults outside the 18-25 year age range, as is research which includes emerging adults with CP along with people with other disability types.

2.4.1 Definition

In the past decade, significant effort has been invested into identifying a new consensus definition of CP. Earlier definitions have been identified as unsatisfactory given the current level of understanding of CP aetiology, changing views of impairment, function and participation, increased availability of high-quality brain imaging, and acknowledgement that the predominant motor impairment is almost certainly associated with a range of other disabilities (Rosenbaum et al., 2007). The result of the work of an international panel, led by an executive committee, is the following conceptualisation of CP which has since been widely adopted:

_Cerebral palsy describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems_ (Rosenbaum et al., 2007, p. 9).

This seminal work goes on to further clarify that CP: is a diverse condition, in relation to its aetiology, as well as types and levels of severity; excludes conditions that are transient but may be often changing; occurs at a time when motor development is not yet well established; affects gross and fine motor functioning
and organisation; and arises from a single event or distinct series of events which are no longer active at the time of diagnosis (Rosenbaum et al., 2007).

The impairments and functional limitations resulting from CP are directly related to the area of the brain affected and the degree of the damage; therefore the disorder presents in many different ways (Jones, Morgan, & Shelton, 2007). CP is a static brain injury whereby the original brain damage does not worsen. However, impairments, co-occurring diseases, and functional limitations, do change over time, which has the potential to reduce participation and quality of life (Gajdosik & Cicirello, 2001). For example, abnormal patterns of movement and lack of upright movement often lead to orthopaedic problems including scoliosis, kyphosis, muscle and joint contractures, joint subluxation or dislocation, and significantly reduced range of motion (Blackman, 1997).

### 2.4.2 Aetiology

The aetiology of CP is described in terms of causal pathways (Stanley, Blair, & Alberman, 2000). There is rarely one risk factor, but rather a range of risk factors that interact to result in the development of CP (Nelson & Chang, 2008). These risk factors include: pre-conception factors (eg. maternal seizures, history of miscarriage, low socio-economic status, older maternal age); antenatal risk factors (eg. birth defects, perinatal infection, pre-eclampsia); intrapartum risk factors (eg. breech presentation, hypoxic events); and neonatal factors (eg. seizures, infections) (Blair & Stanley, 2002; McIntyre et al., 2012). Risk for CP is categorised into three groups: premature infants, accounting for 40% of all cases; term infants born with neonatal encephalopathy, accounting for 10-20% of cases; and healthy term born infants, accounting for 40-50% of all cases (Badawi & Keogh, 2013; McIntyre et al., 2012).

### 2.4.3 Incidence

Cerebral palsy is the most common physical disability in childhood. The birth prevalence internationally is 2.1 cases per 1000 live births (Oskoui et al., 2013).
Prevalence has just started to decline in Australia and Europe over recent years (Reid et al., 2016; Sellier et al., 2016). In Victoria, Australia, the rate declined between the mid-1990s and 2009 for all levels of severity and complexity, and for children born at all gestations. These declines have been associated with innovations in perinatal practice, including neuroprotective strategies such as therapeutic hypothermia (Reid et al., 2016). The rate amongst very premature infants is trending down, due to the great expertise and evidence base for neonatal intensive care (McIntyre, Morgan, Walker, & Novak, 2011).

Currently there is no cure for CP although with new advances in CP research this is a hope for the future (Badawi & Keogh, 2013). Much can be done however in the areas of therapy, education, environmental changes and technology to maximise function, participation and quality of life (Jones et al., 2007). Most people with CP will have an average life expectancy, however those with very severe physical and intellectual disabilities, and those who are tube-fed may have a reduced life expectancy (Blair, Watson, Badawi, & Stanley, 2001; Hemming, Hutton, & Pharoah, 2006; Hutton, 2006; Strauss & Shavelle, 1998; Strauss, Shavelle, Reynolds, Rosenbloom, & Day, 2007; Strauss, Shavelle, & Anderson, 1998). Even for those with the most severe disabilities, life expectancy has increased significantly in recent decades. For example, mortality of children with the most severe disabilities, and of adults fed by gastrostomy, fell by 50% over the years 1983-2002 (Strauss et al., 2007). These positive advances have led to new challenges for the health professions however, as they attempt to respond to impairments in body functions and structures in a young adult and adult population of people with CP. The implications of CP on body functions and structures are now explored in further detail.
2.4.4 Characteristics of CP: Body functions and structures

2.4.4.1 Classification of CP: Type, distribution and severity

Cerebral palsy is not a single diagnosis, but rather a description of a variety of clinical symptoms. CP is generally classified in three different ways: by motor type, by distribution and by severity of motor impairments and other associated impairments (Blair & Watson, 2006). In relation to motor type, there are four classifications. Spasticity refers to overactive muscles that display a velocity-dependent resistance to stretch. Dyskinesia can be further broken down into athetoid CP, characterised by involuntary writhing movements, or dystonic CP, characterised by involuntary twisting postures or repetitive movements and fluctuating tone (McIntyre et al., 2011). Dyskinesia is usually global in that it most often affects the whole body, and commonly leads to problems with tone regulation, postural control, coordination and speech (Jones et al., 2007). Ataxic CP presents as a loss of muscular coordination and shaky tremors. Lastly, hypotonia refers to a generalised decrease in muscle tone (McIntyre et al., 2011). Spasticity is by far the most common classification, accounting for 85-91% of cases. Dyskinesia accounts for 4-7%, ataxia for 4-6% and hypotonia for around 2% (Australian Cerebral Palsy Register Group, 2013; Reid, Carlin, & Reddihough, 2011).

In relation to topographical distribution, spastic type CP is further classified in relation to the parts of the body affected. Hemiplegia refers to involvement of one side of the body. In most cases the upper limb is more affected than the lower limb. Diplegia refers to predominant involvement of both lower limbs, although upper limbs may be affected to a lesser extent. Quadriplegia refers to involvement of both arms and both legs, with the arms being as affected, or more affected, than the legs. Trunk and oro-facial involvement is also common. Rarely, triplegia occurs, referring to cases where one limb is spared (McIntyre et al., 2011). Hemiplegia (38%) and diplegia (36%) are more common than quadriplegia (26%) (Australian Cerebral Palsy Register Group, 2013).
The recognised and reliable tool for describing and classifying motor function in CP is the Gross Motor Function Classification System (GMFCS) (Palisano, Rosenbaum, Bartlett, & Livingston, 2007; Palisano et al., 1997; Wood & Rosenbaum, 2000). The GMFCS is a five level classification system focused on self-initiated movement in the areas of sitting, transferring and mobilising. Table 2 describes the five levels and the incidence of each.

<table>
<thead>
<tr>
<th>GMFCS Level</th>
<th>Description (Palisano et al., 2007; Palisano et al., 1997)</th>
<th>Incidence (Australian Cerebral Palsy Register Group, 2013)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Walks and climbs stairs without limitation; speed, balance and coordination are impaired</td>
<td>36%</td>
</tr>
<tr>
<td>II</td>
<td>Walks and climbs stairs holding onto a railing, limitations outdoors or in the community, eg on uneven ground or in crowds</td>
<td>25%</td>
</tr>
<tr>
<td>III</td>
<td>Walks using assistive mobility devices. May use a wheelchair for long distances or outdoors on uneven ground</td>
<td>11%</td>
</tr>
<tr>
<td>IV</td>
<td>May walk using a walker for short distances, but use a wheelchair outdoors and in the community</td>
<td>12%</td>
</tr>
<tr>
<td>V</td>
<td>Head and trunk control is limited. Self-mobility is severely limited. May be achieved using powered mobility with extensive adaptations.</td>
<td>14%</td>
</tr>
</tbody>
</table>

Table 2: Gross Motor Function Classification System – description and incidence of GMFCS Levels

The GMFCS originally only described classifications for ages up to 12; this however has since been expanded to include ages up to 18 (Palisano et al., 2007). It has also been shown that classification at age 12 is highly predictive of gross motor function into adulthood, particularly for people with severe disability. People who can walk without mobility devices at age 12 have an 88% probability of having a similar functional ability as an adult (McCormick et al., 2007). However, a large longitudinal study of 657 people with CP aged 16 months to 21 years identified clinically significant declines in gross motor function during the transition to adulthood for people with GMFCS levels III to V, although much variability in the degree of functional loss was noted (Hanna et al., 2009). For those who experience a decline in GMFCS level during adulthood, often this is because of a person’s personal
preference to use an easier, safer, faster mobility aid (eg. a manual wheelchair) because of pain, fatigue, diminished muscle strength, worsening contractures or joint degeneration (McCormick et al., 2007). The GMFCS assesses usual performance, not capacity. Therefore, people who make a personal choice to utilise a mobility aid for environmental (eg. distances of travel required to participate in work or study) or personal (eg social preference) reasons, will be classified as having a lower level of motor function, regardless of whether they still have the capacity to mobilise without an aid (Palisano et al., 2007).

The majority of people who lose their capacity for independent walking in adulthood experience frustration and disappointment, even though their overall independence may increase with the use of mobility aids. Bottos and colleagues (2001) suggest that there should be less focus on achievement of independent walking during paediatric therapy given that a significant number of people who achieve this later lose the ability. Instead they recommend “an approach that is more independence oriented and less concerned with the symbolic importance of independent walking” (Bottos et al., 2001, p. 526).

In addition to the neuro-muscular and movement related impairments that are central to CP, many other health problems are associated with the condition. These are now introduced.

2.4.4.2 Impairments co-occurring with CP

An Australian systemic review and meta-analysis (Novak et al., 2012) of research provides a higher level of evidence around the incidence of these co-occurring impairments than has previously been available. This review appraised 82 studies, including 30 which were found to be of suitable quality for inclusion in the meta-analyses. Results showed that nearly half (49%) of people with CP also had an intellectual disability (IQ<70), including 28% with a severe intellectual disability (IQ<50). Other commonly co-occurring impairments included being nonverbal (23%), pathologic sleep disorders (23%), pain (75%), epilepsy (35%), excessive drooling (22%), bladder control problems (24%), displaced hips (28%), behaviour
problems (26%), requiring tube-feeding (6%), functional blindness (11%), and severe hearing impairment or deafness (4%) (Novak et al., 2012). There was high or moderate quality evidence of all of the above, except for sleep disorders. The authors noted a particular need for further research in this area (Novak et al., 2012).

This study also found that the presence of these co-occurring impairments was strongly linked to the severity of the motor impairment, with the exception of pain and behaviour problems. Pain is commonly present across all levels of physical disability while behaviour disorders are more common in children with less severe motor impairment (Novak et al., 2012). Canadian and Australian population-based registry research concurs that people with GMFCS levels IV and V are significantly more likely to experience comorbidities. Type of CP is also relevant, with people with spastic hemiplegia or diplegia experiencing less comorbidity than people with other types of CP (Delacy, Reid, & Australian Cerebral Palsy Register Group, 2016; Shevell, Dagenais, Hall, & on behalf of the REPACQ Consortium, 2009). Many people with CP will have a number of these impairments in combination, with the potential to further complicate therapy, decrease health status and quality of life for the individual and their family, and increase costs (McIntyre et al., 2011). The impact of comorbidities should be considered to be at least as important as the primary motor impairment when considering the experiences of people with CP. In addition, the presence of such chronic functional limitations contributes to significant social challenges (Rosenbaum, 2003).

The following section moves from what we know about CP as a whole, to explore current knowledge about CP in emerging adults.

2.4.4.3 Body structure and function in emerging adults with CP

A small, but expanding, amount of research has specifically explored body structure and function issues for emerging adults and adults with CP. Musculoskeletal impairments, including hip displacement, contractures, bony deformities, osteoporosis, and dislocations all impact on adults with CP, although the true
incidence of these complications is yet to be documented in large, high quality studies (Murphy, Molnar, & Lankasky, 1995; Tosi, Maher, Moore, Goldstein, & Aisen, 2009). A small (n=30) study of 11-29 year olds with CP also identified that mental health problems are common, with 63% experiencing anxiety and 10% depression (Krakovsky, Huth, Lin, & Levin, 2007). A USA study with 74 people aged 20-30 with CP or spina bifida found that 43% had significant depressive symptoms, compared to 21% of participants without motor disabilities (Galambos, Magill-Evans, & Darrah, 2008). Similarly, 42% of 97 emerging adults surveyed in a recent USA study disclosed experiencing depression (Sienko, 2018). High levels of depression, anxiety and stress have also been reported elsewhere (Colver, 2012; Lindsay, 2016a; Lumsdaine & Thurston, 2017) and one Canadian study identified mental illness as the third most common reason for hospital admission in 23-32 year olds with CP, only exceeded by complications from epilepsy and pneumonia (Young et al., 2011). Bullying and social isolation have been identified as contributing factors to these concerning rates of mental health problems in young people with CP (King et al., 2018; Lindsay, 2016a).

One study which assessed the health status of 48 people aged over 20 years (mean 32.9 years) with CP using the Euro-Qol questionnaire identified that this group’s health is significantly worse than the general population. Those with the lowest level of gross motor function had a poorer health status than those with higher levels of function (Sandstrom, Alinder, & Oberg, 2004). Canadian research with 199 people aged 13-33 found similar results (Young et al., 2010). Only 53.3% reported their health to be excellent or very good and the percentage decreased with age. Quality of life was also impacted, and scores for this group of people with CP were significantly lower than scores in previous studies of people with other severe health conditions. Those with more severe disabilities based on higher GMFCS levels had the poorest quality of life (Young et al., 2010). Recent Australian research provides additional support for the link between higher GMFCS levels and poorer quality of life in relation to physical health (Jiang, Walstabel Reid, Davis, & Reddihough, 2016). Of concern also is that gross motor function may actually deteriorate between adolescence and adulthood for a significant number of people
with CP (Roebroeck, Jahnsen, Carona, Kent, & Chamberlain, 2009; Sandstrom et al., 2004).

An eight-year follow-up study of 31 adults with CP was undertaken in Canada (Usuba et al., 2014). Participants were aged 23-27 at follow-up, and 23% had experienced deterioration in gross motor function over the previous eight years. There were no significant changes, however, in health-related quality of life over the same period. The study compared this group to an older group aged 33-42 and identified that the older group experienced an increased risk of declines in both gross motor function and health related quality of life (Usuba et al., 2014).

Pain and fatigue are also significant challenges for many people with CP. USA research with 100 adults with CP identified that 67% of participants experienced chronic pain in at least one area, especially in the lower back, hips and legs, with 24% being in constant pain. The presence of chronic pain was also associated with higher levels of psychological distress (Engel, Jensen, Hoffman, & Kartin, 2003). A qualitative Australian study explored in further detail the experience of chronic pain for six young people with CP aged 14-24. These young people were in constant pain which was very difficult to relieve and it was noted that this pain had the potential to “spill over into every aspect of your life” (Castle, Imms, & Howie, 2007, p. 448). Participants were frustrated, restricted in their activities and isolated, and feared the ongoing impact of pain on their lives. For these participants, any benefits of pain treatments were only temporary and “nothing worked” long-term (Castle et al., 2007, p. 447). Canadian research with ten 14-25 year olds with CP, GMFCS levels I to III, explored the bodily experience of having CP (Brunton & Bartlett, 2013). This phenomenological study identified fatigue and pain as being the central bodily issues experienced by participants. More specifically, pain related to a feeling of muscle soreness, and fatigue was most often the result of prolonged walking and activity. Participants spoke of pushing themselves too hard physically, of having to develop self-awareness about their physical limits and adapt their activities accordingly, for example by building in rest breaks (Brunton & Bartlett, 2013). Pain, fatigue and physical deterioration have also been reported elsewhere by 19-30 year
olds with CP in Sweden (Bergqvist, Öhrvall, Himmelmann, & Peny-Dahlstrand, 2017). This qualitative research highlighted such experiences occurred particularly when young people pushed themselves to perform activities independently, and in a similar way to peers without disability. Participants emphasised that “doing” is very meaningful, and inherent to their sense of self and sense of belonging. Hence, they pushed themselves to perform activities, regardless of the “price” of pain, mental and physical fatigue, and stress (Bergqvist et al., 2017, p. 4).

The following section briefly introduces the medical and broader healthcare responses to the body function and structure impairments resulting from CP.

2.4.5 Medical and health management of body structures and function

Healthcare services for people with cerebral palsy typically involve the provision of services from a multidisciplinary team. The specific services required will depend on severity of disability and the areas of function affected. Management of CP is a complex issue as it must encompass management of both the motor disorder itself and multiple comorbidities. Typically however, services are likely to be provided by primary care physicians as well as physicians specialising in the area of paediatrics, neurology and orthopaedics, occupational therapists, physiotherapists, speech-language pathologists, orthotists, and social workers (Aisen et al., 2011; Pellegrino & Meyer, 1998; Smith & Kurian, 2012).

Management will typically address such issues as positioning, therapeutic exercise, functional training, stretching, strengthening, communication skills and the provision of adaptive devices and equipment to promote optimal function and environmental participation (Aisen et al., 2011; Koman, Smith, & Shilt, 2004; Matthews & Wilson, 1999; Papavasiliou, 2008). Examples of effective interventions include casting, hip surveillance, constraint-induced movement therapy, fitness training, pressure care, and bimanual training (Novak et al., 2013). Best practice suggests that the most effective treatment approaches are active approaches that
are goal-based, task-specific, and conducted in real-life environments (Novak, 2014). People with CP may require pharmacological treatments for spasticity or associated conditions including epilepsy. Spasticity can also be temporarily alleviated with injections of botulinum toxin A (Aisen et al., 2011; Novak et al., 2013).

Many people with CP require surgical management in addition to less invasive therapies, orthoses and equipment. Surgeries may be in response to a range of problems, including joint dislocations or subluxations, scoliosis, misalignment or instability of joints and soft tissue contractures. Surgeries may address a range of goals, including improved function, pain reduction, improved cosmetic outcomes, and reduction of related symptoms (Aisen et al., 2011; Koman et al., 2004; Roberts, 2012). Recent advances in neuroscience suggest that the central nervous system has some potential for plasticity throughout the lifespan, leading to the development of new treatments designed to capitalise on this plasticity, including constraint-induced movement therapy. Other recent technological advances requiring further study include robotic therapy, the addition of virtual reality into physical interventions (Aisen et al., 2011) and stem cell therapies (Smith & Kurian, 2012).

Historically, medical management of people with CP has focused heavily on children and on trying to ‘fix’ the underlying impairments and help people perform activities ‘normally’. It is now recognised that this approach may limit the participation of people with disability. Rosenbaum and Gorter (2011) recently proposed a series of other ‘F-words’ which they feel better suit our current state of knowledge about disability. It is now acknowledged that promoting ‘function’ and participation should be a key goal, regardless of whether this is achieved in the way most people without disabilities would achieve it. Current thinking also emphasises the importance of providing supports and resources to the whole ‘family’, considering exercise and ‘fitness’ goals, and focusing on ‘fun’. Focusing on fun means that people should be supported to participate in activities they enjoy, with adaptations if needed. Developing ‘friendships’ is another priority for young people, and service
providers should consider how they can encourage opportunities for the development of meaningful connections. Lastly, the ‘F-words’ approach recognises the importance of thinking about the ‘future’ and encouraging positive expectations about the possibilities available to people with disability (Rosenbaum & Gorter, 2011).

Unfortunately, however, the current state of knowledge around interventions for cerebral palsy remains firmly focused on the body structure, function and activities levels of the ICF. A recent systemic review of interventions for treating children with cerebral palsy identified an issue of significant concern: “there were no proven effective interventions for addressing the participation, environment, or personal factors levels of the ICF, even though these are philosophical priorities” (Novak et al., 2013, p. 899). The state of knowledge around healthcare service provision specifically for emerging adults with CP, as they transition between paediatric and adult services, are discussed in section 2.6: emerging adults with CP and the environment.

The following sections discuss what is currently known about how the presence of CP and associated impairments impacts on emerging adults’ experiences of activities and participation, and the influence of environmental and personal factors. Research focused on these areas has become significantly more prevalent since 2000 than in earlier research, reflecting greater recognition that disability is the result of the interaction between body structure and function issues and contextual issues (Kembhavi, Darrah, Payne, & Plesuk, 2011).

2.5 Emerging adults with CP: Activities and participation

This section explores the current state of knowledge in relation to the outcomes and experiences of emerging adults with CP in relation to their daily activities and participation. There is no existing research that specifically explores the experiences of young people with CP in the context of the theory of emerging adulthood. Indeed
the application of the concept of emerging adulthood to youth with any type of
disability requires much more exploration (Hinton & Meyer, 2014; Stewart, 2013).
While not from formal research, one personal account of emerging adulthood
written by a person living with cerebral palsy has been published in a recent
textbook (Shapiro, 2017). Matthew Shapiro, 25, highlights the importance of facing
challenges head on and being self-determined. Faced with challenges securing full-
time employment, he established a disability consultancy company. He aspires to a
career in public service, and later politics. Matthew’s story emphasises his
motivation to be a role model for others with disabilities, through education,
advocacy and mentoring. He highlights the need for adults who assist people with
disabilities during the transition to adulthood to be “facilitators and not dream
 crushers” (Shapiro, 2017, p. 5). The current study offers insights into the stories of
other emerging adults with CP, and contributes to redressing current gaps in
knowledge.

It is recognised that transition experiences are individual and complex and
influenced by a multitude of interactions occurring between factors. These
interactions and complexities require further study (Gorter et al., 2014; Stewart et
al., 2010). However, for ease of reading, this section is divided into three inter-
related parts, based on domains within the activities and participation component
of the ICF. Experiences and outcomes in relation to communication, mobility, self-
care and domestic life are explored first, followed by relationships, social and civic
life. Lastly, experiences and outcomes in the major life areas of emerging adulthood
are detailed; education, training and employment.

2.5.1 Communication, mobility, self-care and domestic life

In one Australian study evaluating the health status of 66 young people with CP, 37
percent of the study subjects were dependent on others to perform activities of
daily living (ADL), as measured by the Barthel Index (Cathels & Reddiough, 1993).
More recent case-control research with 20-30 year olds with CP, also in Australia,
identified that while half of young people could walk independently, only 35.5%
were independent in self-care. They were also much more likely to be living with
their parents than a population-based control group (80% compared to 21% respectively) (Reddihough et al., 2013). For people with more severe disabilities, communication difficulties have been identified as a particular challenge, which can reduce the capacity of some young people to “have a say” in what happens in their lives. There was evidence in one study with 15-20 year olds with high support needs that little effort had been put in by some schools and residential homes to maximise a young person’s communication abilities, or even to utilise existing skills (Morris, 2001, p. 19).

Research in the Netherlands identified that even emerging adults (18-22 years) with high levels of gross motor function (82% GMFCS I or II) and normal intelligence commonly experienced problems in everyday life (Nieuwenhuijsen et al., 2009). Fifty-nine percent of the 87 participants reported problems with self-care, 47% with functional mobility, 52% with productivity (including work, study and household management) and 37% with leisure activities, in particular active recreation such as sport (28%). Participants rated functional mobility and work as the issues of highest importance to them, indicating a need for rehabilitation services to continue to address these issues into adulthood for emerging adults with CP (Nieuwenhuijsen et al., 2009). Other research has identified similar restrictions in mobility, self-care, employment, community living and leisure activities for emerging adults with CP, even for those without cognitive impairment (Donkervoort et al., 2007). Seventy percent of the variance in outcomes in daily activities, and 66% of the variance in social participation was attributable to GMFCS level, level of education, and age, indicating that these factors play a significant role in young people’s outcomes. It is likely that environmental and other personal factors including self-efficacy may also contribute to functional outcomes, although further research is needed in this area (Donkervoort et al., 2007). The limited knowledge basis currently available in this area is explored in sections 2.6 and 2.7.

Recent Australian research specifically explored the housing outcomes and experiences of people with a broad range of disabilities, utilising statistical data and qualitative interviews (Wiesel et al., 2015). People with disabilities are significantly
more likely to remain living with their parents, are over-represented in social housing and homelessness, and are significantly less likely to own their own home than people without disability. Many live in group homes or institutional settings. Barriers identified include a shortfall in accessible housing stock, affordability, difficulty accessing finance, a lack of rental history and references, and discrimination from potential landlords (Wiesel et al., 2015). Unemployment and underemployment also influence the capacity of many emerging adults with disabilities to leave their parental home, along with the need for ongoing daily assistance (Leiter & Waugh, 2009). International research specifically exploring housing of people with CP identified similar poor outcomes. Of 72 Italian adults with CP aged between 19 and 65 years, 75% remained living with their parents and only 12.5% lived by themselves. In Canada, 21.4% of 70 23-33 year olds with CP were living alone or with a partner, while 61.4% remained at home with their parents (Young et al., 2006). The remainder were living in institutions or group homes. Outcomes are particularly poor for those with comorbid intellectual disabilities (Bottos et al., 2001), however even young people with no intellectual disability and mild CP, as represented by GMFCS Level I, lag behind their peers without disabilities in relation to independent housing (Donkervoort, Wirgerink, van Meeteren, Stam, & Roebroeck, 2009).

An emerging concern in research is that ADL function for people with CP may in fact deteriorate during adulthood. One Japanese study identified functional deterioration in relation to locomotion and eating meals in 35% of adult participants (Ando & Ueda, 2000). A recent longitudinal study in The Netherlands highlighted increases in pain and fatigue, and deterioration in mobility and self-care during adulthood. Perceived health and functional level also decreased (Benner, Hilberink, Veenis, Stam, et al., 2017). Longitudinal Canadian research identified that such functional declines into adulthood were most common in people with more severe levels of disability (Hanna et al., 2009), while USA research found high incidence of pain and fatigue across all GMFCS levels in 18-30 year olds with CP (Sienko, 2018).
It is clear from this limited body of knowledge that emerging adults with CP are likely to experience challenges and poorer outcomes in the areas of mobility, self-care and domestic life in comparison to their peers without disability. What is missing from this discussion is the first-hand perspective of young people about their experience of these challenges; how they describe them, how they feel about them, and what stories they tell about them. The current study contributes to filling this gap.

2.5.2 Relationships, social and civic life

The limited Australian and International research around relationships, social and civic life has found emerging adulthood for young people with CP to be fraught with challenges. Young people with CP participate in less social activities, have less social contact, less intimate relationships and are provided with less information about important topics such as relationships and sex than their peers without disabilities (Blum et al., 1991; East & Orchard, 2014; Stevenson et al., 1997; Wiegerink et al., 2006; Wiegerink, Roebroeck, et al., 2010). People with severe or multiple disabilities, and those with cognitive impairments, face particularly high levels of disadvantage (Bottos et al., 2001; Morris, 2001; Reddihough et al., 2013; Tan et al., 2014; Wiegerink, Roebroeck, et al., 2010). Young people with the ability to walk without restrictions have higher levels of social and community participation than people with lower levels of gross motor function (Boucher, Dumas, Maltais, & Richards, 2010; Palisano et al., 2009). However, even those with the mildest CP (GMFCS Level I), have poorer outcomes than their peers without disability (Donkervoort et al., 2009).

The social and leisure activities young people with CP do participate in are more likely to be informal, passive, home-based, and performed alone or with parents rather than with peers (Shikako-Thomas, Shevell, et al., 2013). Unfortunately, research indicates that as children with CP move into emerging adulthood, their participation in recreational, physical and skill-based activities becomes even more restricted (Imms & Adair, 2017; Orlin et al., 2010). One recent study has found some positive increases in social activity participation during this period; however the lack
of comparison with young people without disability makes it difficult to interpret this finding (Imms & Adair, 2017). Young people with CP aged 9-21 and their parents have reported a range of facilitators or barriers to participation in physical activities specifically. These include physical limitations related to impairments in body structure or function, including fatigue or pain, environmental factors including availability (or lack) of adaptive equipment and devices, the presence (or lack) of knowledgeable support people, accessibility (or lack) of facilities and programs, and personal factors including self-perception, identity, and level of confidence (Shimmell, Gorter, Jackson, Wright, & Galuppi, 2013). One valuable exception identified as beneficial by some young people is participation in disability sport. Participants with mobility impairments aged 17-23 in a recent Scottish study identified benefits to not only physical health, but also social support and a sense of belonging, self-esteem and confidence, and reduced boredom and loneliness (Lumsdaine & Thurston, 2017).

In respect to relationships with parents, emerging adulthood is a time of renegotiating the parent-child relationship. Qualitative research in Canada with 20-23 year olds with CP identified that young people were ready for increased autonomy from their parents. Some desired this because it was what other young people had and others because of increasing conflict within the family. Personal care needs were a barrier to increased autonomy for some young people whose families could not afford private services (Magill-Evans, Wiart, Darrah, & Kratochvil, 2005). This sentiment was echoed in qualitative research with the parents of fourteen 12-19 year olds with cerebral palsy, which identified physical dependence as a barrier to the privacy afforded to most emerging adults by their parents (Shikako-Thomas, Bogossian, Lach, Shevell, & Majnemer, 2013). Research conducted in the USA (Maggs et al., 2011) has identified that parents and their emerging adult children with CP do not necessarily agree on priorities for activities and participation, which could be a trigger for some of the conflict reported above. Young people were more likely to emphasise goals in education, employment, money management, transportation and travel, whereas their parents focused
more on priorities around self-identity, including friendships, hobbies and self-advocacy (Maggs et al., 2011).

Most young people aged 12-22 with CP in one study reported strong relationships with their parents. However, 33.3% of participants identified that they were treated like children and overprotected by their parents. Participants resented this treatment, and also displayed lower happiness, self-esteem and higher levels of anxiety than those who felt they were treated in an age-appropriate manner (Blum et al., 1991). A more recent Swedish study (Bjorquist et al., 2014) explored the qualitative transition experiences of twelve 17-18 year olds with CP from their own perspective, and identified similar themes in relation to parents. Participants enjoyed the security of living in their parental home and the fact that it meant they were rarely alone. However, they also reported feeling controlled and overprotected at times. They enjoyed opportunities to be away from their parents, even to simply be able to close their door. They looked forward to an independent future, but were not yet ready to move away from home, and worried about what it would be like and what support they would need (Bjorquist et al., 2014).

This same group of young people also reported many challenges in finding and maintaining friendships and relationships. Some experienced teasing and bullying, and many friends were only seen at school or during formal extracurricular activities. Participants especially felt they did not have the knowledge or confidence to pursue a romantic relationship. Practical challenges were also noted with participating in social and leisure activities. The fact that activities needed to be organised in advance was problematic and participants wished for a greater level of spontaneity (Bjorquist et al., 2014). Research conducted in the UK with people with severe disabilities identified similar challenges regarding making friends and participating in leisure activities. Unfortunately, the observation component of this research also identified that quite often young people are not effectively supported to make and interact with friends by their carers or teachers (Morris, 2001). Narrative research with Australians with CP aged 14-16 reinforced the importance of relationships with family and friends to these young people; they do want to be
actively involved in social and leisure activities, reflecting goals common to most young people (Cussen, Howie, & Imms, 2012). This emphasises the need for more work to be done to both build the capacity of young people and break down the barriers they face in forming relationships.

The struggles for emerging adults with CP continue in relation to intimate relationships. An Australian case-control study with 335, 20-30 year olds with CP found that only 20% of participants had ever been married or partnered, compared to 70% of a population control group (Reddihough et al., 2013). Another Australian study with 60 people with physical disability identified that 38.6% had never experienced intercourse (McCabe, 1999). International research from Sweden and Italy has identified similar low levels of participation in intimate relationships, along with very few adults with CP having had children (Bottos et al., 2001; Sandstrom et al., 2004). A recent meta-analysis including data from 89,943 emerging and young adults with a range of chronic illnesses and disabilities found that the rate of being married/living in a de-facto relationship was reduced by 25% and the rate of having children by 38%, in comparison to peers without disability (Pinquart, 2014). Those with intellectual disability are particularly disadvantaged (Bottos et al., 2001; Reddihough et al., 2013), while people with physical disability, such as CP, have lower participation in relationships and sexual intercourse than those with sensory impairments (Retznik et al., 2017).

Research has identified that despite the low participation rates in romantic relationships and sexual activities, young people with CP have the same level of sexual interest as their peers without disabilities and a strong desire to know more about sexuality (East & Orchard, 2014; McCabe, 1999; McCabe et al., 2000; Wiegerink, Stam, et al., 2010). Unfortunately, research in the UK has identified that adults and carers often assume that sexuality is irrelevant to these young people, despite evidence to the contrary (Morris, 2001). Qualitative research in the USA with health professionals and disability service providers similarly highlighted a lack of discussion regarding sexuality with youth with physical disability, along with an unmet need for information about adaptation for sexual behaviours (Secor-Turner,
McMorris, & Scal, 2017). Of concern within Australian research, only 56% had ever received any sex education. Those that had received education were likely to have received it from the media or formal sex education classes, which is in comparison to the general population who are more likely to learn about sex from their parents or friends. This lack of discussion may convey negative messages to people with physical disability about their sexuality and lead to negative feelings about sexuality (McCabe, 1999). Other barriers to sexual experience include inadequate social skills, social isolation, lack of opportunity and practical barriers to dating, difficulty finding partners, and a fear of rejection (Howland & Rintala, 2001). Poor outcomes in this area are of particular concern given that research has shown a direct link between having a partner and maintaining sexual relationships, and measures of quality of life for adults with CP (Maestro-Gonzalez et al., 2018).

In sum, emerging adults with CP have the same goals as their peers in relation to having an active social and civic life, and participating in meaningful relationships. Despite this, their experiences remain restricted. Little is known about how young people feel about this, with few opportunities having been provided for emerging adults with CP to tell their stories about relationships and social life. The current study adds to knowledge in this area.

2.5.3 Major life areas: Education, training and employment

In relation to education, training and employment, a recent Australian case-control study (Reddihough et al., 2013) explored outcomes of 20-30 year olds with CP compared to an age-matched population sample. Young adults with CP had significantly lower levels of educational attainment, with only 50% having completed secondary education compared to 80% of the controls, and 36% having completed tertiary education compared with 53% of controls. They were also much more likely to be unemployed, with only 36.3% working compared to 80% of the control group (Reddihough et al., 2013). The employment rate of people with disability as a whole in Australia currently sits 30% lower than that of people without disability. Statistics from the year 2015 identified that just over half (53.4%) of people with disability were participating in the labour force compared to 83.2%
of people without disability (Australian Bureau of Statistics, 2016). People with severe or profound disabilities are at the greatest risk of being unemployed, with only 25% in the labour force. This figure is lower than when the survey was last conducted in 2012, when 29.7% of this group were working. Even those Australians with disability who are working are much more likely to be working part-time and to be underemployed than people without disability (Australian Bureau of Statistics, 2016). Australia is performing poorly in comparison to other Organisation for Economic Cooperation and Development (OECD) countries in this regard, currently ranked 21/29 in relation to employment rates of people with disability (OECD, 2010).

International research has identified similar trends in education and employment restrictions for young adults with CP (Benner, Hilberink, Veenis, van der Slot, & Roebroeck, 2017; Darrah, Magill-Evans, Galambos, & Nickerson, 2008; Huang, Wang, & Chan, 2013; Sandstrom et al., 2004; Verhoef, Bramsen, Miedema, Stam, & Roebroeck, 2014). A meta-analysis including data from 89,943 emerging and young adults with a range of chronic illnesses and disabilities found that the rate of completing higher education was reduced by 23% and the employment rate by 25% in comparison to people without disability. Young people with neurological disabilities including CP or sensory disabilities, and those with highly visible disabilities, had the lowest rates of success (Pinquart, 2014).

Participants in an Italian study of 72 adults with CP had a low level of education, with only seven having attended university or college. Unemployment was also high; 66.1% were not working and 16.1% worked in supported employment. Only 17.7% had achieved competitive employment (Bottos et al., 2001). A Danish Cerebral Palsy Register study of 819 participants aged 21-25 identified that significantly less young people with CP versus a control group of people without disability had achieved a vocational (17% v 38%) or tertiary (9% v 20%) qualification. Employment outcomes were similarly disappointing, with only 29% of participants being competitively employed in comparison to 82% of controls (Michelsen, Uldall, Kejs, & Madsen, 2005). Canadian research has identified similar poor outcomes,
with only 27% of 70 23-33 year olds with CP having attended any college or university, 35.7% working, and only 20% working full-time (Young et al., 2006). A more recent Canadian study with youth aged 16-19 with physical disability found similar results, with only 35.5% of youth with disability having a current job or previous work experience compared to 70.5% of their peers (Lindsay, McDougall, Menna-Dack, Sanford, & Adams, 2015). A recent review identified that even participation in volunteer work is difficult, with young people with disability facing challenges finding accessible opportunities, suitable transport options and welcoming supervisors (Lindsay, 2016b). This is of concern given the links between volunteer work and transition to paid employment, increased community engagement, improved social and work skills and self-confidence (Lindsay, 2016b).

Challenges in relation to education and employment have also been noted in previous qualitative research. In a UK study with seventy-two 21-35 year olds with a range of disabilities, employment rates were low and those who were working were mostly in poorly paid jobs (Hendey & Pascall, 2001). Some participants avoided looking for work for fear of losing their benefits. Barriers to employment identified by participants included a “hostile” labour market, discriminatory employers, limited support for personal assistance and difficulty earning enough to cover the additional support costs required (Hendey & Pascall, 2001, p. 14). A recent National inquiry by the Australian Human Rights Commission (2016) identified similar barriers to employment through its 120 public consultations and 342 submissions. The inquiry identified employment discrimination against people with disability as “ongoing and systemic” and concluded that discrimination results from negative assumptions around the capacity of people with disability, attitudes and stereotypes, unfounded beliefs that people with disability present a significant work health and safety risk, a lack of knowledge and skills to facilitate inclusive workplaces, and low levels of awareness of supports available (Australian Human Rights Commission, 2016, p. 12). In 2014-15, 41% of disability discrimination complaints received by the Australian Human Rights Commission were in relation to employment discrimination (Australian Human Rights Commission, 2016).
It is important, and disappointing, to note that participation in employment of adults with CP does not appear to have improved to any great extent in recent decades. American research published in 1995 with 117 adults with CP aged 17-51 identified that fewer than half (48.7%) were employed (O'Grady, Crain, & Kohn, 1995). Over twenty years ago, these authors hoped that increased educational opportunities, assistive technology and improved legal rights would lead to improved participation of adults with CP (O'Grady et al., 1995). Unfortunately, outcomes remain poor and much more needs to be done to facilitate improved participation and success in education and employment. Australian statistics present similar worrying findings, with the overall employment rate of people with disability having changed very little in over 20 years (Australian Human Rights Commission, 2016). Of particular concern, as previously noted, is that the employment rate of people with severe and profound disability actually decreased by nearly five percentage points between 2012 and 2015 (Australian Bureau of Statistics, 2016).

Improving outcomes in this area is vital because employment has the capacity to improve social inclusion, mental health, self-esteem, and quality of life, and to foster a sense of purpose (Cocks et al., 2015; Merton & Bateman, 2007). In comparison, unemployment leads to poor outcomes including poverty, distress, social exclusion and anxiety (Australian Council of Social Service, 2014). People with disabilities face even greater disadvantage than other people experiencing unemployment (Cocks et al., 2015). Recent Australian research has demonstrated that 20-30 year olds with CP have poorer quality of life in relation to performance in productive roles such as employment, than their peers without disability (Jiang et al., 2016). The worst outcomes are currently seen for young people with low levels of education, intellectual disability, bilateral CP, and more severe physical limitations (GMFCS IV and V) (Benner, Hilberink, Veenis, van der Slot, et al., 2017; Bottos et al., 2001; Darrah et al., 2008; Huang, Wang, et al., 2013; Lindsay, 2011a; Michelsen et al., 2005; Van Naarden Braun et al., 2005). Those with low incomes and those living in rural areas also face additional disadvantage (Lindsay, 2011a). A recent International systematic review has also identified concerning findings in
relation to gender, with the majority of research reviewed finding employment outcomes are worse for young women than men. Contributing factors identified include lowered expectations, parental overprotectiveness and poorer self-confidence (Lindsay, Cagliostro, Albarico, Srikanthan, & Mortaji, 2017).

Despite the additional challenges identified for people with more severe physical limitations, intellectual disability, and young women, even emerging adults with CP GMFCS Level I and no intellectual disability have significantly lower levels of employment than their peers without disability (Donkervoort et al., 2009). Research in the UK has shown that young people with disability at age 16 have similar aspirations in relation to expected level of qualifications, attainment of a professional occupation, and pay rates, as their peers without disability. However by age 26, their outcomes fall well behind their peers (Burchardt, 2005). This discrepancy between aspirations and outcomes is further evidence of the need for improvements in this area.

In summary, successful transitions reflect those that enable a young person to engage in adult roles which align with their goals, strengths, and needs (King, Baldwin, Currie, & Evans, 2005). It is clear from the above discussion that the participation and engagement of emerging adults with CP is often limited in a range of life areas in comparison to that of young people without disability. Of additional concern is that current evidence suggests that participation has not improved in recent years, and that young people do desire a greater level of participation (Meulenkamp, Cardol, van der Hoek, Francke, & Rijken, 2013). Despite this evidence, in-depth personal accounts of experiences have rarely been told, and the current study contributes to this gap in knowledge.

It is now widely recognised that a person’s impairment is only one of a number of factors influencing their experiences. Important interactions exist between a person’s impairment and their environment, and a range of personal factors also influence experience. All areas must be addressed in order to facilitate improved participation of emerging adults with CP (Stewart et al., 2013). The current state of
knowledge about environmental and personal factors influencing experience is now explored.

### 2.6 Emerging adults with CP and the environment

Young people with CP and other physical disabilities want to participate in their community, to fit in. They want mentors, advocacy, networks, peer support, and services to focus on environmental supports and facilitating opportunities for community participation (Morris, 1999; Stewart et al., 2001). They have similar aspirations to all young people: fitness, education, training and a career, financial security, friends, a relationship and hobbies and interests (Emerson, Honey, & Llewellyn, 2008). Morris summarised the desires of sixteen 17-29 year olds with complex health conditions: “they want the same things that any young person wants as they grow into adulthood: they want friends, sex, money, a place to call their own and the freedom to do the things they enjoy doing” (Morris, 1999, p. 137). Unfortunately, they experience many environmental barriers to achieving these goals, including bullying, negative attitudes, discrimination, lack of physical access and transport options, and a lack of friends to facilitate an independent social life that does not rely on family (Morris, 2001).

This section discusses these issues in more detail. It explores what is currently known about the experiences of emerging adults with CP in relation to environmental barriers and facilitators. There are a multitude of factors constituting environment and multiple interactions between environmental factors contributing to young people’s overall experiences. For simplicity, this section is divided into three parts, reflecting related key domains within the environment construct of the ICF. Current knowledge around support, relationships and attitudes is explored, followed by what is known about the services, systems and policies contributing to emerging adults’ experience. What is known about the influence of the physical environment, products and technology is also detailed.
2.6.1 Support, relationships, and attitudes

Research indicates that emerging adults with CP face many environmental issues in regards to support, relationships and attitudes. Some experiences reflect environmental facilitators, however many reflect the presence of environmental barriers. In her study of 15-20 year olds with high support needs, Morris referred to many of the young people being “institutionalised within the community”, living extremely limited and isolated lives with little contact with the community, especially with other people without disabilities (Morris, 2001, p. 44). King and colleagues’ qualitative research with 10 young people aged 18-20 reinforced similar concepts. Participants wanted to have a sense of belonging, to feel accepted, and to fit in, both with groups of people without disabilities, and also with disabilities. However, many experienced difficulties fitting in and felt a lack of acceptance from their peers, reinforcing the need for significant efforts to promote attitudes of acceptance within the community (King et al., 2000). Very recently, this view has been reaffirmed as still pertinent today, with a systematic review of qualitative research with 2-25 year olds with CP identifying social isolation and exclusion from peers as a major theme which threatens young people’s self-image and confidence (Lindsay, 2016a). The negative outcomes of a lack of acceptance have been reinforced by parents of 12-19 year olds with CP, who linked negative attitudes and stigma with adverse impacts on their child’s overall quality of life (Shikako-Thomas, Bogossian, et al., 2013). Another recent focus group study confirmed the ongoing barriers to participation experienced by 19-35 year olds with CP as a result of negative stereotypes and prejudice (Bagatell, Chan, Rauch, & Thorpe, 2017).

Negative attitudes, stereotypes, stigma and a lack of respect for difference were identified in Australian qualitative research with emerging adults as major barriers to citizenship for people with disability (Yeung, Passmore, & Packer, 2008). In another qualitative study, poor attitudes due to a lack of knowledge or understanding were identified as “the number one barrier facing all persons with disabilities” (Stewart et al., 2014, p. 2001). Participants also identified other environmental barriers including the low expectations others hold in relation to
what young people with disability are capable of, and difficulties participating in mainstream community activities, which in turn reduces the opportunities to change negative attitudes and misperception. This led to participants’ concern that “nothing’s going to change” (Stewart et al., 2014, p. 2001).

A Greek qualitative study explored the reflections of thirty-two 19-26 year olds with physical or sensory disabilities specifically in relation to their experiences of primary and secondary schooling (Vlachou & Papananou, 2015). Findings emphasised the social aspect of education and identified that while there were examples of meaningful peer relationships, a significant number of young people struggled with feeling different to their peers, and many faced “disablism”, exclusion and bullying (Vlachou & Papananou, 2015, p. 80). Of additional concern were experiences that have also been reported elsewhere, of teachers demonstrating ignorance, low expectations, negative assumptions, overprotectiveness, exclusion, or only tokenistic attempts at inclusion (Lumsdaine & Thurston, 2017; Vlachou & Papananou, 2015). Challenges continue in tertiary education, with 20 university students with disability in the UK reporting feeling “extravisible” to their peers, being initially unaware of support available and falling behind before seeking help. Even those who did seek help reported having to advocate and push for adjustments to be put in place and contend with extensive delays (Goode, 2007, p. 42).

A qualitative meta-synthesis of 15 research studies explored the perceptions of children and youth with a range of disabilities in relation to the impact of the environment on participation (Kramer, Olsen, Mermelstein, Balcells, & Liljenquist, 2012). The perspectives and attitudes of peers and educators were seen to influence school participation significantly. Those who had a good understanding of disability were able to provide appropriate support, while others under or over-estimated support needs. Good participation outcomes were noted where services were individualised to the unique needs of the person with disability and collaborative decision making about reasonable adjustments was employed,
including active input of the young person. Bullying from peers was commonly cited as a significant barrier to participation (Kramer et al., 2012).

Qualitative research with children and adolescents (Lindsay & McPherson, 2012) and adult women (Freeborn & Mandleco, 2010) with CP has identified similar environmental barriers to participation in education. Participants reported experiencing being talked down to or ignored by teachers, teachers who did not understand their disability or adjustments needed, their academic capabilities not being recognised, and some were even accused of being given an unfair advantage when adjustments were put in place for them. Teasing, bullying, social rejection, exclusion and even physical abuse by peers were also commonly experienced (Freeborn & Mandleco, 2010; Lindsay & McPherson, 2012). Other qualitative research has also emphasised similar challenges arising through the stigma attached to disability; in one study it was identified that not looking ‘disabled enough’ was a barrier to accessing support for people with milder CP, leading to the frustration of having to justify their right to access support, and feelings of guilt that perhaps there were people more ‘worthy’ of assistance (Read, Morton, & Ryan, 2015). University students with a range of disabilities have reported adjustments not meeting their needs, or choosing not to disclose their disability to seek adjustments until they were experiencing serious difficulties in their study due to the risk of stigma (Järkestig Berggren, Rowan, Bergbäck, & Blomberg, 2016). Similarly, 17-29 year olds with a range of physical disabilities highlighted in a qualitative study the lack of understanding and knowledge of disability demonstrated by some teaching staff, lack of acceptance of peers, and low expectations by parents and educators. Such factors influenced young people’s decisions around disclosing their disability and seeking adjustments in post-secondary education (Lindsay, Duncanson, et al., 2018).

Evidence also suggests a strong influence of support and attitudes on the experiences of emerging adults with CP in relation to employment and volunteer work. In a survey of 15-30 year olds with physical disability in the UK, examples of prejudice and discrimination were prevalent, and young people cited negative
attitudes toward people with disabilities as one of the greatest barriers to employment, along with a lack of accessibility in premises (Doyle, Moffatt, & Corlett, 1994). Many employers are even hesitant to take on young people with disability in volunteer roles, contributed to by negative attitudes and a lack of knowledge of how to provide support and adjustments (Lindsay, 2016b). We know that people with disability face obstacles and barriers to securing employment, including discrimination and employer misconceptions and negative attitudes about capacity to meet job requirements, risk, and the costs of employing people with disability (Deloitte Access Economics, 2011). These views remain widespread among employers, despite Australian research evidence suggesting the contrary; that people with disability cost less to recruit, are generally equally or more productive than colleagues without disabilities, take less time off work and have fewer workplace accidents (Graffam, Shinkfield, Smith, & Polzin, 2002). In addition to these common and prevailing misconceptions, employers also report finding it difficult to access information and support to help them employ people with disability (Deloitte Access Economics, 2011). Employers often have limited understanding of disability, lack the skills required to effectively accommodate staff with disability and may not be aware of available programs, policies and supports (Lindsay et al., 2015).

A conceptual model of approaches and strategies to support successful transition to adulthood of young people with disability identified the need for more supportive environments as one of five key outcomes necessary to facilitate role engagement. The need to both break down environmental barriers at the systems level, and increase community education and advocacy, were emphasised (King et al., 2005). The importance of such work becomes clearer when the personal impacts of unsupportive environments and attitudes are considered. Survey research in Korea identified that discrimination, negative perceptions and attitudes were the most frequent experiences leading young people with physical disabilities to feel a sense of despair and loneliness. Many respondents reported feelings of exclusion, loss, rejection, alienation and spending too much time alone (Kim & Kang, 2003). Fear of stigma and discrimination, and negative past experiences, also often contribute to
the decision by young people with disabilities to not disclose their disability to employers (Lindsay, Cagliostro, Leck, Shen, & Stinson, 2018). This can have significant impacts on young people’s experiences at work, as without disclosing they cannot request necessary workplace accommodations.

Despite people with disability commonly experiencing negative attitudes, ableism, and even blatant discrimination, and being personally impacted by these experiences, they often choose not to make formal complaints against those who discriminate against them (Harpur, 2014). Reasons given for this include limited emotional, financial and time resources, limited prospects of a successful claim, and a fear of further victimisation. In Australia, the Disability Discrimination Act (1992) relies on people with disabilities making complaints and initiating litigation, a process many people with disability are hesitant to even commence. One study of lawyers and advocates with disability identified that even people in fairly empowered positions were reluctant to submit discrimination claims (Harpur, 2014). More research is required to understand this phenomenon, as it seems unlikely the problem will resolve without effective means of retribution towards those who continue to discriminate against people with disability.

2.6.2 Services, systems and policies

This section explores the state of current knowledge in relation to the environmental influences of services, systems and policies on the functioning and/or disability of emerging adults with CP. For ease of reading, this section is divided into a number of subsections: healthcare and community services; education and employment services; transport; and policy and legislative context.

2.6.2.1 Healthcare and community services

Emerging adults and adults with CP, although generally experiencing good health, still do have health concerns, for example musculoskeletal problems, pain, fatigue, sleep problems, dental problems and incontinence. They may also experience changes in mobility and functional status, as well as mental health problems
(Hilberink et al., 2007; Murphy et al., 1995; Tornbom, Jonsson, & Sunnerhagen, 2013; Turk, 2009). Despite these ongoing health needs, Australian and international research has demonstrated a marked decline in access and exposure to healthcare and community services during emerging adulthood, including access to specialists, general practitioners, therapists and social workers. This leads to a lack of ongoing monitoring and intervention by both primary and allied health providers (Cathels & Reddihough, 1993; Doyle et al., 1994; Hilberink et al., 2007; Ng et al., 2003; Stevenson et al., 1997).

In a Swiss study, 209 adult specialists were surveyed about their service provision to young people who had recently transitioned from paediatric services (Suris, Akre, & Rutishauser, 2009). Of concern, less than half of respondents reported routinely discussing issues such as sexuality, nutrition, emotional well-being, or family issues during appointments, over half (54%) did not provide opportunities for young people to discuss concerns without their parents present, and less than half (46%) had any contact with the young people’s paediatric specialist (Suris et al., 2009). There is also a significant lack of preventative health participation in this population, for example a lack of engagement in exercise, and in preventative health screening, such as mammography and cervical screening (Bax, Smyth, & Thomas, 1988; Bottos et al., 2001; Hilberink et al., 2007; Kent, 2013; Lariviere-Bastien & Racine, 2011; Murphy et al., 1995; Turk, 2009).

An inadequate transition from paediatric to adult healthcare services has been identified as a potential reason for the decline in access to healthcare services during emerging adulthood. Challenges include emerging adults with CP not being comfortable to leave the care of paediatric specialists, adult specialists in primary care, orthopaedics and neurology not having been trained sufficiently in the management of CP, and a continuing misassumption in the clinical community that CP is the domain of paediatric specialists (Aisen et al., 2011). It is clear that a lifespan perspective is needed to ensure adequate follow-up of adults with CP by adult healthcare providers (Hilberink et al., 2007).
Most research in this area is general in nature, involving combinations of participants from various disability and chronic illness groups, including CP. Two studies were found exploring the specific healthcare experiences of emerging adults with CP. The first explored the healthcare transition experiences of 86 young people 13-23 years with CP and their families from their own perspective (Darrah et al., 2002). This qualitative study identified the importance of caring and supportive people, issues of fatigue resulting from constantly having to “work the system”, experiences where communication was ineffective or the perspectives of families were ignored, the frustration of having to repeat their story again and again, difficulties finding information about available services, and the influence of negative attitudes and a lack of acceptance of young people with CP (Darrah et al., 2002, p. 545). The second study used focus groups to explore the experiences of nine, 19-34 year olds with CP in the USA, and identified a number of similar issues. Participants noted a steep fall in service provision after leaving high school, challenges getting access to information and navigating complex systems, frustrations of having to provide information multiple times, funding delays, a lack of information about aging with CP and health professionals’ lack of knowledge about CP in adulthood (Bagatell et al., 2017).

Young people with CP were also included in two qualitative studies with people with a range of other disabilities; however their experiences were not differentiated from those of the broader group (Fiorentino, Phillips, Walker, & Hall, 1998; Young et al., 2009). In the first study, conducted in the UK, the group of 87 young people and carers overall found the transition to be confusing, and many reported feeling uncertain and abandoned (Fiorentino et al., 1998). In the second study conducted in Canada with 30 young people and parents, participants reported concerns around access to healthcare, knowledge of professionals in the adult setting, a lack of information provided to them and an overall feeling of uncertainty (Young et al., 2009).

The first-hand experiences of young people with other disabilities and health conditions, such as cystic fibrosis (Brumfield & Lansbury, 2004; Nasr, Campbell, &
Howatt, 1992; Westwood, Henley, & Willcox, 1999), diabetes (Court, 1993) and sickle cell disease (Hauser & Dorn, 1999) have been explored and have found the transition to adult services to be a “big shock” and “huge leap” (Brumfield & Lansbury, 2004, p. 227). Of those young people who do make the transition, many are not active participants in the process and are disappointed with the outcomes (Brumfield & Lansbury, 2004; Patterson & Lanier, 1999). A lack of coordination and planning, starting planning too late, insufficient exchange of information, and inadequate communication have all been identified as affecting the transition to adult healthcare for young people with disabilities and chronic illnesses (Betz, 2004; Brumfield & Lansbury, 2004; Morris, 1999; Parker & Hirst, 1987; Stewart, 2006; Stewart et al., 2001).

It has also been pointed out that there is a need for health services to look beyond body structure and function issues and contribute to the effective preparation of young people with physical disabilities for adulthood, especially in relation to the development of life skills, including communication and social skills, self-awareness, assertiveness, independent living skills, and skills for work (Doyle et al., 1994). Twenty five years ago, 15-30 year olds with physical disabilities (35% CP) surveyed in a UK study reported a lack of information about career options, independent living options, sexuality and family planning (Doyle et al., 1994). This does not appear to have changed. A recent focus group study with 19-35 year olds with CP in the USA also identified the need for improved guidance around navigating complex service systems, and increased attention from health care providers around sexuality, intimate relationships and having children, topics often ignored by practitioners (Bagatell et al., 2017). Inadequate recognition by health professionals of the mental health needs of young people with disability has also been identified, despite a higher prevalence of mental health problems (Lumsdaine & Thurston, 2017). There is some recent evidence of positive outcomes from Canadian programs focused on broad preparation of young people with disability for adulthood, including residential life skills programs (McPherson et al., 2018) and life skills coaching (Keenan, King, Curran, & McPherson, 2014), however evidence of such programs in Australia is lacking.
Despite the range of challenges identified above, it is generally accepted that a transfer to adult services is necessary to facilitate developmentally appropriate care (Blum et al., 1993; Sawyer, 2003), and to assist young people with disabilities gain greater control over, and play a more active, self-determined role in their own healthcare (Bailey, O’Connell, & Pearce, 2003; Brumfield & Lansbury, 2004; Conway, 1998). Since the mid-1980s much has been written about how best to support the transition of young people with CP to adult healthcare services, and to adulthood more broadly (Halpern, 1985). The vast majority have been conceptual and anecdotal reports. There is, however, very little evidence of effectiveness of approaches and strategies to support transition (Beresford, 2004; Betz, 2004; Betz, Nehring, & Lobo, 2015; Binks, Barden, Burke, & Young, 2007; King et al., 2005; Rosen, Blum, Britto, Sawyer, & Siegel, 2003; Stewart, Stavness, King, Antle, & Law, 2006; Watson, Parr, Joyce, May, & Le Couteur, 2011). Similarly, we have heard little from young people themselves about their personal experiences of transitions from paediatric to adult services. Indeed, there is not the evidence to know whether service transitions are considered priorities for young people with CP from their perspective.

Keeping in mind the limited evidence available, recommendations for quality healthcare transition include:

- the establishment of a ‘medical home’ within primary care that provides coordination of care including facilitation and monitoring of care by specialists, therapists, educators and community agencies (Cooley & the Committee on Children with Disabilities, 2004) or alternatively a community-based “navigator” or facilitator (Stewart et al., 2009);
- utilising the ICF framework to consider the full range of factors influencing the transition, not just those of body structure and function (Nguyen & Gorter, 2014; Rosenbaum & Stewart, 2007);
- developing a comprehensive care plan which includes recognition of transitions taking place outside of the health system, for example in education, social welfare and housing; including efforts to reduce environmental barriers, build
the skills of the individual and their family (Nguyen & Gorter, 2014; Rosenbaum & Stewart, 2007), and improve inter-professional collaboration (Lindsay, Duncanson, et al., 2018);

- taking a person-centred, strengths-based approach (Stewart et al., 2009; Vaks et al., 2016);
- addressing mental health issues and empowering the young person to learn to self-manage their condition and build self-determination skills (Nguyen et al., 2016; Vaks et al., 2016; While et al., 2004);
- paediatric providers making themselves available to consult with adult providers to share their expertise in childhood-onset conditions (Vaks et al., 2016);
- support for the family as they step back from their role in managing their child’s healthcare (Betz, 2004; Betz et al., 2015; Stewart et al., 2001; Vaks et al., 2016);
- provision of accurate, current and accessible information and resources (Nguyen, Stewart, & Gorter, 2018; Stewart et al., 2009; While et al., 2004); and
- inclusion of capacity building for the young person, family and wider community (King et al., 2005; Stewart, Antle, Healy, Law, & Young, 2007; Stewart et al., 2009; Stewart et al., 2013; Wynn, Stewart, Law, Burke-Gaffney, & Moning, 2006). Capacity building through peer mentorship in particular has shown positive outcomes (Lindsay, Hartman, & Fellin, 2016; Nguyen, Stewart, & Gorter, 2018), although high quality program evaluations are lacking.

In addition to health services, challenges have been identified in the delivery of community supports and services, including personal care (Hendey & Pascall, 2001). Young people who need support for personal care have reported that the services restrict their spontaneity as they are reliant on the times allocated by the service. This leads young people to weigh up the pros and cons of continuing to receive personal care from their parents to maintain greater flexibility in their daily life, but perhaps at the expense of developing an adult relationship with their parents (Hendey & Pascall, 2001). A recent qualitative exploration with 16, 16-21 year olds, including 12 with CP, identified other factors contributing to the experience of working with personal assistants (Hultman, Forinder, & Pergert, 2016). Participants in this study also spoke of having to weigh up the benefits of more autonomy from
their parents with the restrictions of working with personal assistants who often have set hours with little flexibility. Positive experiences were noted where young people and their assistants had similar interests, enjoyed each other’s company, and were mutually committed to maintaining a good relationship. Assistants that were sensitive to the young people’s needs, responsive, familiar with preferred routines and effective communicators were also highly regarded (Hultman et al., 2016).

In response to the lack of flexibility offered by traditional personal care services, an Australian example was identified of a service established in 1992 to offer flexible and individualised personal care services to people with disabilities. The Mobile Attendant Care Service (MACS) offers personal care to fee-paying service users between 6pm and 6am in certain areas of Brisbane, Queensland. Service users can either prearrange scheduled service times, or call in for unscheduled, occasional support (Mobile Attendant Care Service Inc, 2017). MACS was seen to be ahead of its time in relation to the truly flexible and person-centred service offered.

With the recent introduction of the National Disability Insurance Scheme (NDIS) in Australia, more opportunities are becoming available for people with disabilities to negotiate their support needs directly with attendant carers, fostering improved flexibility, choice and control. As yet there is limited research evidence about personal perspectives of service users, and the NDIS was introduced after data collection had completed for the current study. In acknowledging recent expansions on consumer directed attendant care services under the NDIS, however, one example is “Hireup” (www.hireup.com.au). Hireup is an Australian enterprise set up by an occupational therapist whose brother required attendant care and who found through lived experience that existing provider models did not give the flexibility and consumer control he and his brother needed. Hireup provides opportunities for people with disability to choose, hire, and manage independent care workers. Providers such as Hireup are based on principles of self-directed and self-managed care. Research with 19-29 year olds with physical disabilities in the UK has, however, highlighted additional challenges that can arise when self-directing
personal care (Mitchell, Beresford, Brooks, Moran, & Glendinning, 2017). These include concerns about the responsibilities of employing and managing staff, feelings of being overwhelmed in trying to access information about the processes required to self-manage care, and feeling ill-equipped to manage situations of poor staff performance. Participants highlighted the need for additional training and information, and many desired ongoing support from their parents or professionals in helping to manage challenges (Mitchell et al., 2017).

In sum, despite evidence of ongoing need, many potential challenges have been identified in the literature in relation to effective healthcare and community service provision for emerging adults with CP. There are many gaps in the evidence base. Also very limited within the discussion is the first-hand account of emerging adults themselves about their experience of health and community services, particularly within the Australian context. The current study contributes new evidence to this gap.

2.6.2.2 Education and employment services

As briefly introduced above, in recent times it has been recognised that the intense focus by rehabilitation professionals specifically on healthcare transition has been at the expense of attention on other important adult goals (Vogtle, 2013). As articulated clearly by Vogtle, “it is time to refocus on the needs of adolescents and adults with CP and apply therapeutic expertise to support them in achieving success in employment and other adult endeavours” (Vogtle, 2013, p. 973). Similar sentiments have been emphasised by Rosenbaum (2003):

*The challenge to be addressed by service providers, educators, prospective employers, policy makers and others is to begin to anticipate and plan appropriately for the full incorporation of adults with CP into the life of their community, a goal fully consistent with the World Health Organisations’ focus on participation. This challenge is one that must be addressed by the whole community, and should involve the imagination and political will of professionals and families from all areas of society. To do less would be to marginalise young people with CP and to squander the developmental and functional gains they have made in their developing years* (Rosenbaum, 2003, p. 973).
In relation to education services, there is evidence that interagency collaboration and continuity of support during transition planning increases the likelihood of young people engaging effectively with further education or employment (Riches, Parmenter, & Robertson, 1996). A recent qualitative Australian study explored perceived successful school experiences for students with CP, and similarly highlighted the importance of collaboration between families, schools, and external agencies, along with a welcoming school culture and effective leadership (Bourke-Taylor, Cotter, Lalor, & Johnson, 2017). Despite this, other research has identified a lack of collaboration between schools and post-school services, including tertiary education, employment, accommodation, and recreation services. This is a significant barrier to effective transitioning of Australian youth with disabilities (Meadows et al., 2014; Winn & Hay, 2009). Teachers in particular struggle to implement strategies that they view as being under the control of regional or systemic sources, for example cross-departmental arrangements and training for families and providers. There is a need for greater transition knowledge at the systemic level, and improved funding structures to allow school students to experience post-school options including work experience and make informed decisions about transition pathways (Meadows et al., 2014). For example, the National Disability Coordination Officer Programme, funded by the Australian Government to support people with disabilities to successfully transition from school into tertiary education and employment, has only 31 full-time equivalent positions across the whole of Australia (Australian Government Department of Education and Training, 2016).

Effectiveness of service delivery is also impacted on by the ability of schools and agencies to attract and retain qualified and experienced staff (Winn & Hay, 2009). The focus on mainstream schooling means that many students with disabilities now have little, or no, access to teachers with specialised knowledge of support for students with disability and post-school options. Therefore, there needs to be an increased emphasis within teachers’ pre-professional education and continuing professional development on skills for supporting students with disability, post-
school options, and on providing comprehensive career development and transition planning for this group. Education for young people, parents, the community and employers is also needed (Meadows et al., 2014; Stewart et al., 2007; Stewart et al., 2009; Winn & Hay, 2009; World Health Organisation, 2011). Additional challenges exist in tertiary education, where academics are experts in their subject area, but do not necessarily have any training or qualifications around inclusive education practices (Järkestig Berggren et al., 2016).

Australian career development guidelines for young people with disability emphasise the need for schools and services to: be responsive to the unique aspirations and needs of individuals; encourage and build the capacity of young people to be self-managing and self-determined; ensure suitable work experience opportunities are provided; foster the development and engagement of support networks; provide accessible career information; and develop strong relationships with other service providers (Career Industry Council of Australia, 2012a). An initial trial of these guidelines identified positive feedback around their usability (Career Industry Council of Australia, 2012b); however more research is needed on the implementation and effectiveness of these guidelines. There is also some evidence from a recent systematic review that formal mentoring programs have the potential to support young people with disability transitioning to post-secondary education and employment. However, opportunities to participate in such programs are not routinely available, and more rigorous research is needed to establish their full impact (Lindsay et al., 2016).

Qualitative research adds to the evidence around environmental barriers faced by emerging adults with CP in relation to education. A Greek qualitative study with thirty-two 19-26 year olds with physical or sensory disabilities explored their perceptions of primary and secondary schooling and found evidence of physical accessibility barriers, a lack of resources, and inadequate provision of reasonable adjustments to the curriculum or teaching strategies (Vlachou & Papananou, 2015). Similarly, qualitative research with Australian university students with disabilities identified that students perceived that nearly all of the barriers to academic success
they faced were environmental. These included unsupportive attitudes by teaching and administrative staff, inaccessible course materials, peer ridicule, low expectations from others, frequent staff turnover in disability, health and other services, and adjustments not being implemented in a timely manner (Ganguly, Brownlow, Du Preez, & Graham, 2015).

In relation to employment, research clearly shows that environmental barriers including prejudice and discrimination significantly contribute to the higher rates of unemployment for people with disabilities (Lindsay, 2011b; Lindstrom, Kahn, & Lindsey, 2013). However, it has also been identified that there is an important role employment services can play in facilitating the capacity of young people with physical disability in relation to their employment readiness and job-interview skills (Lindsay, 2011b; Lindstrom et al., 2013). Unfortunately, experiences of participating in employment services have not always been positive. In Australia, the Government recently undertook a review of, and redeveloped, Disability Employment Services (DES) in response to continuing barriers to employment for people with disability, with the new DES system commencing on 1 July 2018 (Australian Government Department of Social Services, 2018). The review identified barriers including a lack of awareness about services, and too much focus on job placement at the expense of effective job-matching to ensure job suitability, satisfaction, and effective performance (Australian Government Department of Social Services, 2015).

International qualitative research has identified similar issues. Canadian research found that although some participants had successfully secured appropriate employment through one-on-one support, others found employment services unhelpful and jobs that were recommended unsuitable to their skills, needs or interests (Magill-Evans, Galambos, Darrah, & Nickerson, 2008). A large observational cohort study in the USA explored the employment outcomes of 3162 adults aged 16-54 with CP and the relationship between outcomes and vocational rehabilitation services provided. Multivariate logistic regression was used to explore relationships in the data. Less than half (49.6%) of participants had secured
employment at the time of ceasing vocational rehabilitation. This research identified aspects of employment services which contribute to more positive employment outcomes. These included on-the-job training conducted by a prospective employer, job placement assistance, on-the-job support including job coaching by a service provider, maintenance services, including monetary support for basic living expenses, and rehabilitation technology, including workplace modifications and access to assistive technology (Huang, Holzbauer, et al., 2013).

In brief, a number of environmental issues have been identified in relation to the provision of education and employment services. Unfortunately, the emphasis within current literature appears to indicate the existence of more barriers than facilitators. Little is known however about the first-hand experiences and perceptions of emerging adults with CP from their own perspective, and the current study contributes new knowledge in this area.

2.6.2.3 Transport

A qualitative study with parents of children with cerebral palsy in five European countries identified that availability of suitable transport was an important environmental facilitator which allowed people to effectively participate (McManus et al., 2006). For most families this meant the purchase of an accessible vehicle, because public transport options and accessible taxis were limited. This study also identified bureaucracy and a lack of easily accessed information about available services and financial supports as environmental barriers. Parents often only found out about transport options by word of mouth, or they received contradictory advice. Derogatory attitudes of the public further contributed to negative experiences while accessing the environment (McManus et al., 2006). Research from the UK with sixteen 17-29 year olds with disability emphasised that a lack of transport options can significantly impact on access to leisure activities, education, employment and opportunities to make and maintain friendships (Morris, 1999). Canadian qualitative research has identified a lack of accessible, reliable and flexible transport options as a key barrier to social participation for the 17-30 year olds with
CP, in particular the inability to be spontaneous in activities and the requirement to plan ahead and allow extra time (Darrah et al., 2010; Stewart et al., 2012).

The same Canadian research team also completed previous research with 20-30 year olds with motor disabilities (Darrah et al., 2008). This research identified that only 13% of the 72 young adults had an unrestricted, independent means of transport, i.e. their own car and driver’s licence. This was in contrast to 69% of a comparison group without disability (Darrah et al., 2008). Canadian research exploring employment status of 15-30 year olds with disabilities has identified access to transport as a significant predictor of involvement in paid employment (Darrah et al., 2008; Lindsay, 2011b; Magill-Evans et al., 2008), findings supported by other research (Blomquist, 2007; Darrah et al., 2010). Barriers related to public transport availability and suitability are commonly reported. However many young people in one qualitative study also cited environmental barriers in relation to being able to drive, including the high cost of specialised driving lessons and modified vehicles (Magill-Evans et al., 2008).

It is clear from international research that transport availability can be an important facilitator of environmental access. Likewise, a lack of access to appropriate transport is a major environmental barrier for people with disability. The current study adds to this body of knowledge by exploring the perspectives of Australian emerging adults with CP in relation to their experience of transport.

2.6.2.4 Policy and legislative context

Significant changes to disability policy have taken place in recent years in both International and Australian contexts. This section introduces a brief history of the key policies and legislation of relevance to Australian emerging adults with CP. It is important to note that some of the policies, in particular the introduction of the NDIS, have been implemented after data collection for this research was complete.
Legislation and policy protecting and promoting the rights of Australians with disabilities is not new. Australia has had a Disability Discrimination Act (DDA) since 1992. The objects of the DDA are detailed in Table 3.

<table>
<thead>
<tr>
<th>Objects of the Disability Discrimination Act</th>
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<td>(a) to eliminate, as far as possible, discrimination against persons on the ground of disability in the areas of:</td>
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<tr>
<td>(i) work, accommodation, education, access to premises, clubs and sport; and</td>
</tr>
<tr>
<td>(ii) the provision of goods, facilities, services and land; and</td>
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<tr>
<td>(iii) existing laws; and</td>
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<tr>
<td>(iv) the administration of Commonwealth laws and programs; and</td>
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<tr>
<td>(b) to ensure, as far as practicable, that persons with disabilities have the same rights to equality before the law as the rest of the community; and</td>
</tr>
<tr>
<td>(c) to promote recognition and acceptance within the community of the principle that persons with disabilities have the same fundamental rights as the rest of the community.</td>
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With regard to International policy, the United Nations (UN) has led policy to promote the rights of people with disability for some decades. In 1993 the UN adopted the Standard Rules on the Equalization of Opportunities for Disabled Persons which provided non-legally binding policy guidelines promoting the equal rights of people with disability. In 2006 the Convention on the Rights of Persons with Disabilities was introduced to take policy guidelines to the next level, with countries that ratified the convention accepting legal obligations under the treaty. Australia ratified the Convention in July 2008. The Convention aims to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity” (United Nations, 2006). The Convention is underpinned by eight general principles, which are outlined in Table 4.
Table 4: Convention on the Rights of Persons with Disabilities – General Principles (United Nations, 2006)

Also of relevance is Australia’s National Disability Agreement, which came into effect on 1 January 2009. The National Disability Agreement is an agreement between Australian Commonwealth, State and Territory Governments providing a national framework for the provision of Government support to people with disability (Council of Australian Governments, 2009). Building on this work, the Council of Australian Governments (COAG) in 2011 endorsed the National Disability Strategy 2010-2020. The Strategy outlines a coordinated plan across all levels of Government to improve the lives of Australians with disabilities, their families and carers, and aims to ensure the principles underpinning the UN Convention are upheld. Its vision is “an inclusive Australian society that enables people with disability to fulfil their potential as equal citizens”. The Strategy focuses on six priority areas: inclusive and accessible communities; rights protection, justice and legislation; economic security; personal and community support; learning and skills; and health and wellbeing (Australian Government Department of Social Services, 2011).

Also in 2011, the Productivity Commission released the report from its inquiry; “Disability Care and Support”. The Report found that “the current disability support system is underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate
supports”. It recommended the establishment of the NDIS to provide insurance cover for all Australians in the event of significant disability (Australian Government Productivity Commission, 2011, p. 2).

COAG agreed to the development of a NDIS in 2012 and in 2013 the NDIS Act was enacted, the Scheme was created and the National Disability Insurance Agency formed to implement it. Implementation commenced in July 2013 with four trial sites and continues to expand. Progressive rollout to full scheme is currently underway (National Disability Insurance Agency, 2016a). The NDIS consists of a number of elements, including the provision of information, referral, and capacity building, links to services and activities, individualised plans, and where necessary, supports to individuals over their lifetime. The NDIS also aims to raise community awareness, encourage greater inclusion and facilitate access to mainstream services, community activities and other government initiatives (National Disability Insurance Agency, 2016b). The broad policy intention underlying the current approach to disability service provision in Australia includes the principles of fairness by way of equal rights, facilitation and choice in exercising those rights, and inclusion through the removal of barriers to participation (PricewaterhouseCoopers, 2011). Much more work is required to achieve these essential outcomes.

In summary, the rights of Australians with disability have specifically between protected by Disability Discrimination legislation since 1992 and since 2008 Australia has been, and continues to be, in a period of major disability reform. Despite the presence of significant legislation and policy supporting the rights of people with disability, it is clear from this literature review that emerging adults with CP and people with disabilities in general, face ongoing challenges. This study hears directly from emerging adults with CP about their experiences, challenges, and hopes for disability policy.

2.6.3 Physical environment, products and technology

No specific research could be located exploring the impact of the physical environment on the experiences of emerging adults with CP. However, it is clear
from the broader research evidence that the physical environment, including the
natural environment, geographical location, and the built environment, has the
capacity to either facilitate or hinder the active participation of people with
disability. In relation to geography, there is evidence that living in rural Australia can
generate additional challenges for those living with disability. These include limited
access to services and supports, long waiting times for therapy services, a lack of
choice of providers and transport challenges (Gallego et al., 2017; Pini, Philo, &
Chouinard, 2017). A recent survey of 166 carers highlighted that availability of
services in rural locations becomes even more restricted after the age of 18 years,
emphasising particular challenges during emerging adulthood and beyond (Gallego
et al., 2017).

In relation to the built environment, unfortunately, it is more often barriers, than
facilitators, that are identified. The overall design and accessibility of environments,
along with specific characteristics including temperature, terrain, lighting, noise,
and crowding can all pose barriers to people with physical disabilities (Law et al.,
2007). In a UK qualitative focus group study with people with physical, hearing and
vision disabilities, it was identified by participants that inaccessible built
environments served to emphasise their sense of difference and excluded them from places they wished they could go. Inaccessibility of some places, like public
toilets, was particularly degrading and humiliating, as was the tendency to have to
enter venues via the back or side door rather than the main entrance. Participants
spoke of the frustration of having to constantly phone ahead to identify accessible venues, prohibiting the spontaneity enjoyed by others. They also cited frustration with a seeming lack of awareness of policy makers, town planners, and property developers in relation to the access needs of people with a range of disabilities (Imrie & Kumar, 1998).

Australia has had standards in place around access for many years, which currently
include the Disability (Access to Premises – buildings) Standards 2010, the Building
Code of Australia, and Australian Standards 1428 - 2009 Design for Access and
Mobility (Australian Human Rights Commission, 2013). However, these standards
only apply to new building work, and there is evidence in Australia and other countries of low levels of compliance with access legislation and policy (World Health Organisation, 2011). It is clear that much more work is needed to improve the physical environment in order to promote true equal access and inclusion for people with disability.

In relation to technology, international research from the UK with 25 augmentative and alternative communication users with CP aged 14-24 years reinforced that this group has a strong desire to utilise the internet and social media (Hynan, Goldbart, & Murray, 2015). They also believe that it will enrich their social relationships, enhance opportunities for self-determination, reduce isolation and possibly initiate dating opportunities. However many challenges were identified, including difficulties in the interface between speech generating devices and mainstream technologies, lack of privacy for those young people who require assistance to access the internet and social media, availability of help for those who require it, and funding and technical support issues (Hynan et al., 2015). A small recent Australian research study found that teaching emerging adults with communication disabilities, including CP, to use social media did result in enhanced social participation and communication for the eight young people involved (Raghavendra, Newman, Grace, & Wood, 2015). However, the vast majority of communication remained between participants and close family, family friends, or paid communication partners. Future research is needed to explore whether over time, increased social connections can be made with people outside one’s family (Raghavendra et al., 2015), and more generally to explore the impact of social media and other technologies on the lives of people with disabilities including CP.

In summary, this section has outlined the state of current knowledge in relation to the impact of the environment on the experiences of emerging adults with CP. It is clear that environmental barriers, and unfortunately less so facilitators, have a significant impact on young peoples’ participation and inclusion. There is however a clear gap in the evidence base in relation to the first-hand stories of emerging adults with CP about their experience of environment, and the current study
contributes to this gap. The next section introduces the literature in relation to the personal factors influencing experience.

### 2.7 Personal factors influencing experiences of emerging adults with CP

Personal factors are not as clearly detailed within the ICF as the other domains, nor have ICF core sets been developed for adults with CP that set out personal factors that should be considered. When concluded, this will elaborate personal factors of particular relevance. Until this is available, the general ICF framework provides examples of personal factors that may contribute to health including gender, age, race, character, coping styles, social background, education and past and current experience (World Health Organisation, 2001). There is a paucity of research specifically around the personal factors influencing the experiences of emerging adults with CP. The evidence available relates predominately to the factors of character and coping styles, and social background. These are now explored.

#### 2.7.1 Character and coping styles

A small Australian qualitative study with nine 18-30 year olds with CP explored their perceptions of citizenship and the findings offer insight into some of the character, personal attributes and goals of this group (Yeung et al., 2008). Participants believed that citizenship meant making an active contribution to their community, giving back, and taking responsibility for themselves and others. They also considered citizenship to involve feeling a sense of inclusion and belonging, including recognising one’s own intrinsic worth. Many made active choices to demonstrate this through participating in community activities and committees, with the goals of being a role model to others with disability, advocating on behalf of them, or sharing their story to raise community awareness (Yeung et al., 2008). A large International study of 502 emerging adults with disability highlighted that a positive disability identity contributes to an increased sense of belonging,
particularly for those who self-identify with their disability (Raver, Murchake, & Chalk, 2018).

A qualitative exploration with 10 emerging adults with a range of disabilities highlighted the importance of creating their “own meaning” and to share their experiences of disability in the hope that others may learn from them and experience less challenges than they had. The authors labelled this an “altruistic sense of duty towards others with disabilities” (Mannino, 2015, p. e137). Other research provides evidence of similar themes, with participants wanting to feel worthwhile and be able to help others through sharing their story (Kim & Kang, 2003; Read et al., 2015). A Canadian phenomenological study reinforced that it is not unusual for young people with CP to feel strongly about contributing to society, to breaking down stereotypes, and mentoring others (Stewart et al., 2012). Emerging adults with disabilities are particularly likely to engage in advocacy type activities when they feel a strong sense of affiliation with the disability community (Nario-Redmond & Oleson, 2016).

The same Canadian research mentioned above (Stewart et al., 2012) also identified other personal factors that influenced young people’s capacity to participate in social activities. These included a social personality and self-confidence. Other Canadian qualitative research with 10 young people with CP aged 18-20 provides additional insights into personal factors, including their goals and view of what it means to be successful (King et al., 2000). Young people viewed success as being happy in life, which included being believed in, believing in yourself (self-efficacy), and being accepted by others (a sense of belonging). Happiness was linked to achieving goals and feeling fulfilled. Participants noted that they often faced barriers from other people who had low expectations of what they could achieve. However many used a personal coping style to turn this around by demonstrating a sense of determination to prove their doubters wrong (King et al., 2000). Determination became a defining feature of their character.
Research, albeit limited, also suggests that self-esteem is another personal factor likely to influence experience of young people with CP (Magill-Evans & Restall, 1991). While adolescents with CP, particularly girls, are likely to have significantly lower self-esteem than their peers without disabilities, results from one small study showed that self-esteem tended to increase from adolescence to young adulthood and differences between groups were no longer significant, although women with CP still had the lowest mean self-esteem scores (Magill-Evans & Restall, 1991). The researchers postulated that other personal factors may play a role in this change, such as an increasing ability to be able to separate their self-esteem from negative perceptions in the environment, and the ability to choose activities and environments in adulthood which reduce exposure to negative situations (Magill-Evans & Restall, 1991). Other research with 74 young people aged 20-25 years, mostly with mild CP (76% GMFCS I), identified a link between high self-efficacy and self-esteem and the likelihood of being involved in romantic and sexual relationships (Wiegerink, Stam, Ketelaar, Cohen-Kettenis, & Roebroeck, 2012). In another study, parents of 12-19 year olds with CP linked young people accepting themselves and having good self-esteem with better skills to cope with challenges faced, and improved quality of life overall (Shikako-Thomas, Bogossian, et al., 2013).

Limited research has also been conducted in the area of self-concept; “a person’s overall view of oneself and sense of worth, value and adequacy” (Gannotti et al., 2011, p. 855). A cross-sectional survey of 102 people with CP aged 21-58 in the USA identified that the majority of participants had a healthy self-concept, with less than 15% having low self-concept (Gannotti et al., 2011). Interestingly there was no correlation with GMFCS scores and self-concept, however it was identified that those with high self-concept were more likely to be living independently, employed, sexually active and have a driver’s licence, although the differences were not statistically significant (Gannotti et al., 2011).

Limited research with young people with a range of disabilities has identified important personal factors for a successful transition to adulthood (Stewart et al., 2010; Stewart et al., 2014). These include resilience, perseverance, effective coping
strategies, self-determination, and self-advocacy skills. In addition, it is important that young people have a good understanding of their disability and can articulate their disability-related needs (Stewart et al., 2010; Stewart et al., 2014). A recent Canadian study highlighted that young people who are self-confident, have well developed self-advocacy skills, and are aware of their rights are more likely to disclose their disability and request accommodations in the workplace that they are entitled to (Lindsay, Cagliostro, et al., 2018).

A recent USA study explored key attributes of resilience in a group of 31 high-achieving emerging adults with disability. Identified attributes included acceptance and perseverance - the ability to accept challenges and persevere despite adversity, the presence of social support, and having a purposeful life (Mannino, 2015). Perseverance includes a preparedness to work “harder and longer” than peers without disability to achieve the same outcomes, both in response to disability related needs, and to compensate for a lack of adjustments provided by institutions (Järkestig Berggren et al., 2016, p. 350). Contemporary qualitative Australian research with 30 high achieving university students with a range of disabilities identified a range of personal factors contributing to their success. These included several aspects of resilience: being aware of strengths and needs; ability to discuss their disability and related needs; confidence to advocate for adjustments and support; and problem solving skills (Ganguly et al., 2015). These concepts are similar to those previously described as self-advocacy skills.

Test and colleagues (2005) developed a conceptual framework of self-advocacy involving four components: knowledge of self, including awareness of disability related needs, strengths, preferences, goals and interests; knowledge of rights in a range of settings, including an understanding of how to advocate for change; communication skills including assertiveness, negotiation, articulation and compromise; and leadership, including advocating on behalf of others, and participating in advocacy organisations (Test, Fowler, & Wood, 2005). Canadian research gives additional support to the importance of self-advocacy skills. Poor self-advocacy skills were found to be a significant barrier to employment, and also
contributed to an unwillingness to disclose a disability and seek reasonable adjustments that may enable the person with disability to be successful in the workplace (Lindsay et al., 2015).

2.7.2 Social background

Social background and financial status are personal factors likely to have a significant impact on the experiences of emerging adults with CP. We know that in general, people with disability are significantly more likely to live in poverty than those without. A recent Australian poverty report identified that 27.4% of people with disability were living in houses earning 50% or less than the median income and nearly half (44.5%) were below the 60% poverty line (Australian Council of Social Service, 2014). The extent of poverty is likely to be even greater when the additional costs of having a disability are taken into account, such as costs of adjustments and equipment, higher transport costs, care and support costs, medical treatment and pharmaceuticals, and the time required by people with disabilities to address barriers to daily living (Saunders, 2007; Wilkinson-Meyers et al., 2015). These additional costs, along with poorer employment prospects, both contribute to the higher rates of poverty among people with disability (Australian Council of Social Service, 2014; Wilkinson-Meyers et al., 2015). Australia is performing particularly poorly in this area, with current OECD rankings placing Australia last (27/27 OECD countries) in relation to relative poverty risk for people with disability (OECD, 2010).

Australian case-control research with 20-30 year olds with CP confirms these worrying financial outcomes for this target population (Reddihough et al., 2013). Nearly 80% of the 335 participants with CP had annual incomes of less than AUD $20,000, compared to 39% in a population control group. Eighty-three percent were in receipt of a disability allowance or pension and 75% of these reported it as their only source of income (Reddihough et al., 2013). Another Australian study utilising data from nationally representative surveys of people aged 15-29 identified that people who self-identify as having a disability, impairment or long-term health condition were significantly more disadvantaged than those who do not (Emerson,
Honey, Madden, & Llewellyn, 2009). They were more likely to be socially isolated, unemployed, to live in poorer neighbourhoods, have poorer health and lower levels of subjective well-being, and these outcomes did not improve between 2001 and 2006. Importantly however, this research also identified that young people with disabilities who had higher levels of social support and lower levels of financial and material hardship had similar levels of subjective well-being to those without disabilities. This is an indicator that personal factors including financial status have a significant impact on well-being, although the cross-sectional nature of the comparisons made in this research mean that causality cannot be confirmed (Emerson et al., 2009).

International research with 21-35 year olds with a range of disabilities has reinforced the potential impacts of socio-economic status on the possibilities and opportunities afforded to young people (Hendey & Pascall, 2001). People who had achieved higher levels of independence were likely to have received financial assistance as well as other support and encouragement from their parents. Less independent participants often had parents with fewer economic, cultural and social resources (Hendey & Pascall, 2001).

In sum, the limited evidence available in relation to personal factors influencing the experiences of emerging adults with CP relates predominantly to character and coping styles, and social background. Character traits including self-confidence, self-esteem, self-concept, self-awareness and self-advocacy are all relevant, along with resilience and a sense of altruism. There is also evidence that many young people cope with barriers they face through sheer determination and perseverance to overcome them and prove their doubters wrong. Lastly, social background and in particular socio-economic status are clear influencers on the experiences of emerging adults with CP.
2.8 What we don’t know: The research problem

The period between the ages of 18-25 is now widely recognised, particularly in developed countries, as a standalone life stage known as emerging adulthood (Arnett, 2000a). Significant research has been undertaken to explore the perspectives of emerging adults from a range of countries, cultures and backgrounds. This research has provided evidence of the broad relevance of the theory of emerging adulthood. It is recognised as a life stage that can be challenging for all young people, as they explore opportunities across a range of life areas, face significant instability and changes in direction, and feel in-between adolescence and adulthood. Much of our current understanding of emerging adulthood comes from quantitative inquiries using standardised survey instruments. It has been recognised that qualitative inquiries exploring the “richness and complexities of emerging adulthood life” are overall very limited (Schwab & Syed, 2015, p. 388). The current study contributes to this gap through presenting the detailed narratives of emerging adults.

It has been emphasised that much more work is needed to fully understand the experiences of emerging adults from vulnerable populations, including people with disability, and to establish the relevance of the theory to these groups (Cote, 2006; Hinton & Meyer, 2014). The current study contributes to closing this gap in knowledge by exploring whether the theoretical constructs of the theory of emerging adulthood are reflected in the stories of a particular group of vulnerable young people; 18-25 year olds with CP.

This chapter has reviewed ‘the story so far’ in relation to knowledge of the stories and experiences of emerging adults aged 18-25 years with CP. Qualitative and quantitative research was reviewed which provided insights into what is currently known about emerging adults with CP: the impact of their disability on body structures and functions; their experience of activities and participation; and environmental and personal factors influencing those experiences. However, this review was composed from a myriad of research papers, each contributing
something to the current state of knowledge, but none providing an overall picture and understanding of the stories of emerging adults with CP from their own perspective. The current study contributes to filling this research gap.

The vast majority of research around transition experiences of young people with disability has historically addressed experiences in particular life areas, or at particular transition points, for example experiences of transitioning from paediatric to adult healthcare services, or experiences in education, or employment (Stewart et al., 2010). Similarly, the limited research which has specifically explored the perceptions and experiences of 18-25 year olds with CP through qualitative methods has often explored issues in isolation, for example experiences of education (Goode, 2007; Vlachou & Papananou, 2015), employment (Hendey & Pascall, 2001; Lindsay et al., 2015), family relationships and influence (Freeborn & Knafl, 2013; Magill-Evans et al., 2005), or social participation and citizenship (Shikako-Thomas, Shevell, et al., 2013; Stewart et al., 2012; Yeung et al., 2008). It has only recently been recognised that transition experiences are individual and complex and influenced by a multitude of interactions occurring between personal and environmental factors. There is an increasing recognition that all aspects of a young person’s life need to be considered as a whole and that the interactions and complexities between factors require further study (Gorter et al., 2014; Stewart et al., 2010). There is thus a need to explore the whole story of emerging adulthood from those who are living it, and to develop an understanding of key themes within and across these stories. The current study adds to this understanding.

Many previous studies have also explored the experiences of people with CP but in research that: mixes them in with people who have other types of disabilities and health conditions; combines the experiences of 18-25 year olds with those of younger and/or older participants; and/or explores perceptions of people other than the person with disability themselves. The current study contributes to filling the gap in current knowledge by focusing specifically on the experiences of emerging adults aged 18-25 years with CP from their own perspective.
Just as the theory of emerging adulthood has been proposed as relevant to exploring the experiences of 18-25 year olds during this important transitional life stage, the ICF has been proposed as a relevant framework for exploring the experiences of those with disabilities (Alford et al., 2015). More specifically, the adoption of the ICF framework to explore the full range of experiences of adults with CP has been recommended, and the importance of gaining input from adults with CP themselves has been emphasised (Haak et al., 2009). However, there remains a gap in knowledge in relation to how 18-25 year olds with CP describe their experiences from their own perspective, and whether the constructs of the ICF are in fact reflected within the themes developed from their stories. The current study addresses this gap in knowledge and in doing so provides a description of participant experience from the standpoint of a benchmark conceptual framework of functioning, disability and health. It also provides empirical evidence that may be of direct use to the further application of the ICF through findings that can be used in the development of an ICF Core Set for CP – a project being launched through the ICF Research Branch in late 2018 (www.icf-research-branch.org/icf-core-sets-projects2/neurological-conditions/686-icf-core-set-for-adults-with-cerebral-palsy).

The specific research questions to be answered by this research, therefore, are:

1. **What are the stories of emerging adults aged 18-25 years with CP?**

2. **What themes can be developed from the stories of emerging adults aged 18-25 years with CP?**

3. **Are emerging adulthood and ICF theoretical constructs reflected in the themes developed from the stories of emerging adults aged 18-25 with CP?**
2.9 Synopsis

During emerging adulthood, young people with CP face the significant developmental challenges and transitions encountered by all emerging adults. However, they also face additional challenges associated with their disability. This literature review has described emerging adulthood as a contemporary stage in the lifespan, existing predominantly for young people in developed countries. The ICF was introduced and explored as a framework for understanding experiences of health and disability. Cerebral palsy, as the lifelong disability at the centre of this research, was introduced and what we know about the experiences of emerging adults who have CP was explored in the context of the ICF domains of body functions and structures, activities and participation, and environmental and personal factors. Following this discussion, the research problem and gaps in existing knowledge was articulated. There is a need to understand the stories of emerging adults with CP from their own perspective, to develop key themes from their stories, and to explore if, and how, the constructs of the theory of emerging adulthood and the ICF are reflected within these themes. The specific research questions explored by this study to address these gaps were detailed. The following chapter describes the research design and methods employed to answer these questions.
Chapter 3. Storytelling: Research Design and Methods

3.1 Introduction

This research aimed to understand the stories of emerging adults with CP from their own perspective, to develop themes from these stories, and to explore if and how key theoretical constructs were reflected within these themes. To do so, the research was framed by a constructivist perspective and utilised narrative inquiry as its methodological focus. Following exploration of constructivist perspectives and narrative inquiry, this chapter describes the participant selection and recruitment strategies utilised in this study. The emerging adult participants are introduced, followed by an introduction to myself as the researcher. Attention to the researcher’s own story in relation to the phenomenon under study is an important element of narrative inquiry, as it is recognised that it is impossible to separate the researcher from the research. Data collection and analysis methods are also presented in this chapter, and ethical considerations explored.

3.2 A constructivist research perspective

The constructivist paradigm emphasises that people seek to understand the world in which they live, and do so by developing varied and multiple subjective meanings of their experiences (Creswell, 2014). Accordingly, constructivist research does not seek to identify a single reality. Rather, it asserts that there are multiple realities constructed by individuals, and in the case of research, these realities are influenced by the interaction between interviewer and participant (Denzin & Lincoln, 2000; Lincoln & Guba, 1985). Constructivist researchers look to understand the complexity of experience to make sense of the meanings others have about the world in which they live. They achieve this through open-ended questioning, and
maintaining a focus on the views of participants using inductive processes. Thus a constructivist perspective is core to many qualitative research designs (Creswell, 2014). Gergen emphasises a key value of constructivist research being its potential to bring to the fore the voices of those under study (Gergen, 1999). A constructivist paradigm was therefore integral to achieving the aims of the current research; to understand the varied stories of emerging adults with CP from their own perspective.

Polkinghorne (1988) further articulates the importance of constructivist approaches in relation to the study of people and human problems. He advocates the use of methods that are “especially sensitive to the unique characteristics of human existence”; methods which pay attention to the stories people tell (Polkinghorne, 1988, p. x). These stories demonstrate how people make sense of their life experiences, how they respond to these experiences, and how they create meaning in their lives (Polkinghorne, 1988). As this research aimed to understand experiences of emerging adults with CP, a qualitative, narrative inquiry approach was adopted as the appropriate methodological focus.

### 3.3 Methodological focus: Narrative inquiry

Narrative inquiry has been defined as a methodology “in which stories are used to describe human action” (Polkinghorne, 1995, p. 5). Narrative inquiry is based on the claim that stories “constitute a fundamental form of human understanding, through which individuals make sense of themselves and of their lives” (Ylijoki, 2001, p. 22). A life narrative allows people to interpret “what they are and where they are headed” (Polkinghorne, 1988, p. 14). Even as children, stories are fundamental to learning to understand the world around us and our place within that social world. Stories continue to absorb us throughout our lives and become the “vehicle through which the reality of life is made manifest...we live by stories – both in the telling and the realising of the self” (Gergen, 1994, p. 186). Through listening to stories, understanding is gained about the way that people make meaning of their everyday lives within historical, social and cultural contexts. Shared beliefs are understood
and values are conveyed (Bruner, 1990; Gergen, 1994; Kramp, 2004; Polkinghorne, 1988). Stories “assist humans to make life experiences meaningful. Stories preserve our memories, prompt our reflections, connect us with our past and present, and assist us to envision our future” (Kramp, 2004, p. 107). This overarching view of the positive products of story-telling is the foundation of narrative inquiry research methods. For the purposes of this study the terms story and narrative are used interchangeably (Kramp, 2004; Polkinghorne, 1995).

Narratives involve the integration of events and human actions into a goal-directed story which is organised in terms of time (Polkinghorne, 1988, 1995). Narratives consider the influence of the past, present and future, and are presented within a specific place, or sequences of places (Clandinin & Connelly, 2000; Kramp, 2004). Integration occurs when a thematic thread, or plot, is employed to allow individual events and happenings to take on a “narrative meaning” (Polkinghorne, 1995, p. 5). Events and happenings are then “understood from the perspective of their contribution and influence on a specific outcome” (Polkinghorne, 1995, p. 5). A plot weaves together “a complex of events to make a single story” (Polkinghorne, 1988, p. 19). This story, or narrative whole, reveals greater meaning than when individual events are viewed in isolation. For example, the following sentences viewed individually, “I left school in year 10”, “I started an apprenticeship”, “I took some time off”, do not provide the complexity of understanding that is revealed through the full narrative from one of the present study’s participants:

I left High School in Year 10 and started a hair dressing apprenticeship. That went down the gurgler. I hated it. Went to TAFE, started a course, hated that, it wasn’t what I wanted. Then I had a bit of a mental health crisis, took some time off, went back and did [another course] at TAFE, which was brilliant... I didn’t really know what I wanted to do...I kept going from one thing to another [Megan].

Narrative inquiry can take various forms and there are many examples of different approaches to narrative inquiry within the literature across numerous disciplines including sociology, psychology, anthropology and human sciences (Reissman, 2008). Within the health and social sciences, narrative inquiry has been identified as
particularly valuable in understanding the lives of those whose experiences depart from “normative” expectations, such as those with disability (Bruner, 1990; Mishler, 1991; Reissman, 1993), hence its appropriateness to the current study. The work of Donald Polkinghorne (1988, 1995) has guided the approach to narrative inquiry utilised in this research, and will now be explored.

3.3.1 Narrative analysis and analysis of narratives

Polkinghorne (1995) made an important distinction between two types of narrative inquiry. He based the two types on the two different, but complementary and equally valid, ways of understanding the world identified by Bruner (1985): narrative cognition and paradigmatic cognition.

3.3.1.1 Narrative cognition and narrative analysis

Narrative cognition is designed to understand the outcome of the interaction between a person’s previous learning and experiences, present situation, and future goals and purposes. Narrative inquiry based on narrative cognition is labelled by Polkinghorne as narrative analysis (Polkinghorne, 1995). Understanding is expressed by way of a story with a plot that retains the complexity of the situation under exploration and the emotions and motivations attached to it. Stories defined as using narrative cognition are complex accounts with a beginning, middle, and end, as distinct from a simple listing of a series of events. The plot, or point, of the story, functions to enable researchers to select from the multitude of data collected, those descriptions of happenings, events and actions that relate to each other and are directly relevant to the story (Polkinghorne, 1995). The result of narrative analysis is “an explanation that is retrospective, having linked past events together to account for how a final outcome might have come about” (Polkinghorne, 1995, p. 16). The events are recounted in a time-ordered way that makes it clear how they contributed to the overall “point” (Gergen, 1994, 1999).
3.3.1.2 Paradigmatic cognition and analysis of narratives

Paradigmatic cognition, in contrast, refers to methods that classify instances into categories and subcategories based on common attributes. Paradigmatic reasoning is common to both qualitative and quantitative research designs, however is used in different ways. In quantitative research the categories, or units of measurement, are usually identified before data collection. In qualitative research conceptualisation may take two forms. It includes the inductive discovery of categories or themes from within the data, and may also utilise deductive processes to explore how well data fits with pre-determined concepts, usually those reflected in an existing theoretical framework or frameworks (Berg, 2007; Polkinghorne, 1995). Narrative enquiry based on paradigmatic cognition is referred to by Polkinghorne (1995) as analysis of narratives. It requires the collection of stories as data followed by paradigmatic analysis that results in “descriptions of themes that hold across the stories” (Polkinghorne, 1995, p. 12).

The key benefit of analysis based on paradigmatic cognition is the ability to “bring order to experience by seeing individual things as belonging to a category” (Polkinghorne, 1995, p. 10). It enables general knowledge about a collection of stories to be gained. It does however by necessity “underplay the unique and particular aspects of each story” (Polkinghorne, 1995, p. 15), which are maintained in the alternative narrative analysis. To achieve the benefits of both approaches to narrative inquiry, they can be utilised in combination.

3.3.1.3 Complementary use of narrative and paradigmatic approaches to narrative inquiry

There is no set approach to undertaking a narrative inquiry. Within the literature a range of different approaches are described, and various combinations of approaches have been successfully utilised. The different approaches are not mutually exclusive (Smith & Sparkes, 2008). For example, Ylijoki (2001) interviewed 72 students and used a narrative analysis approach to construct four different core narratives around the experience of writing a master’s thesis. McCance, McKenna
and Boore (2001) identified common themes using *paradigmatic analysis of narratives* and also constructed six storied case studies using *narrative analysis* in their research exploring caring in nursing practices. Cussen, Howie and Imms (2012) used *narrative analysis* to construct individual stories for all of their adolescent participants and then derived common themes about aspirations for the future using *paradigmatic analysis of narratives*. Other researchers have also previously employed Polkinghorne’s dual techniques successfully (eg. Bailey & Jackson, 2003; Kramp, 2004; McCormack, 2004). Bleakley (2005) goes as far as to describe *narrative analysis* and *analysis of narratives* as being as complementary as a “lock and key: approaches of analysis and synthesis look different apart but constitute a unit together” (p. 537).

### 3.3.2 Approach to narrative inquiry in the present study

In the current research, both forms of narrative inquiry described by Polkinghorne (1995) were employed, each with a different purpose. Firstly, each participant’s story is told individually. Each young person had a unique and important story to tell. With the paucity of research in this area from the perspective of emerging adults with CP, it was essential to include each story (as constructed) as a whole to reveal the lives of these young people from their own voices. Implementing a *narrative analysis* approach allowed the synthesis of participants’ descriptions and stories into an individualised narrative of each emerging adult’s experience that was organised by time. These constructed narratives are reflective of the data, but at the same time offer an order and meaningfulness that is not apparent within the data itself (Polkinghorne, 1995). They include numerous direct quotes in the participants’ own voices and offer a depth that is unequalled by other forms of data analysis. *Narrative analysis* provided the answer to the first research question: *what are the stories of emerging adults aged 18-25 years with CP?*

In addition, I wanted to understand the themes, commonalities and differences evident across stories, and to understand whether the concepts of the two theoretical frameworks (developmentally focused emerging adulthood, and disability-focused ICF) are reflected across the stories. For this reason, a
paradigmatic analysis of narratives approach was subsequently utilised to identify common and contrasting concepts appearing across stories and to develop themes. This inductive analysis of narratives provided the answer to the second research question: what themes can be developed from the stories of emerging adults aged 18-25 years with CP? Concurrently, a deductive analysis of narratives approach, based on key concepts within the theory of emerging adulthood and the ICF, was used to answer the third and final research question: are emerging adulthood and ICF theoretical constructs reflected in the themes developed from the stories of emerging adults aged 18-25 with CP?

While it may be seen that potential theoretical tensions could arise when combining data-driven inductive, and theory-driven deductive analysis of narratives methods, it is important to note that these approaches were used concurrently in the current study for different purposes and to answer distinct research questions. The author has published on the complementarity of such dual approaches to analysis (Sharp, Bye, & Cusick, 2018). Other examples of the successful combination of inductive and deductive analysis, to complement specific research questions, can be found within literature (eg. Fereday & Muir-Cochrane, 2006; Yukhymenko, Brown, Lawless, Brodowinska, & Mullin, 2014).

3.3.3 Narrative inquiry to reveal experiences of disability

The utilisation of integrated narrative analysis processes has also been specifically recommended for disability research, because of its capacity to “consider the storied voices of individuals with disabilities as a mechanism to empower not only themselves but others as well”, and concurrently to identify themes that reveal “the more universal experiences of disability” (Smith-Chandler & Swart, 2014, p. 427-428). Narrative inquiry puts the perspectives of people with disability “in the foreground of debates about care and constructions of impairment and disability”, in contrast to other types of research which neglect the perspectives of people with disability (Goodley & Tregaskis, 2006, p. 632). People who do not have disabilities are outsiders to the experience of living with disability and therefore cannot provide the same level of insight as people with disability (Franits, 2005). Smith and Sparkes
(2008) noted that telling stories of disability has the potential to teach people with
disability and others about the complexity and diversity of experience and “displace
the tragedy story, challenge and resist social oppression” (p. 19). Narrative inquiry
can contribute much to disability studies through its capacity to give voice to people
whose voices have so often been discounted (Clandinin & Raymond, 2006; Holloway, 2007).

This research aimed to understand the stories of emerging adults with CP. Along
with support for the use of narrative methods to explore disability, the developer of
the theory of emerging adulthood and others have encouraged researchers to
utilise narrative methods as a legitimate way to learn about the experiences of
emerging adults (Arnett, 2006c, 2014; Sestito & Sica, 2014). Narrative inquiry was
therefore identified as the most appropriate method to achieve the aims of this
research, because of its ability to reveal, construct, and compare the stories of
emerging adults with CP. In-depth interviews would allow these stories to be
revealed, and facilitate the capturing of a “vivid understanding of the variance that
exists among emerging adults” (Arnett, 2006c, p. 327). The next important step in
the research process was to locate emerging adults with CP who were willing to
share their stories.

3.4 Participant recruitment and selection

A recruitment method was required which would allow the identification of
participants with CP who were able to share their experiences and stories of
emerging adulthood. Purposive selection was identified as the appropriate sampling
strategy for this qualitative study, and more specifically, criterion sampling.
Purposive selection refers to selection of “information-rich cases” capable of
providing the researcher with an in-depth understanding of issues relevant to the
purpose of the study (Patton, 2002, p. 230). Participants are selected who have
first-hand and in-depth knowledge of the topic under study, and are therefore best
placed to facilitate answering of the study’s research questions (Teddlie & Yu,
2007). The focus of selection is not on how many sources, or on how much data can
be collected, but rather on whether the data will be sufficiently rich to gain an understanding of experience (Polkinghorne, 2005). For this reason, it was not appropriate or necessary to set a minimum sample size.

Criterion sampling refers to a specific type of purposive selection whereby people must meet a certain criterion to be involved in the research, for example they have to have had a certain life experience (Palys, 2008). In the current study, participants needed to have a diagnosis of CP, and be in the emerging adult life-stage. The following sections describe the specific participant selection criteria, methods used to locate potential participants, and recruitment strategies.

### 3.4.1 Participant selection criteria

Purposive selection was undertaken during the recruitment stage of this project. The participants were emerging adults, aged 18 to 25, who had CP. Participant selection criteria were determined at the outset of the study, to ensure selection of participants who were currently experiencing emerging adulthood with CP, and could therefore share their stories of this life stage. The selection criteria were:

1. **Aged between 18-25 years**
   The study aim was to understand the experience of emerging adults; hence participants needed to be “living their stories”. Emerging adulthood was operationally defined as ages 18-25 years on the basis of theoretical literature on the emerging adulthood life stage (Arnett, 2000a). Therefore, participants were required to be within this age range during their involvement in the study. In line with the narrative inquiry approach, maximum variation of ages within the sample was not specifically sought, however by chance participants did fall across the whole of the emerging adulthood age range.
2. **Diagnosed with CP of any classification and severity**

This study aimed to understand the specific stories of emerging adults with CP, therefore participants needed to have this diagnosis. Participants with all types and levels of severity of CP were sought to capture a potentially wide range of variability in stories and experience. Potential participants with additional diagnoses, including sensory impairments and intellectual disability, were eligible to participate, except where excluded for not meeting other criteria below. Because participants were not minors, and volunteered for the study knowing it required a diagnosis of CP for inclusion, it was decided that potential participants could self-identify as having CP with the only verification being the conversation in the first interview where the interviewer, with clinical expertise in CP, could make confirmatory observations and delve further into the participant’s history. No person who self-identified as having CP was excluded after the first interview.

3. **Ability to provide written informed consent**

For ethical reasons, it was important to ensure that all participants were capable of understanding the implications of their involvement in the project, and able to provide written informed consent. Because it is known that approximately 50% of people with CP also have an intellectual disability to some degree (Novak, 2014), the ability of each potential participant to provide informed written consent was determined by the researcher during the first interview through observation informed by her previous clinical expertise and through the content of interview conversation. This process involved provision of both written and verbal information in plain English, answering any questions the potential participant had, and then asking potential participants to describe what their participation in the study would involve. Questions were asked to clarify young people’s understanding and ability to consent. For example, “what will you have to do in this research?”, “what can you do if you don’t want to talk to me anymore?”, “is there anything bad that might happen during this research?”, and “do you have to answer all of my questions?” Similar strategies have previously been utilised to determine informed
consent in research with people who have intellectual disability (Arscott, Dagnan, & Kroese, 1998).

4. Ability to communicate, either verbally or using augmentative or alternative communication, at a level that allows active participation in interviews in the English language

This research specifically set out to capture the experiences and views of emerging adults with CP themselves, rather than the views of third-parties. Until recently, research on young people with CP has often sought the views of parents and healthcare providers, at the expense of views of young people themselves. It is critical to understand the perspective of emerging adults themselves, as discrepancies have been identified between the views of young people and their parents (Garth & Aroni, 2003; Schiariti et al., 2014). It was essential to consider the emerging adults’ communication skills because both speech impairment and intellectual disability are commonly associated with CP (Novak, 2014). Considering the interactive and collaborative nature of interviewing, and to ensure sufficient depth in the data collected, it was necessary for participants to have communication skills sufficient to allow the active exchange of ideas and experiences. This was determined during initial contact with potential participants prior to inclusion in the study, and participants were offered the opportunity to use whatever varied means of communication they preferred. For example, interviews could be conducted verbally face-to-face, verbally by phone, through written email exchange or by using an augmentative communication device face-to-face.

3.4.2 Locating potential participants: Recruitment

To locate potential participants, a variety of recruitment techniques were used to advertise the study in areas where emerging adults with CP were likely to become aware of it and could initiate contact. The Cerebral Palsy Alliance (then called The Spastic Centre) (https://www.cerebralpalsy.org.au/) was identified as a key provider of services to people with CP in NSW and therefore the most appropriate organisation through which to advertise. Specific techniques employed during advertisement of the study included the following:
1. Advertisements (Appendix A) were mailed to each site of the Cerebral Palsy Alliance, including metropolitan, regional and rural sites, with a request that they be displayed in locations where emerging adults with CP were likely to see them, including centre foyers, supported employment, and community participation sites.

2. Advertisements were emailed to service providers working with emerging adults within the Cerebral Palsy Alliance. Service providers were asked to pass on details of the study to their clients.

3. Advertisements and feature articles presenting a profile of the investigator and details of the project were placed on the following websites:
   a. The Cerebral Palsy Alliance website which had a section for latest news and projects, as well as information about the services, policies, history and activities of the Cerebral Palsy Alliance.
   b. The *Y Connection* website which aimed to develop and strengthen connections between 17-30 year olds with a disability and offered information, support and discussion forums (*Y Connection* was an initiative of the Cerebral Palsy Alliance at the time of the study; *Y Connection* has since been disbanded).

4. Advertisements and feature articles about the research were also published in the following documents:
   a. The *CP Research News*, a newsletter with a distribution of approximately 1250 copies, through sites of the Cerebral Palsy Alliance, other service providers and institutions, and the Cerebral Palsy Alliance Research Foundation website (R. Cummins, Information Manager, Cerebral Palsy Alliance, personal communication, April 24, 2007).
   b. *I Am*, the quarterly magazine of the Cerebral Palsy Alliance, with a distribution of roughly 6000 people with CP, families, supporters and media personnel (J. Mitchell, Marketing Officer, Cerebral Palsy Alliance, personal communication, April 24, 2007).
   c. *The Scene*, the Cerebral Palsy Alliance’s fortnightly e-newsletter distributed to approximately 900 people with CP, families and service
providers (R. Cummins, Information Manager, Cerebral Palsy Alliance, personal communication, April 24, 2007).

5. The researcher made visits to the following departments within the Cerebral Palsy Alliance to discuss the project and seek support in recruiting clients to the study. Note that the organisation has since been restructured, and departments renamed, with the introduction of the NDIS:
   a. The Adult Resource Program which provided assessments, advice, support and information to clients of the Cerebral Palsy Alliance aged 18 and over.
   b. Business Services, an Australian Disability Enterprise, which offered supported employment to adults with CP and other disabilities in the packing industry.
   c. The Sydney Employment Development Service, the employment arm of the Cerebral Palsy Alliance, a DES which assisted adults with CP and other disabilities to secure open employment.
   d. The Community Access Services, which provided community participation programs for adults with CP who have severe and multiple disabilities.

6. Later, a postal mail-out of the advertisement and telephone calls were made, by the Cerebral Palsy Alliance, to clients on their database who were born between 1981 and 1988 (and therefore 18-25 and meeting the age-related inclusion criteria at the time of recruitment) to let them know about the study and seek interested participants. This required an amendment to existing ethics approval and was initiated as an add-on recruitment strategy as recruitment had been slower than anticipated.

The above strategies were employed to raise awareness of the study and advertise for appropriate participants. The advertisements provided basic details of the aims of the study and initial information about the characteristics of participants sought. Telephone and email contact details for the researcher were also included and interested young people were asked to contact the researcher directly. Volunteers from metropolitan, regional and rural areas were welcome, as were people from
varying cultural, family, and socio-economic backgrounds. Indeed, a heterogeneous group of people with variations in these areas was welcomed, to gain a broader understanding of the range of experiences of emerging adults with CP.

As participants became involved in the study, recruitment was further extended through snowballing techniques (Domholdt, 2000). Participants were asked if they could pass on information about the study to other emerging adults with CP in their social networks, and many chose to do so. This was important, as some young people with CP may not have been in current contact with service organisations like the Cerebral Palsy Alliance. Some participants also volunteered to pass the information onto members of organisations they were involved in, through newsletters such as those distributed by the NSW Cerebral Palsy Sport and Recreation Association (https://www.cpsara.org.au/) and the Disability Education and Employment News (https://ndco.cds.org.au/newsletters/).

3.4.3 Eligibility screening and study enrolment

Following advertisement, referral or other contact about the study, initial contact was made with the researcher. Recruitment predominantly took place when a potential participant or a member of their family, usually a mother, contacted the researcher directly, after having seen an advertisement for the study. In most cases this initial contact was made via email. In a small number of cases, however, participants were provided information about the study by a third party, usually a service provider, and gave the service provider permission to pass on their contact details to the researcher. In these cases, the researcher then contacted the potential participant by phone or email.

During the initial contact, potential volunteer participants were screened to ensure they met the participant eligibility criteria. The screening took place via telephone and/or email interview. During the initial telephone or email contact, young people were also provided with verbal or written information about the aims of the study and what they would be required to do should they become involved. Depending
on their geographical location, communication needs, and preferences, potential participants could select face-to-face, phone or email interviews, or a combination.

Following initial contact, potential participants who were interested in becoming involved and met the eligibility criteria were either mailed or emailed the written participant information statement (Appendix B), containing information about the purpose of the research, what they would be required to do, potential risks involved in participation, and the likely outcomes of the research. The researcher contacted potential participants by telephone approximately a week after sending the information statement. They were offered the chance to ask any questions arising from the information statement, and then asked if they were willing to participate. A convenient time and location for the first interview was arranged with emerging adults who consented. The information statement was again provided at the initial interview and there was an opportunity to ask questions. Participants were asked to recount their understanding of the research, and clarifying questions were asked to ensure consent was informed. Written consent was also gained at the first meeting, except in cases where the first interview was via email. In these cases (n=3) the consent form (Appendix C) was mailed and returned signed prior to commencement of data collection.

The multi-method targeted recruitment strategy described above took place between October 2005 and November 2006. During the recruitment timeframe, a total of 27 potential participants contacted the researcher, or were contacted by the researcher after permission had been gained from the young person by a service provider. Eighteen emerging adults agreed to take part in the study and provided written, informed consent. This represents, to the author’s knowledge, the largest sample of emerging adults with CP to be engaged in a narrative inquiry. There were no later withdrawals from the study. Of the nine potential participants who did not take part, two did not meet the inclusion criteria. The other seven eligible emerging adults chose not to be involved due to personal circumstances. Reasons provided included not having time to devote to the in-depth study and family difficulties.
3.5 Introducing the emerging adults

The eighteen emerging adults who participated in this study are introduced in this section. The demographic details of the emerging adults are summarised in Table 5, including their age at first interview, self-classification as an adult, their highest level of education, primary activity, income sources, community access options, and type and severity of CP. All names used are pseudonyms.
<table>
<thead>
<tr>
<th>Participant</th>
<th>Pseudonym</th>
<th>Age at first interview</th>
<th>Self-defined as adult?</th>
<th>Highest level of education</th>
<th>Primary activity</th>
<th>Income source</th>
<th>Community access options</th>
<th>CP Type</th>
<th>GMFCS Level~</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chris</td>
<td>Chris</td>
<td>24</td>
<td>^</td>
<td>Year 12</td>
<td>Activities at home</td>
<td>DSP</td>
<td>Mother, power wheelchair</td>
<td>Spastic quadriplegia</td>
<td>V</td>
</tr>
<tr>
<td>Daniel</td>
<td>Daniel</td>
<td>24y7m</td>
<td>Yes/No</td>
<td>Bachelor's degree</td>
<td>University, part-time work</td>
<td>DSP</td>
<td>Parents, public transport</td>
<td>Doesn’t know</td>
<td>II</td>
</tr>
<tr>
<td>Erin</td>
<td>Erin</td>
<td>25y3m</td>
<td>Yes</td>
<td>Honours degree</td>
<td>Open employment</td>
<td>Work</td>
<td>Drives</td>
<td>Spastic diplegia</td>
<td>I</td>
</tr>
<tr>
<td>Hayley</td>
<td>Hayley</td>
<td>22y6m</td>
<td>Yes/No</td>
<td>Bachelor's degree</td>
<td>University</td>
<td>DSP</td>
<td>Parents, taxi, electric scooter</td>
<td>Athetoid</td>
<td>III</td>
</tr>
<tr>
<td>Jack</td>
<td>Jack</td>
<td>22y3m</td>
<td>Yes</td>
<td>Year 12 HSC</td>
<td>Open employment</td>
<td>Work</td>
<td>Parents, electric scooter</td>
<td>Spastic diplegia</td>
<td>III</td>
</tr>
<tr>
<td>Jessica</td>
<td>Jessica</td>
<td>18y10m</td>
<td>Yes/No</td>
<td>Year 12 HSC</td>
<td>University</td>
<td>Centrelink</td>
<td>Drives</td>
<td>Hereditary spastic diplegia</td>
<td>II</td>
</tr>
<tr>
<td>John</td>
<td>John</td>
<td>18y5m</td>
<td>Yes/No</td>
<td>Completing HSC</td>
<td>School</td>
<td>DSP</td>
<td>Parents, taxi, electric scooter</td>
<td>Spastic quadriplegia</td>
<td>III</td>
</tr>
<tr>
<td>Justin</td>
<td>Justin</td>
<td>19y</td>
<td>Yes/No</td>
<td>Year 12 HSC</td>
<td>University</td>
<td>DSP</td>
<td>Drive, parents</td>
<td>Doesn’t know</td>
<td>III</td>
</tr>
<tr>
<td>Lauren</td>
<td>Lauren</td>
<td>20y11m</td>
<td>Yes/No</td>
<td>Year 12 ACT Senior Secondary Cert.</td>
<td>Own business</td>
<td>DSP</td>
<td>Parents, taxi</td>
<td>Spastic quadriplegia</td>
<td>V</td>
</tr>
<tr>
<td>Megan</td>
<td>Megan</td>
<td>22y1m</td>
<td>Yes</td>
<td>TPC***</td>
<td>University</td>
<td>DSP, family</td>
<td>Public transport, learning to drive</td>
<td>Spastic diplegia</td>
<td>II</td>
</tr>
<tr>
<td>Michael</td>
<td>Michael</td>
<td>22y6m</td>
<td>Yes/No</td>
<td>Year 12 HSC</td>
<td>University</td>
<td>Centrelink</td>
<td>Drives</td>
<td>Spastic diplegia</td>
<td>II</td>
</tr>
<tr>
<td>Mitchell</td>
<td>Mitchell</td>
<td>18y</td>
<td>Yes/No</td>
<td>Completing HSC</td>
<td>School</td>
<td>DSP</td>
<td>Parents, taxi</td>
<td>Spastic quadriplegia</td>
<td>III</td>
</tr>
<tr>
<td>Nathan</td>
<td>Nathan</td>
<td>20y8m</td>
<td>Yes</td>
<td>Year 12 HSC</td>
<td>Open employment</td>
<td>Work</td>
<td>Drives</td>
<td>Spastic hemiplegia</td>
<td>I</td>
</tr>
<tr>
<td>Paul</td>
<td>Paul</td>
<td>19y6m</td>
<td>No</td>
<td>Year 12 Lifeskills**</td>
<td>Supported employment</td>
<td>DSP**, work</td>
<td>Parents, public transport</td>
<td>Spastic hemiplegia</td>
<td>II</td>
</tr>
<tr>
<td>Rachel</td>
<td>Rachel</td>
<td>18y6m</td>
<td>Yes/No</td>
<td>Year 12 HSC</td>
<td>Commencing university</td>
<td>Centrelink</td>
<td>Parents, learning to drive</td>
<td>Spastic diplegia</td>
<td>III</td>
</tr>
<tr>
<td>Rina</td>
<td>Rina</td>
<td>21y6m</td>
<td>Yes/No</td>
<td>Year 12 HSC~~</td>
<td>University</td>
<td>Parents</td>
<td>Parents, taxi</td>
<td>Spastic quadriplegia</td>
<td>V</td>
</tr>
<tr>
<td>Scott</td>
<td>Scott</td>
<td>20</td>
<td>^</td>
<td>TAFE Certificate</td>
<td>Activities at home</td>
<td>DSP</td>
<td>Mother, public transport</td>
<td>Spastic diplegia</td>
<td>III</td>
</tr>
<tr>
<td>Simon</td>
<td>Simon</td>
<td>21y4m</td>
<td>Yes/No*</td>
<td>Year 12 Lifeskills</td>
<td>Supported employment</td>
<td>DSP, work</td>
<td>Parents, taxi</td>
<td>Doesn’t know</td>
<td>III</td>
</tr>
</tbody>
</table>

Table 5: Demographic details of participants
Key:
* In some respects yes, in some respects no
^ Missing data
^~ Gross Motor Function Classification System
**Lifeskills is a modified curriculum offered in NSW schools specifically for students with special education needs
^^ Disability Support Pension
~~ Higher School Certificate, NSW credential awarded at completion of secondary schooling
***Tertiary Preparation Certificate
The mean age of the participants at the time of the initial interview was 21 years, with a range of 18 years to 25 years, 3 months. All participants were born in Australia and resided in NSW (n=17) or the ACT (n=1). Eleven participants lived in metropolitan Sydney, while five resided in regional towns outside of the city, and two lived in rural areas. Seventeen of the participants resided in their family home, 15 of these with both biological parents and two with their mother only. Only one participant, Michael, currently lived out of home. He was living on campus at his university.

As noted in Table 5 above, the majority of participants were engaged in either study or employment, or both, as their primary daily activity. However two participants were not engaged in work or study at the time of data collection, and spent much of their time alone at home or with their parents. Most participants relied on Commonwealth income support to assist with living expenses, with only three who were working full-time not receiving such financial support. The majority of participants relied on public transport, taxis or support from parents to access their community. Five participants were able to drive.

### 3.6 Introducing the researcher

In narrative inquiry it is important that the researcher tells their own story in relation to the phenomenon under study. This is because “researchers’ personal, private, and professional lives flow across the boundaries into the research”; it is impossible for the researcher to ignore their own story as they attend to the stories of participants (Clandinin & Connelly, 2000, p. 115). For this reason, I introduce my own story around emerging adulthood, and how I came to undertake this research, as my own experiences have inevitably influenced the research process and findings. This personal reflection (see text box) is included for dual purposes. It helps me, as the researcher, to explicitly understand the role of my own story throughout this research process and into the findings, and hopefully it also helps the reader, to understand the context, circumstances and subjectivities that have contributed to this research (Josselson & Lieblich, 2003).
I commenced this research in 2004 as an inexperienced 23 year old, after just completing undergraduate honours in occupational therapy (OT). I still lived at home and had wonderful support from my parents who encouraged me in my studies. I worked part-time in a newsagency. I had never had a full-time job, lived away from home, or travelled the world. I started a PhD because I did not feel like clinical OT was for me... and I wasn’t sure what to do.... and well... because people told me I could! I chose to study the experiences of people with CP because I had greatly enjoyed previous times spent with people with CP during university placements and volunteering, and because I have two cousins who have CP. I decided to focus on the 18-25 year age range because I had become passionate about transitions during my undergraduate honours research and emerging adulthood is a key developmental transition period. This research was especially appealing to me as I was an emerging adult myself and hoped I would connect well with participants in the same life stage. As mentioned in Chapter One, the research focus has evolved over time as I listened to, and learned from, participants and others.

Skip forward fourteen years – it is 2018, I am 37 years old, and I am finally finishing that PhD. The last fourteen years have been such a journey, sometimes hard, but mostly good. And although I am yet to call myself a Dr, I can call myself so many other things which are very important to me – a mum, a friend, a daughter, a mentor, an academic, as well as someone working to improve the lives of people with disabilities by breaking down barriers in our society. I finally feel that I have reached that elusive ‘adulthood’. I never realised when embarking on a PhD with emerging adults, that my own journey to adulthood would influence the final product.

My journey included relationship breakdowns, new relationships, health problems, a new job in research with the Cerebral Palsy Institute, the new challenge of working full-time and studying part-time. I moved out of home, got engaged, later married and bought my first home. I started another new job, with the National Disability Coordination Officer Program, working to improve transitions and participation of people with disability in tertiary education and employment. This role provided a whole new level of insight and knowledge, and reinforced the earlier decision to broaden the narrative domain of the study from its original healthcare focus.

A couple of years on I took a management role in the same program which added another layer of complexity to my work/study juggles. This escalated a few weeks later when we found out with great delight that we were expecting a baby! We sold our home and bought another back in the town where I grew up. Having family support close by has meant the world to me since Cooper was born in November 2010. Cooper has blessed our lives and I am constantly amazed by my now 7-year-old son, the things he learns every day, and the things he teaches me. I returned to work when Cooper was 5 months old to play the juggling act of mummy, wife, home-maker, manager... not to mention friend, daughter, aunty... and PhD Candidate!

Four years ago life took another very challenging turn as I had to get used to life as a single mum. More recently, there have been more big transitions,
with me having taken on a new full-time role as an academic, Cooper starting “big school”, a new relationship, and yet another house move.

My journey has had a huge impact on the final product of this research. I am positive that this is not the same thesis I would have written if I’d have finished this PhD as an inexperienced 26-year-old. I like to think that the final thesis reflects my own development over the past 14 years, in research, in work, and in life.

3.7 Data collection: In-depth interviews

In-depth interviews were utilised as the primary data collection method for this study. “In-depth interviewing is conversation with a specific purpose - a conversation between researcher and informant focusing on the informant’s perception of self, life, and experience and expressed in his or her own words” (Minichiello, Aroni, Timewell, & Alexander, 1995). In-depth interviewing allows the researcher to access and understand participants’ interpretations of social reality (Minichiello et al., 1995). While structured interviews often approach respondents as passive providers of answers to strict ordered questions, in-depth interviews instead seek to gather a deep understanding of informants’ perspective. They dispense with formal schedules, strict question ordering, and close-ended questions (Fontana & Frey, 1998; Minichiello, Aroni, Timewell, & Alexander, 1990). Instead, researchers begin only with general topics they wish to learn about, and the development of the interview relies on “social interaction between interviewer and informant to elicit information” (Minichiello et al., 1990, p. 92).

In-depth interviews are recognised for facilitating the collection of a greater breadth of information than other forms of interviewing, as they do not impose any restrictions or pre-developed categories, which may restrict the field of inquiry (Fontana & Frey, 2000). Such in-depth, unstructured interviews, are much more likely to elicit stories from participants, as respondents are “invited to speak in their own voices, allowed to control the introduction and flow of topics, and encouraged to extend their responses” (Mishler, 1986, p. 69). The particular approach that
guided the in-depth interviewing in the current study was the active interview, as described by Holstein and Gubrium (1995).

3.7.1 The active interview

The active interview was selected as the appropriate approach to interviewing for this study because it encourages participants to talk about their experiences narratively. Indeed, the active interview is described as an “occasion for narrative production”, when disparate aspects of “experience, emotion, opinion and expectation” are combined into a “coherent, meaningful whole” (Holstein & Gubrium, 1995, p. 28). It is thus compatible with the narrative inquiry design and narrative data analysis methods employed in this study. The active interview is also based on the constructivist perspective which underpins narrative inquiry. It recognises that all people “have worthwhile stories to tell” and therefore was the approach deemed most congruent with the study’s aim of understanding the stories of emerging adults with CP (Holstein & Gubrium, 1995, p. 26).

The active interview recognises that all participants in an interview are inevitably involved in “meaning making”; both the interviewer and respondent are necessarily and unavoidably active and collaborative (Holstein & Gubrium, 1995, p. 4). The interviewer and respondent interact dynamically to produce meaningful stories. The active respondent does not passively answer questions by providing facts and details of experience. Rather, they actively construct and transform these facts and details, piecing experiences together, assembling and modifying their story. Information is added, and stories are modified and refined, over the course of the interview or interviews. The active interviewer promotes respondents’ interpretive potential, assisting them to consider alternatives and develop topics in ways relevant to their own experiences. Thus, the active interviewer “invites and assists narrative production” (Holstein & Gubrium, 1995, p. 29). These interviews allow for in-depth responses and do not dictate the course of the interview or use pre-set questions, however they “loosely direct” the interview by setting certain parameters and introducing certain topics during the interview to elicit responses that are relevant to the aims of the research (Holstein & Gubrium, 1995, p. 29).
Holstein and Gubrium (1995) refer to this as setting the ‘narrative terrain’ of the interview.

### 3.7.2 Narrative terrain

The narrative terrain of this study was guided by the theory of emerging adult development (Arnett, 2000a) and the ICF (World Health Organisation, 2001). The focus was on understanding participants’ meaning, within their personal contexts, of the experience of emerging adulthood as a person with disability. It aimed to understand their stories and whether and how the constructs of emerging adulthood (2000a) and the ICF (World Health Organisation, 2001) were reflected within their stories. The broad interview guide used during interviews to focus attention to the narrative terrain of the research is included in Appendix D. Interviews were planned around these overall aims, but were conducted in such a way that the diverse experiences of participants, which contributed to their personal meaning making, were explored in-depth. For example, experiences during the transition from school to work were an integral part of some participants’ stories, while for others it was relationship experiences, community access or societal perceptions and acceptance. Some participants found it important to explore and reflect on experiences that occurred earlier in their lives and how these experiences led to or influenced their emerging adulthood, while others were most comfortable discussing their current and recent experiences. To maintain the narrative terrain while allowing for the in-depth exploration of individual experiences, various interview techniques were employed. These are now described.

### 3.7.3 Interview techniques

Funnelling was an interviewing technique usefully employed in this study (Minichiello et al., 1995). Funnelling is a process of questioning which starts with general and broad questions. Narrower questions dealing with more specific or personal issues are utilised later (Minichiello et al., 1995). An initial guiding question was used at the beginning of each interview: “Can you tell me about your
experience of life in the past few years?” This question was purposefully very broad; to allow participants to raise any issue they felt was important and relevant to their story. More specific questions, based on participants’ previous responses were then utilised to assist development of the interviews. The narrative terrain, as described above and in Appendix C, was kept in mind to help guide the interview when participants requested further direction.

Funnelling was also a useful technique when dealing with sensitive issues. It has been said to be less threatening to participants as it allows them to initially consider sensitive issues on a non-personal level (Minichiello et al., 1995). For example, a participant may initially be asked a broad question such as “What do you think it means to be an adult?” This may be followed by the more specific and increasingly personal questions, such as “How do you know if a person has reached adulthood?”, “Do you think you have reached adulthood?”, “What influences your perception of whether you are an adult or not?”, “Has having CP played a role in your views of adulthood?”

A recursive model of interviewing (Schwartz & Jacobs, 1979) is recommended as an appropriate method for use in in-depth interviews, and was also found to be helpful in this study. Recursive questioning enables the interviews to take on a conversational style, whereby the answer to one question leads to the next question. The direction of the research is therefore influenced by the interaction between researcher and participant. For example, if a participant had been emphasising how much perceptions of disability within their community had influenced their experience, following questions might ask for particular examples of experiences of societal perceptions, how the participant felt at these times, and how it influenced their later approach to similar circumstances.

Another technique utilised in this study was to draw on the background knowledge gained through early interviews to help guide those that followed. Holstein and Gubrium (1995) maintain that background knowledge provides direction and helps connect the abstract research aims to the concrete experience of participants. Prior
to initial interviews, the researcher had gained general background knowledge through literature, however the knowledge developed during early interviews proved vital in clarifying and highlighting issues. Issues expected to be highly important to participants based on the literature sometimes turned out to be less important than other issues which were rarely discussed in literature. The background knowledge gained through interviews led the researcher to better understand participant experience and the personal context in which those experiences occurred. Knowledge was gained about their families, where they went to school, their friends, what they like to do, who they spend the most time with, and how they get around their community. This background knowledge was helpful not only to progress the development of future interviews with each individual, but also to guide interviews with other participants.

Background knowledge was particularly useful in introducing or developing narratives around sensitive issues. Through anonymously introducing an experience described by another young person, participants often felt more comfortable to share a story of their own, and to describe how their experience was similar to or different from the other person (Holstein & Gubrium, 1995). For example, when a conversation about relationships had been initiated, the researcher used examples such as “Another young person I have spoken to sometimes feels that her relationships are not really reciprocal, have you ever had this experience?”, or “Other young people have told me they find it really difficult to meet people who are interested in being in a relationship with a person with disability. How do you feel about this?”

The techniques described above were utilised in interviews of varying formats, including face-to-face, email and telephone interviews. These are now described.

3.7.4 Interview formats

The majority of interviews in this study were conducted face-to-face with only the participant and researcher present. Face-to-face interviews were conducted at a time and location convenient to the participant, most commonly this was the young
person’s home. Some young people felt most comfortable sitting in the lounge room, while others preferred to use the dining table, and one participant chose to use their bedroom. Other locations included university settings and coffee shops. Four participants’ parents joined in one or more interviews very briefly, while one father was quite involved in his daughter’s interviews. While the focus of the study was on understanding emerging adults’ stories from their own perspective, family preferences for interviews were respected, and family perspectives were included where requested. One participant chose a telephone interview for one of his interviews as he lived in a rural setting quite a distance from Sydney. This was of benefit to both the participant and researcher, as the interview could be conducted at a convenient time for both. In other instances, the researcher travelled long distances for face-to-face interviews if that was a participant’s preferred method of interviewing.

It was anticipated at the outset of this study that for some young people with CP, face-to-face interviews may not be the most suitable forum for exchanging stories and communicating in-depth. This is because for some people with CP, verbal communication is difficult and tiring, and speech may be difficult for unfamiliar listeners to understand. The Internet provides young people with disabilities such as CP an alternative method of communication. It can reduce fatigue for people who find verbal communication tiring, and make communication easier for people who experience difficulty concentrating on ideas when speaking takes extreme effort and control (Padilla, 2003). Also, emerging adults are some of the widest users of the Internet; in 2002 84% of people aged 18-24 in Australia were accessing the internet (Australian Bureau of Statistics, 2005). High levels of email use and the presence of countless websites offering chat rooms, discussion boards and forums reflect the popularity of web-based communication for young people. For these reasons, email was offered as an alternative interview forum in this study.

In recent years, the potential of email interviewing has been explored and its popularity as a data collection method has increased. Interviews via email allow the researcher and participants to communicate at their convenience, in the comfort of
their own surroundings, and offer them time to consider their exchanges (Lakeman, 1997; Roberts & Woods, 2000). Email has previously been used as a data collection method in multiple health-related research studies. For example, it has been used to explore cancer pain experiences (Im & Chee, 2004), narratives of children with long-term health problems (Fleitas, 1998), the lived experience of acquired brain injury (Padilla, 2003), and the experiences of mothers post birth trauma (Beck, 2005). Email has also previously been used as a data collection method in conjunction with face-to-face interviews (Fleitas, 1998; Padilla, 2003). In this study email interviews gave young people, who may not have been able to participate in face-to-face interviews for reasons including verbal communication challenges, time constraints or geographical location, an opportunity to have their say (Ison, 2009). Four participants chose to complete some of their interviews by email, with one using it as the predominant mode of communication. A peer-reviewed paper describing the practice, benefits and potential limitations of email interviewing has been published as a result of this study and is included as Appendix E (Ison, 2009).

3.7.5 Multiple interviews over time

As the focus of this study was on understanding the experience of emerging adulthood from participants’ perspectives, opportunities had to be provided to enable them to tell their story in as much detail as they felt necessary. Not surprisingly, participants wished to share different amounts of detail. They were different ages, had different experiences, and lived in different circumstances and contexts. Some participants felt they had reached adulthood, and could reflect back on this period over a relatively short amount of time. Others felt like they were beginning or still moving through emerging adulthood, and felt it important to share experiences over a longer period. This allowed them to reflect on new experiences shortly after they occurred, and interpret how these experiences influenced their changing views of emerging adulthood. It was important that participants were the drivers of the project, and consequently the decision regarding when participation ceased was theirs to make. For this reason, the data collection process did not follow a pre-set structure and was not the same for each participant. No minimum or maximum number of interviews was specified as a narrative approach was being
utilised and therefore interviews continued until the young person felt they had “told their story”.

Each participant was involved in at least one face-to-face interview which lasted between one and four hours. For most this was the first interview, but for three participants the first interviews were conducted by email. For these participants, information and consent processes were completed prior to the first interview using a combination of email, telephone and mail communication. When the first interview was to be face-to-face, information about the study was communicated both prior to, and at the first interview, and informed consent was gained at the interview.

The first interview was an opportunity for the participant and researcher to get to know each other, and to begin to explore issues of importance to the participant. Demographic details were also gathered at this time. Following the first interview, one participant who had been involved in a face-to-face interview chose to complete the remainder of her involvement by email, two who had been involved in email interviews decided to continue face-to-face, and one who started using email subsequently participated in one telephone and one face-to-face interview. The remaining 14 participants preferred to complete all of their interviews face-to-face.

Second and further interviews were used as an opportunity to clarify and expand on experiences, introduce new ideas and discussions, and discuss new experiences that had occurred since the previous interview. Interviews continued until the participant felt that they had no new information to provide, that their story of emerging adulthood was complete, or that their story to date was complete and they were unable to offer more time to the research. Some participants preferred to participate in multiple interviews over a short space of time, while others were happy to leave a longer period between interviews so their story truly captured experience of emerging adulthood over time. Table 6 outlines the number of interviews and time period over which each participant was involved in the study, along with the interview formats.
Table 6: Number, time period and format of interviews

Key:
m=months
^ 1 email = email plus reply from researcher
* Face-to-face interview
~ Telephone interview

<table>
<thead>
<tr>
<th>Participant Pseudonym in alphabetical order</th>
<th>Participation profile</th>
<th>Participant Pseudonym in alphabetical order</th>
<th>Participation profile</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chris</td>
<td>1 FTFI*</td>
<td>Megan</td>
<td>2 FTFI over 10m</td>
</tr>
<tr>
<td>Daniel</td>
<td>4 FTFI over 20m</td>
<td>Michael</td>
<td>2 FTFI over 6m</td>
</tr>
<tr>
<td>Erin</td>
<td>3 FTFI over 10m</td>
<td>Mitchell</td>
<td>1 FTFI and 7 emails^ over 16m</td>
</tr>
<tr>
<td>Hayley</td>
<td>1 FTFI and 30 emails^ over 15m</td>
<td>Nathan</td>
<td>3 FTFI over 8m</td>
</tr>
<tr>
<td>Jack</td>
<td>2 FTFI over 3m</td>
<td>Paul</td>
<td>3 FTFI over 5m</td>
</tr>
<tr>
<td>Jessica</td>
<td>3 FTFI over 10m</td>
<td>Rachel</td>
<td>4 FTFI and 4 emails^ over 13m</td>
</tr>
<tr>
<td>John</td>
<td>1 email^, 1 TI~, 1 FTFI over 4m</td>
<td>Rina</td>
<td>3 FTFI over 4m</td>
</tr>
<tr>
<td>Justin</td>
<td>2 FTFI over 2m</td>
<td>Scott</td>
<td>1 FTFI</td>
</tr>
<tr>
<td>Lauren</td>
<td>3 FTFI over 12m</td>
<td>Simon</td>
<td>3 FTFI over 5m</td>
</tr>
</tbody>
</table>

3.7.6 Interview records

All face-to-face interviews were recorded using a digital voice recorder, and subsequently transferred to password protected computer files and compact disc backup files. Some interviews were also audio-taped as a back-up. The telephone interview was recorded using an Internet based program and saved to an electronic file and compact disc. All interviews were transcribed verbatim with the participants’ consent for analysis. The email interviews were copied verbatim into a single Word file for each participant.

Field-notes were also kept during data collection, and provided a useful record of events, feelings, observations, and ideas that were often referred to during analysis. Shortly after each interview, time was set aside to write up the field-notes and reflect on the experiences of the participants. Field-notes contained details of the key issues and experiences raised by the participant, and relevant information about how the participant engaged with the researcher and with any other persons.
present during the interview. Spradley (1979) refers to this as an ‘expanded account’ of the interview. Field-notes also included a ‘journal’ of the researcher’s experiences, ideas, feelings and reactions, and initial ‘analysis and interpretation’; ideas on key themes, similarities and differences between participants’ stories, and ideas of issues to be followed up in greater depth during subsequent interviews.

A total of 42 face-to-face, 42 email, and 1 telephone interview were conducted between November 2005 and August 2007. Completion of the in-depth interviews led to the collection of hundreds of pages of data for analysis. The analysis process took place throughout and beyond data collection. Although data collection and analysis were intertwined, for ease of explanation, procedures used to analyse the abundant and rich data are described separately in the following section.

### 3.8 Data analysis

As mentioned previously, both narrative analysis and analysis of narratives were utilised in this study. Polkinghorne (1995) reinforces that both types of narrative inquiry can make important contributions to knowledge and produce valued results. For ease of explanation, procedures used during narrative analysis and analysis of narratives are described here separately. In reality though, both forms of analysis were intertwined. For example, common and contrasting themes were developed even during the process of narrative analysis, and these were noted down for further exploration during more targeted inductive analysis of narratives. Concepts from the theory of emerging adulthood and ICF formed part of the researcher’s background knowledge. These concepts therefore influenced all stages of data analysis, along with being explicitly explored during the deductive analysis of narratives. A book chapter describing the analysis procedures utilised within this research has recently been published (Sharp et al., 2018).

Data analysis was an iterative process undertaken during a lengthy period of time between November 2005 and August 2018. Data analysis commenced at the time of the earliest interviews, providing opportunities to move between the existing data,
and strategies to collect new and additional data building on that previously collected (Liamputtong, 2009). Data analysis continued well beyond the end of data collection, with the researcher also requiring some periods of leave which extended the analysis timeframe. Benefits of prolonged immersion with data, and continuing data analysis well into the writing process have been highlighted, including allowing for the ongoing refinement of interpretations (Liamputtong, 2009; Taylor, Bogdan, & DeVault, 2015).

### 3.8.1 Narrative analysis procedures

A separate narrative analysis was undertaken for each of the eighteen participants. The development of the narratives aimed to address the following criteria, first articulated by Dollard in 1935 (Polkinghorne, 1995):

1. Descriptions are included of the cultural and social context of the story;
2. Information is provided about the subject of the story (the research participant), for example their age, developmental stage, and relevant information about their disability;
3. Explanations are included of the relationships between the participant and other significant people in their life;
4. The story concentrates on the goals, choices, interests, plans, purposes and actions of the participant; on their meanings, their vision of the world;
5. Recognition is given to historical experiences and events that have influenced the participant’s life story;
6. The story is bounded by time; it has a beginning, middle, and end; and
7. The narrative offers a meaningful explanation of the participant’s experiences and actions, drawing together separate data elements in a credible and understandable way (Polkinghorne, 1995).

Polkinghorne (1995) offers some guidance around the actual process of constructing narratives, and these were flexibly implemented in the current study. The researcher first considered the story’s ending, or outcome. This provided a lens through which to identify parts of the data that were relevant to, or contributed to that outcome. These data elements were then arranged chronologically and the
connections between events and happenings were articulated. Numerous direct quotes were included to demonstrate key points using the voice of the participant. The aim of this process was to construct a narrative in which “the range of disconnected data elements are made to cohere in an interesting and explanatory way” (Polkinghorne, 1995, p. 20). Developing the narratives involved a recursive process of movement between the participant’s data and the emerging story. Early attempts at writing the narrative were tested against the data, and if events or actions were identified that contradicted the emerging plot further development and refinement was undertaken (Polkinghorne, 1995). A separate Word document for each participant was utilised during this process rather than any qualitative data management software.

It is important to note the significance of the term ‘constructing narratives’. The narratives presented in this thesis are the researcher’s construction of the participant’s experiences. They are not neutral depictions of the participants’ life stories. The construction is influenced by the researcher’s own experiences, views and priorities, as described in the introduction to the researcher (Polkinghorne, 1995). It is also influenced by the data produced through the dynamic and collaborative interactions between researcher and participants during in-depth interviews, and by the narrative terrain of the research detailed above (Holstein & Gubrium, 1995). The constructed narratives are not the same stories the participants would tell if they were asked to write their own story of emerging adulthood. They are not the same stories another researcher may write after undertaking similar research. But they do aim to offer an understandable and credible explanation of the participants’ experiences, including many examples in their own voices. The stories aim to “fit the data while at the same time bringing an order and meaningfulness that is not apparent in the data” (Polkinghorne, 1995, p. 16).

Narrative analysis resulted in the development of 18 individual constructed narratives, one for each participant. These are presented in Chapter Four, and
provide the answer to the first research question: what are the stories of emerging adults aged 18-25 years with CP?

3.8.2 Analysis of narratives procedures

In contrast to the narrative analysis, analysis of narratives was designed to compare and contrast stories, develop key themes, and explore these themes through the theoretical lens of emerging adulthood and the ICF. While the analysis of narratives form of narrative inquiry is different to other types of qualitative research in that its data is in the form of stories, it is similar to other qualitative research in its analytical methods. Polkinghorne (1995) thus describes the data analysis methods proposed for grounded theory by Glaser and Strauss (1967) and later Strauss and Corbin (1998) as being appropriate tools for inductively analysing narratives. Two key grounded theory techniques were employed in this study: asking questions and making comparisons (Strauss & Corbin, 1998). These analytical tools were employed to assist the researcher to grasp the meaning of events, to sensitise the researcher to undiscovered properties and dimensions within the data, and to facilitate the linking of categories.

Asking questions enables a researcher to focus in on what the data is indicating, to understand structure and process, to identify connections between concepts, to stimulate thinking, and to increase sensitivity to what to look for in future data (Strauss & Corbin, 1998). Key questions asked of the data included “Who? When? Why? Where? What? How? How much? With what results?” type questions (Strauss & Corbin, 1998, p. 89). For example, “what is going on here”, “why is this important”, “how did this experience make them feel”, and “how did they respond”. Making comparisons allows incidents within the data to be compared to other incidents in order to group them into categories according to similarities and differences (Strauss & Corbin, 1998). Questions the researcher asked of the data to help guide comparisons included “did other participants have a similar experience”, “did others report different experiences”, and “what seems to be influencing the differences in experience?”
Berg (2007) suggests that while inductive analysis allows the researcher to ground categories within the data, and therefore most directly present the perceptions of participants, it is also reasonable that researchers should draw on their experience with the study phenomena during analysis. Understandings gained from theoretical perspectives, existing scholarly literature and research undertaken in the field can be drawn on and further clarified or explored through deductive analysis methods (Berg, 2007). Researchers can explore whether their data fit with a predetermined theory or pre-existing knowledge in the field (Polkinghorne, 1995). As this was the first study to explore the experience of emerging adults with CP from their own perspective, in addition to inductive analysis it was important to explore how themes developed from participant stories related to existing knowledge and theory, in particular the ICF and theory of emerging adulthood.

Therefore, during the iterative process of analysis, deductive coding was also completed according to concepts within the guiding theories. Examples of the five features of emerging adulthood, namely identity explorations, instability, self-focus, feeling in-between, and possibility, were recorded when they appeared in the transcribed data, and later in the constructed narratives. Concepts related to the ICF were also recognised and coded, for example: passages where participants discussed interpersonal interactions and relationships; community, social and civic life; education, work and economic life; attitudes; support; services and systems; and experiences of accessing the community.

Inductive and deductive data analysis was undertaken concurrently during all stages of analysis. Analysis of narratives involved reviewing each narrative independently and making notes and comments on the page margins. Key passages were highlighted using a different colour for each key theoretical concept. Deductive coding was recorded in the margins of the page, including the theoretical codes and codes developed through the researchers’ scholarly experience with the research phenomena (Berg, 2007). For example, where a participant was talking about how a particular experience had influenced the way he or she viewed him or herself, this
was labelled ‘identity exploration’. When a participant spoke of the influence of others’ attitudes on their experiences it was labelled ‘attitudes’.

Inductive coding was concurrently recorded in the margins. This form of coding consisted of codes grounded directly in the narratives, which may or may not have been identified through deductive means (Strauss & Corbin, 1998). For example, codes were identified including bullying, transport and driving, mental health problems, disclosure, and giving back. As analysis continued, the researcher developed knowledge of codes which had previously, or were commonly, appearing in the data, and this “pool of concepts” was used to help guide further analysis (Strauss & Corbin, 1998, p. 114). Early codes were updated and developed as greater understanding of the nature of the concepts was gained (Strauss & Corbin, 1998). In addition to the analysis conducted on hard copy transcripts and constructed narratives, Microsoft Word documents were utilised to store codes, and exemplar passages from transcripts and narratives relevant to each code. These were refined and regrouped during data analysis as themes were developed through an iterative process.

Analysis of narratives resulted in the development of themes from the participant narratives, and an understanding of how the theoretical constructs of the theory of emerging adulthood and the ICF are reflected within these themes. This exploration is presented in Chapter Five, and provides the answers to the second and third research questions: what themes can be developed from the stories of emerging adults aged 18-25 years with CP?; and are emerging adulthood and ICF theoretical constructs reflected in the themes developed from the stories of emerging adults aged 18-25 with CP?

The following section details the strategies employed to enhance the trustworthiness of the findings.
3.9 Trustworthiness

Trustworthiness in relation to qualitative research refers to the degree to which the findings are a genuine reflection of the lived experiences of the phenomenon being investigated (Barbour, 1998; Curtin & Fossey, 2007). A number of strategies were employed within the current study to enhance trustworthiness and these are now described.

- **Member-checking:** Time was provided at the beginning of second and subsequent interviews to allow the researcher to reflect on key issues arising during the interviews, initial themes, and allowing clarification and further exploration and explanation by the participant. This was not possible, however, for the two participants who only had one interview.

- **Researcher triangulation:** The research team consisted of four people (the primary researcher, and a three member supervisory panel) who all brought different experience and expertise to the research. This facilitated a reflective approach, particularly to data analysis, which allowed the exploration of a broader range of ideas and emerging themes than would have been identified by a single researcher. Interview transcripts were shared with all members of the research team, allowing familiarity with the data. Regular consultations took place during the data analysis process, with the primary researcher presenting emerging findings for discussion, peer review and refinement.

- **Prolonged engagement:** Interviews were conducted over a period of time allowing participants to reflect on and expand on their ideas and experiences over time.

- **Thick description:** Detailed descriptions are provided about the context of the research, and the specific methods employed to collect and analyse data. Similarly, detailed participant information is provided to allow readers to evaluate transferability of the findings to their own area of interest, and substantial direct quotes from participants are utilised within the constructed narratives.

- **Reflexivity:** The active role and influence of the researcher throughout the data collection and analysis process was explicitly acknowledged. The researcher’s
own experiences, biases and values were explored in relation to their impact on the research process.

### 3.10 Ethics considerations and approvals

Prior to commencement of this study, approval was gained from the Human Research Ethics Committees of the Western Sydney University (then called University of Western Sydney) (Appendix G), where the researcher was enrolled as a PhD Candidate, and the Cerebral Palsy Alliance (then called The Spastic Centre) (Appendix H), which was involved in recruitment for this study. Later, the researcher transferred her studies to the University of Wollongong due to the relocation of her primary supervisor. Ethics approval was then also secured from the University of Wollongong (Appendix I). Specific ethical considerations which influenced the conduct of all aspects of this study are now described.

#### 3.10.1 Voluntary participation

Participation in this study was voluntary. Advertisements were used to recruit participants, and interested emerging adults were asked to contact the researcher directly. In a minority of cases, potential participants were told about the study by a third party and gave permission for their contact details to be passed onto the researcher. Both recruitment methods ensured that no coercion occurred, and maintained the anonymity of emerging adults who met the eligibility criteria, but were not interested in taking part. Potential participants were provided with written and verbal information detailing all aspects of the project; no deception was involved. It was made clear to all potential participants that there would be no disadvantage or negative impacts of choosing to not participate, and that they were free to withdraw from the study at any time without consequence.

#### 3.10.2 Informed consent

All participants were required to provide written informed consent prior to commencement of data collection. All participants were aged over 18 years and
therefore did not require consent of their parents. Multiple techniques were utilised to ensure that consent was in fact informed; this was imperative as a minority of participants had mild intellectual disability. During initial contact, all potential participants were provided with both verbal and written information in plain English about the aims of the study, the requirements of participants, the potential risks involved in participation, and the expected outcomes of the research. All potential participants were offered the opportunity to ask questions and clarify the information. Participants were asked to explain to the researcher what they perceived their participation in the research to involve, and were provided further clarification where necessary. As described in 3.4 above, questions were asked to clarify young people’s understanding and ability to consent. These included, “what will you have to do in this research?”, “what can you do if you don’t want to talk to me anymore?”, “is there anything bad that might happen during this research?”, and “do you have to answer all of my questions?”. All participants were able to engage with these strategies appropriately, and were deemed to have capacity to provide informed consent.

3.10.3 Right to withdraw

It was made clear to participants from the outset that they were free to withdraw from the study at any time without consequence. There was no relationship between the researcher and any participant, and choosing not to participate did not influence the participant’s relationship with any service provider in any way. No participants chose to withdraw from the study after enrolling. However, participants played an active role in identifying when their participation would cease. Participants were encouraged to be involved until they felt they had told their story and there was no coercion to participate beyond that time.

3.10.4 Confidentiality and anonymity during data management

This research involved the collection, storage, and analysis of personal information from participants. Accordingly, the privacy and confidentiality of this information was respected throughout the project. All information in paper and audio-tape form
was stored in locked filing cabinets in the researcher’s offices throughout the research. All electronic voice recordings and transcripts were password protected and only accessible by members of the research team. All identifying information, including names, suburbs, schools and workplaces, was removed from interviews during transcription, and each participant was given a pseudonym. Pseudonyms are used throughout this thesis, and will be used in all publications and presentations resulting from this research. Where external transcription services were utilised, transcriptionists signed confidentiality agreements prior to commencement, and care was taken to minimise the risk of a geographical or other relationship between the participant and transcriptionist. In accordance with the State Records Act 1998, State Records Authority of New South Wales General Retention and Disposal Authority - University Records GDA23 (Government of New South Wales, 2005), and the Australian Code for the Responsible Conduct of Research (National Health and Medical Research Council, Australian Research Council, & Universities Australia, 2007), all data will be kept for a minimum of 5 years from publication, and then destroyed.

3.10.5 Managing risks to participants

Because of the personal and sensitive nature of the information gathered during this project, there was a risk that participants may become upset or distressed. Potential participants were made aware that all members of the research team were qualified occupational therapists who would be available to discuss any concerns with them, or to assist them to find another person to talk to. All participants were also provided with the contact details of the CP Helpline, a national, 24-hour, free service offered by the Cerebral Palsy Alliance. The CP Helpline is supported by national relay and translation services, and is thus very accessible for most people with CP. It provides the opportunity to talk with qualified personnel confidentially, and to be referred to social work and counselling services if required. To the researcher’s knowledge, this service was not required by any participant.
All interviews took place at times and locations chosen by participants to ensure their comfort and convenience. During interviews, some participants did become somewhat upset or irritated when discussing issues that were personally difficult. In these situations, the interviewer, a qualified occupational therapist, was able to respond appropriately with empathy and active listening skills. Participants were allowed time to share their feelings and concerns, and offered opportunities to move onto a different subject or stop the interview. No participants became distressed to a point where they indicated this necessary.

3.10.6 Funding issues

Participants were not paid for their participation in this research. The Cerebral Palsy Alliance was not paid for their support of recruitment, nor were any individual staff. This research has been conducted with the support of the Australian Government Research Training Program Scholarship. The first one and a half years of this study were funded by an Australian Post-Graduate Award Scholarship and Western Sydney University Top-Up Scholarship. This scholarship supported the researcher to complete the initial period of the study full-time, and was surrendered when the researcher took up employment. The researcher also received $7000 from Western Sydney University’s School of Biomedical and Health Sciences Student Project Funding scheme, and $2000 from the University of Wollongong’s School of Health Sciences. These funds were used for minor equipment items, travel costs, research training, internet access and transcription by a professional typist. This project was also supported by volunteer transcriptionists identified through The Cerebral Palsy Alliance volunteer department. Volunteers, who all had previous experience communicating with people with cerebral palsy, were trained by the researcher and accuracy checks of transcripts conducted. The funding and support provided by the above bodies did not influence the research design, procedures or results.
3.11 Synopsis

To understand the stories of emerging adults with CP, a narrative inquiry approach was adopted. Narrative inquiry was introduced within this chapter, and the recruitment strategies were detailed. The participants and researcher were introduced. This chapter then outlined how the stories of emerging adults with CP were collected, constructed, and compared using in-depth interviews, narrative analysis and analysis of narratives. Finally, trustworthiness and ethical considerations which influenced the conduct of this research were discussed. The following two chapters present the results of this study. Chapter Four gives voice to each of the 18 participants, through the individual presentation of narratives developed using narrative analysis methods. Chapter Five presents the themes developed from the stories using inductive analysis of narratives. It also presents a deductive analysis of narratives through an exploration of how the constructs of the theory of emerging adulthood and the ICF are reflected within the themes developed from the stories of emerging adults aged 18-25 with CP.
Chapter 4. Emerging adults with CP: Their stories

4.1 Introduction

This chapter presents the constructed stories of the eighteen emerging adults who participated in this study. These reflect the findings of the first research question: what are the stories of emerging adults aged 18-25 years with CP? The stories were developed through narrative analysis processes that were guided by the narrative terrain (Holstein & Gubrium, 1995) of the study, which included the theory of emerging adult development and the ICF. The focus of narrative analysis was to understand participants’ meaning, within their personal contexts, of the experience of emerging adulthood as young people with CP. Meaning and experience are both very personal and very individual. It is for this reason that all eighteen individual stories are presented separately within this chapter, while the following chapter identifies and explores commonalities and contrasts between stories. Each story commences with a short précis in bold font, including a quote from the participant illustrative of their overall experience, attitude or approach to emerging adulthood.

4.2 Nathan’s story

Nathan’s story reflected his passion to live his life surrounded by people who accepted him for who he was. He was passionate about facilitating opportunities for other young people, especially those with disabilities. He was also determined to prove his doubters wrong: “I hate people saying I can’t do things. I’ve said to people ‘if you say ‘you can’t do something’, I’ll deliberately go out there to prove you wrong’”.
At the time of Nathan’s last interview at age 21, he said he had reached adulthood, and was “really happy with the way things are going at the moment”. Nathan’s view was that “life experience says when adulthood kicks in”. He felt that his own life experiences, and the many challenges he had faced, had “sped up” his path to adulthood. These challenges had begun when Nathan was diagnosed with left spastic hemiplegia as a baby. His cerebral palsy was mild; GMFCS Level I. He walked without any support, however had a pronounced limp and noticeable spasticity in his left arm. At age 12 he was also diagnosed with epilepsy.

Nathan is an only child with supportive and loving parents. For eight years of his adolescence, Nathan’s grandma also lived with his family while she battled dementia and was cared for by Nathan’s mum. This was an extremely challenging time for Nathan as her behaviour was often difficult and sometimes violent. He initially “resented” her living with them, but later could accept this experience as a challenge which led to positives, including giving him “a lot of patience” and the perspective that “there’s someone always worse off than yourself. And there’s a tonne of people worse off than myself”. Nathan’s parents always encouraged him to try new things and do his best. He felt that his parents taught him to have a positive attitude; he remembered them often saying “there is no such word as can’t”. As a result, Nathan grew up feeling like he could “have a go at everything”:

_Mum and dad have always given me the opportunity to try things, and that’s also what I think has made me so open with my CP. Like my family and friends have basically... shaped who I am, which is with anyone, but I think more so because of the way they’ve taken me, the way of like, showing me, there’s no such word [as can’t]..._

As a child and adolescent, Nathan attended mainstream schools within the Catholic education system. He was teased and bullied in school and on the sporting field. Mostly, this was verbal “taunting”, however he remembers one time when the bullying resulted in a physical fight with a peer. Unfortunately, one of the cases of taunting Nathan remembered most vividly actually came from a parent of another child he was playing soccer against. They said “that kid there shouldn’t be playing soccer! How bad must his parents feel, making him go out there and run around the
field, getting knocked over”. Nathan was thankful that a parent from his team stood up for him, saying “that kid’s parents are giving him a go, and he wants to [play]”. Like all young people, Nathan really wanted the acceptance of his peers. However, they continued to give him “crap” until about the age of fifteen. Around that time he saw a change in the maturity of some peers. While some would still tease him, others were starting to say “no, that’s childish”. By the time he was sixteen, Nathan had found a group of friends who were supportive and accepted him:

“That was the first time I started to realise how good the friends I was with were. And then [if] anyone put crap on me outside of that group, well I walked back into that group. The maturity level started to change...and the acceptance.

Apart from the negative experience of being bullied, Nathan mostly had a very good experience at school, in particular in relation to accessing support. He said his teachers were “bending over backwards to try and help me”. He was given access to a typewriter, and later a laptop computer, to make his notes and a scribe and extra time for exams. In his final year of school, Nathan needed this support more than ever. He was treated with medication for severe acne and experienced a time of deep depression when he did not want to get out of bed or go to school. He considered this depression to be a side effect of the medication. With support from his close friends and family, and adjustments to enable him to complete his exams, including a scribe and supervisor that would come to his own home when necessary, Nathan improved greatly and managed to complete his final high school exams successfully.

Also important to Nathan’s story during adolescence and emerging adulthood were his experiences with swimming. Nathan had swum for exercise and for fitness as a child and earlier in his adolescence, especially after he had to stop playing soccer at age 12 because of his epilepsy diagnosis. When Nathan reached his mid-teens he took his swimming to the next level and started competing successfully against other people with disabilities at regional, state, national and international levels. His achievements increased his confidence and led to opportunities to develop other
skills. He travelled and competed overseas with financial support from his parents and local community. He also joined a state Sport and Recreation committee, where he developed organisational and business skills that would later give him a “heads-up” in the workforce.

Swimming also provided Nathan with an opportunity to volunteer for a learn-to-swim program for children with disabilities. This later led to paid employment as a swimming instructor, teaching children with disabilities every weekend. Nathan loved teaching learn-to-swim, and was proud of what he had achieved through swimming and what he could pass on to his students. He felt that teaching and being responsible for the safety of his students had made him act like an adult and “grow up a lot faster”. Nathan enjoyed the responsibility and he enjoyed giving something back to others after having been given many opportunities himself: “I want to give back to the disabled kids what people have given me. I want people to have the same opportunities I’ve been given”.

While Nathan loved teaching learn-to-swim, he did not really think of it as “work” at all – it was just something he loved to do. He knew the skills he had gained - working with people, having responsibility, being a representative - would help him make the transition from school to the full-time paid workforce and he was determined to have a successful career. Towards the end of year 12, Nathan’s school signed him up with a DES provider. While they helped him develop his resume, Nathan felt that overall his case manager was “hopeless”. He thought the things they were offering, like workplace support and travel training, would be very helpful if he had an intellectual disability, but not for his CP. He did not feel he needed this support and was determined to “handle it myself”.

Almost immediately after finishing school, Nathan was successful in gaining a competitive traineeship with a large state government department. He found this position himself and without the support of the employment service. Nathan was upfront in disclosing his disability and his employer received some funding through an Australian government initiative to support him. Nathan initially found this
frustrating as in his view he never saw anything from this funding, such as aids or equipment to support his computer use or to make his seating more suitable. He did not need these adjustments to do his job, so he did not demand them, but they would have made things easier and he was disappointed his employer did not even ask if he could benefit from any adjustments. He said it initially made him feel they were “using” him “for money” or to meet some kind of disability employment quota. As part of his traineeship, Nathan attended TAFE (technical college) one day per week. There he did receive support of a note taker as his handwriting was illegible, however this support did not continue in the workplace. Nathan was determined to succeed, with or without support, and he successfully completed the traineeship. Afterwards, he won a competitive full-time, permanent position in the same department. In hindsight, he was able to see the positive side of the opportunities and challenges his traineeship had given him. He was no longer worried about whether having a disability had influenced his initial employment:

So now I’ve got a permanent job because of that opportunity – even whether it be because I’ve got the CP or whether it’s because of me but… I’ve got a job… and that’s one of the hardest things for a lot of people to get.

Nathan was generally happy with his work and was very pleased to have a secure job, but his career goals did not end there. He wanted to use his current job “as a stepping stone” for future career moves and was exploring the possibility of completing some additional study through his employer. He was hoping this would assist him with his long-term goal of a position in sports administration through which he could help other young people with disabilities:

I like my job but I don’t like the fact that I don’t see the results of what I do. I’d actually like to sit there in employment and implement a program that would help something or develop something that would eventually grow into something really, really good. That’s what I love and if I could do that full-time I would…. I’m happy where I am, though I’d like to change. I don’t feel like I’m working for the benefit of anyone and that’s what I don’t like.
In the meantime, Nathan had identified other non-work opportunities to give back to his community. He was actively involved in a service club – Rotary - which had provided further chances to extend his experience and challenge his abilities. Nathan was about to take on a facilitator role at a Rotary leadership camp. This followed his own participation in the camp the previous year, doing activities he never thought possible, including rock climbing. He found the camp an “amazing”, challenging experience that “worked wonders” for his confidence. As a facilitator at the upcoming camp, Nathan was passionate about providing those experiences to others.

As an emerging adult Nathan was living with his parents, but was “paying his own way” and purchasing his own car. He was “grateful” that he had been able to achieve independence by successfully learning to drive although it had been a long process. He had some licence conditions, including using a spinner knob on his steering wheel, and only driving automatic cars with power steering. He enjoyed being able to get around by himself and had a busy leisure life. As a result of his past experiences, Nathan “picked” his friends “very carefully”; he chose to control his own social networks. Nathan had friends without disabilities, mostly from school, and also friends who also had disabilities that he had met through sporting clubs. For all of them Nathan’s CP had “never really been an issue”: “my friends are proud of me and all that I’ve achieved…they know I’ve got CP but they don’t treat me like I have CP”. Nathan actively pursued friendships based on the type of people he wanted to be around. His view was that if people thought they were too good to be his friend, then they were not worth worrying about: “If they’re up themselves they can go and get screwed, because everyone’s equal…I’m enjoying going out there and being myself and not having to worry about keeping people happy...” At the time of his last interview, Nathan did not have a partner, although he had had two short-term girlfriends in the past who both also had CP. Nathan was looking forward to a future where he would have an intimate relationship and he hoped having CP would be irrelevant: “I think of myself as able bodied, I want to be treated the same”.

148
Nathan had learnt to be both proud and accepting of his disability and of what he had achieved. He chose to look at “the good side of bad situations”. He had always been open about his cerebral palsy and said that he “wouldn’t have it any other way”. Nathan believed that having CP had opened many doors for him and he had grown to be very “comfortable” with his disability: “I’ve just been given so many opportunities, and I’ve tried to use every single one of them to the best of my ability”. Nathan was now focused on playing an important role in facilitating similar opportunities for other young people.

4.3 Rachel’s story

Rachel’s focus was on living her own life as independently as possible whilst also taking every opportunity to mentor and guide others. She was determined to succeed and to look for the positives in every experience: “Something can be the absolutely worst experience you can possibly have but you do have the capacity to turn it into a positive. It’s just up to you whether you want to or not.”

At the time of her last interview Rachel was 20 years old and about to embark on the first year of a university double-degree. She had just taken a ‘gap’ year, where she had spent a year travelling, working part-time tutoring school students, doing voluntary work, public speaking about her experiences, and spending time developing her independence in preparation for university and living alone. Prior to her gap year, Rachel had completed her Higher School Certificate (HSC) over two years, through a Board of Studies program known as Pathways that allows students flexibility to accumulate their HSC over, up to, five years. Rachel excelled in her HSC, receiving recognition at local and state levels for her outstanding academic achievements and was awarded a university scholarship. Rachel was looking forward to moving out of home and into university residential accommodation, although feeling somewhat “overwhelmed”. She was keen to make this transition as smooth as possible, and had taken active steps to prepare well. She had spent time choosing the most appropriate university to meet her needs, arranging for reasonable adjustments to her timetable and assessments, and modifications to her
room. Rachel was confident that she would cope successfully with living alone and with university studies. She had come a long way to reach this point.

Rachel was diagnosed with spastic diplegia as a young child, GMFCS level III. She grew up in a very supportive home, the youngest of three children. She learnt to walk using a walker and attended a mainstream school. She was able to remain mobile using the walker throughout the majority of her school years. Socially, she experienced teasing in primary school, being “called things like retard and spastic”. As a young adolescent Rachel continued to feel that she did not “fit in that well”. She did not feel that people understood what she was going through and wished she had the opportunity to connect with other young people with disabilities. As an emerging adult, she was determined to help other young people with disabilities have an opportunity to connect with other people in similar circumstances, something she had never had. She volunteered at a local school and was a mentor to students with disability. Rachel had used her own initiative to set up this arrangement, and in the future also hoped to have a support group established in her local area: “if there's a forum available for young people with CP to get in touch with others who are bit older and who have the wisdom of past years, that would be really good for them”.

By the age of 18, persistent pain and increased spasticity in her legs was making walking more and more difficult for Rachel. She had to transition into using a manual wheelchair for mobility. Rachel found this transition an extremely difficult and challenging time. She was very “angry and frustrated” as maintaining her mobility had been very important to her. She said, “my identity was wrapped up in my ability to walk and when that was taken away I didn’t know who I was”. Rachel’s self-esteem “was basically non-existent” and she became depressed, disconnecting from her family and friends. She was worried about the stigma attached to being a wheelchair user, and admitted that this fear had stopped her using a wheelchair earlier, although physically she probably should have.
The transition into the wheelchair was made even more challenging given the lack of support that Rachel received at this time. The timing coincided with her transition from paediatric to adult healthcare services. Her experience was that this service transition was “all over the place”. During her gap year she went “looking into support services and finding out that there were none”, particularly in her local area:

*There's not a very consistent network. In terms of the whole disability sector that's a really big failing. There really needs to be a more coordinated response in terms of services and things like that... the healthcare system is not good at the best of times and I guess when you have to have a lot of dealings with it, it can be particularly frustrating.*

Not one to give up, Rachel sought help privately, and fortunately her family could assist in paying for these services. She required both emotional support and practical training to learn the advanced wheelchair skills that she would need to become independent. Rachel started seeing a psychologist, something which she had avoided in the past. She remembers people telling her to see someone as a young teenager and her response was “do you think I'm crazy, why don't you put me in a straitjacket and sent me off to the funny farm. I couldn't go and see a psychologist, no no no.” As an emerging adult however, she said:

*I guess because I needed to recognise myself that I needed to go speak to someone... when I was 14 years old... I would have sat there for the whole hour, arms crossed, and you wouldn't have got anything out of me. I guess it comes to that time and I guess as you mature you venture into adulthood and things like that.*

Rachel also made contact with an experienced wheelchair user in her local area who offered to help her develop advanced wheelchair skills. She found this mentoring invaluable, as health professionals had not been able to assist with much more than basic steering and navigation skills. Rachel also got involved in a wheelchair track program and wheelchair basketball, both of which further assisted her to become a highly skilled wheelchair user. By the end of the study Rachel had come to realise many positive things about her move into the wheelchair:
It has helped me come to a full understanding of my disability, in many ways a complete understanding and acceptance of my disability which is something that I didn’t have when I was in the walking frame... Going into the wheelchair has really made me have to sort of find myself and find out who I am separate to this disability. I think you know, it’s ironic, but I’m probably standing taller in the chair now than I ever was when I was walking.

Rachel had chosen to move past the grief she felt at her initial loss of mobility. She focused on new opportunities that had arisen through her being a wheelchair user. Even the ignorance, misconceptions, and access challenges she faced within the community on a regular basis were responded to in a positive and proactive way:

You accept the disability and you move forward with it because I think if you constantly keep loitering and staying at that position... you just sort of miss out on all there is that life has to offer... There’s a lot of ignorance in the world and there are a lot of misguided people in the world and unfortunately I meet more of them than other people would... I guess you have really one of two options. You can get angry and remain angry and be very bitter and jaded about everything, or you can sort of get out there and try and educate people as best as possible... unfortunately there is always going to be the inherent challenges that you encounter because of the disability, but I think you just have to get out there and be your own best advocate.

Another of Rachel's goals in emerging adulthood was to get her driver's license. This was an expensive process that took a lot of time and perseverance. However, she was determined to make it happen as she knew it would make it easier for her to “go where you want to when you want to”. After getting her learner's permit, Rachel’s family had to pay for a formal driving assessment by an occupational therapist. This assessment showed that she would be able to drive using hand controls and a spinner knob on the steering wheel. At the end of the study, Rachel was commencing further driving lessons that were required with a qualified instructor in a modified vehicle. She hoped that in time her family would be able to supervise her and that she would be able to get a modified vehicle of her own. Without any subsidies available to support the expense involved in getting a license or paying for vehicle modifications, Rachel understood “in many senses why people
who use wheelchairs just don't choose to drive”. But she was motivated to make being an independent driver part of her future -“it's a drawn out process but I'll get there, I'm sure”. It helped that her family were able to provide financial and practical support to assist her in achieving this goal.

At the completion of the study, Rachel was about to embark on a new stage in her life, university, where she knew she would again face much change and many challenges. Although it was somewhat overwhelming, Rachel was determined to make sure that this new stage was a positive one:

*It is not only starting uni and being in a whole different environment, it's basically moving out of home, meeting new people, learning to function in a different environment... I guess it's a bit overwhelming but what I've learned is if I can get through what I've been through over the past 18 months, with the wheelchair and things like that, and during one of the most stressful things in your life, the HSC, I don't think I have a lot to worry about.*

Rachel felt that she had reached adulthood “in some respects”. To her this meant more responsibility, making her own decisions and being “in control of your own destiny”. She knew who she was and was secure in this identity. In emerging adulthood, Rachel had developed a group of friends who were “the kind of people who see me and not my disability”. Over time she had learned that people who could not see past her disability were not worth knowing. She had learned to judge whether people were “genuine”; she called this having a “really good bullshit detector”, saying:

*I guess as you get older... you can see when people are really genuine and if they're not I just don't have time for that. The friends I have now are all very unique individuals and for them the disability is basically non-existent.*

Rachel looked forward to the future, where she was planning a successful career and perhaps living overseas for a time. She was not in a hurry to find a relationship, and was determined not to live her life expecting and waiting for this to happen.
Her view was that “if it happens it happens, if it doesn’t it doesn’t”. Rachel knew she would conquer the future challenges she would invariably face:

*I try not to worry about the future, as when you get down to it there will always be challenges because of my CP. But I have overcome all of them thus far and will continue doing so in the future.*

### 4.4 Megan’s story

Megan’s goal was to work with children who had been marginalised, including those with disabilities, to help them reach their aspirations, listen to them, and “validate their experiences”. She was determined to make sure others received what she had not: “if I can talk to other kids with disability, to let them know that life can be shit, but it can also be pretty good. And you know...there will be challenges, if you’ve got a disability you have to struggle through life unfortunately, which is really sad. But in my role hopefully I can be there to help them...”

At the time of her last interview, Megan had recently turned 23 years old and was studying the third year of a social work degree. She felt she was adult in some ways but not in others, saying “I still feel like an awkward 16-year-old”. She was still living in her family home, and although she took responsibility for her own cooking, washing and ironing, she felt that she would not truly be an adult until she had finished her degree, moved out of home and was living independently. She said, “I feel like I have a sense of responsibility now, but I feel very limited by living at home with what I can and I can’t do.” Living in her parents’ home, she had to “respect their rules and boundaries” and at times they would still tell her she could not do things, like travel home alone from the city at night. Megan felt that this had a lot to do with her having a disability: “I think for parents, when your child has a disability, it’s a lot harder to break that contact, to see your child be independent”. Regardless, Megan was determined to gain her independence and knew she would reach this goal – “I really don’t feel like I’m independent at all which is quite sad in a
way. But that’s just how it is at this point in time, I know that will change”. She had already come a long way.

Megan was born three months premature and although she knew she had CP after having been told as a young child, she did not know much about it. During interviews, the researcher was able to see that Megan appeared to have spastic diplegia with significant involvement of her legs but little to no spasticity in her trunk and arms. Megan walked independently – her GMFCS level was II - but her gait was significantly affected. Megan however did not know for sure what type of CP she had, and in fact said “I didn’t know there were types of CP! That was news to me”. She said, “if someone said to me ‘what’s the definition of CP’, I’d say ‘I don’t know/’”. Megan said that as a child she never wanted to know about her CP. She “just wanted to be a kid. I wanted to get on with it”. Other people made this difficult for her, however, as she was bullied through school and constantly reminded of her disability. In emerging adulthood Megan was keen to do something that would mean other children with disabilities might have a more positive experience than her own. She said:

I hated primary school because I got teased constantly, every day, like ‘cripple, retard, spastic, freak’... constantly. I had friends but that didn’t stop the teasing... It does stuff your self-esteem when you’re a kid. When you’re a child everything is magnified, you don’t know how to deal with things... I don’t want anyone to go through that.

Most of Megan’s other memories from childhood are of numerous trips to doctors, hospitals and therapists. She grew to hate these visits, saying “I loathed every minute of it”. She did not feel that there was good reason for some of the interventions she perceived she was subjected to. She spent many months as a child wearing plaster casts on both her legs. She said, “They thought they were doing what was best for me. But I don’t know what the fuss was about, because I could walk anyway. Wearing the casts didn’t help my movement”. Around the age of 13, Megan refused any further casting and although health professionals made it clear this decision needed to be made by her parents, Megan’s mum accepted her wishes as being “fair enough” and agreed she did not have to go back to the disability
service again. Megan remained very upset that health professionals did not seem to understand potential social effects of these sorts of treatments; impacts that were very real and important to an adolescent:

...one time they said they were going to put the casts on again and I said ‘no’. They asked why and I said... I get picked on quite enough. I am not wearing plaster casts to high school. I would be ridiculed so much. I can’t believe you’d even entertain such an idea!’...

Because of her experiences as a child, Megan continued to be “very prejudiced” against health professionals even in emerging adulthood. She was rarely in contact with health professionals, other than a general practitioner (GP) when she was ill. Her experience was that GPs generally do not have a good understanding of CP. She consulted local GPs six times at age 22 when she was experiencing severe and disabling pain in her hip but was dissatisfied that no-one could figure out what was wrong or tell her if it would improve:

...you don’t know what’s going to happen because no-one could give me an answer...I lost all of my independence again like I couldn’t even go up the shops, mum would have to drive me... I thought ‘am I going to end up in a wheelchair?’...all that sort of stuff...I was very angry and incredibly depressed... I was very emotional and very up and down. Because you think ‘am I going to lose my mobility?’... That’s another hurdle.

Interestingly, Megan still refused to consider seeing a CP specialist because of her past experiences and instead eventually got some relief through regular visits to a local physiotherapist who, by her own admission, “didn’t know that much about CP”. Megan also recognised that she should take more responsibility for her own fitness and mobility to try to prevent further problems, but she found it difficult to prioritise these activities:

I haven’t been doing my exercises and that’s something that I really need to do...but it’s also getting a routine...like when I was doing physio[therapy] and uni I was getting up at 5:00 in the morning, having to get up 20-30 minutes earlier to do these exercises. And I understand why I need to do them, but combining them with life... I can’t be
bothered at this point doing my exercises because everything else comes into play...

Megan had left high school after year 10 and had been through a lengthy period of uncertainty where she struggled to commit to a career path. She was determined to find her “niche” but tried many options before finding a career that she felt was truly right for her:

I left High School in Year 10 and started a hair dressing apprenticeship. That went down the gurgler. I hated it. Went to TAFE, started a course, hated that, it wasn’t what I wanted. Then I had a bit of a mental health crisis, took some time off, went back and did [another course] at TAFE, which was brilliant... I didn’t really know what I wanted to do...I kept going from one thing to another, and in the end my parents sat me down and said, ‘You’ve got to finish Years 11 & 12’, because I was going for jobs but no one would employ me...In the end I went back to get Year 12, after much kicking and screaming. Started HSC at TAFE then left that, then went back six months later and did my TPC [Tertiary Preparation Certificate]. I got work in a childcare centre, was there for 18 months, and I knew then that I wanted to work with children – but I also knew I didn’t want to be in a child care centre for the rest of my life....

While working in childcare, Megan came to realise that child protection was the thing she was most passionate about, and this led to her pursuing a social work degree. After a long time of being unsure where she was headed, Megan at age 23 was focused on getting through her university degree, graduating, and gaining full-time employment. She was enjoying her degree, had made a few close friends and felt like she was closing in on the end of a long chapter in her life. She said, “I know I can do it now”. Megan had not accessed any disability support services at university, because she felt she would be “stereotyped”. However, she was glad that these support services were available: “that’s my choice [not to access services], because I don’t like being labelled. I never have. But, those options should be there. I hope other people use them, but I feel I’ve done good [sic] enough on my own”.

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157
Megan was in a much more positive place in her life than she had been for a long time. She had experienced low self-esteem and periods of depression and anxiety, which she attributed to having cerebral palsy:

*I think having CP impacts on other areas of your life. When I was a teenager, I had other problems due to having CP – like my self-esteem – I had mental health problems. I basically hated myself, and that’s really sad that someone loathes themselves that much... I thought that I wasn’t worth anything. I felt that having a disability made me like nothing.*

Megan believed that this feeling stemmed from societal perceptions of disability and the bullying she had faced. It was something she was “still trying to work through” as an emerging adult:

*There are still those days when you think you’re not good enough or I’ve got a disability so I must be second best. It’s just a whole societal thing...it’s engrained into everything...when you have a disability you don’t get acceptance from people, or I guess automatic acceptance...I guess you kind of go through wanting acceptance because sometimes it’s really hard being on the outside. You think “I don’t want to be on the outside I want to be the same as everyone else”...so I guess sometimes I do take things to heart...but I’m coming to terms with a lot of things because I think you’ve got to like yourself, and you’ve got to live your life how you want to live it and I guess set an example to people, because people learn by behaviour...*

Megan felt that societal perceptions played a significant role in whether she had certain opportunities. This included not yet having experienced being in a relationship. She said:

*I’ve never really had a relationship with anybody because I’ve always felt like people haven’t been that interested in me. It’s never been mutual ... like if people are interested in me they’re not going to want me because the first thing they’re going to see is my disability...... I had one male say to me when I was young, about 16, that no one would ever want me because I had a disability. And I’m like ‘fuck you man!’ But you still take it on even though you know it’s not true. That kind of reaffirmed everything [negative] I thought about myself. And in some ways I still think about that now.*

Although Megan said, “if anyone is going to be that shallow I don’t want them in my life, I really don’t”, she still wondered if her experience would have been different if
she did not have cerebral palsy – “if I didn’t have it, would I be out getting dates like so and so...”. While Megan was hoping for a future that would include an intimate relationship, she did have “one or two really good friends” from university who she spent time with socially and felt supported by. She had lost touch with her friends from high school, including her best friend who she felt had not “really been there” for her during challenging times: “you need people there who are going to support you”.

In the short-term, Megan’s goal was to focus on increasing her independence. She felt an important step in the process was being able to drive, and she gained her learner’s permit at the age of 22. Previously her parents had not encouraged her to get her licence or been prepared to give her driving lessons. But Megan was determined and undertook the process of arranging a medical assessment, completing her test and paying for professional driving lessons herself. Her only licence restriction was to drive an automatic vehicle, and Megan said “I only want to drive automatic anyway”. Megan was looking forward to the extra independence having a driver’s licence would provide her. She said:

...that’s another step towards independence and a job when I graduate... [my parents are] always crapping on about me being independent and to have a car is to be really independent...I wanted to go out to the city one night and mum was like ‘no way’ because by the time I got home it was going to be really late. And I was like ‘I’m 23’ but because I would be coming home by myself...so I just cracked the shits and I thought if I had a car this wouldn’t happen...I can’t wait...

Megan was looking forward to moving out of home once she had a full-time job. She knew she would face challenges as a new graduate, including financial challenges of paying “rent, groceries, bills, run a car”, but she was determined to give it a go. Megan was also determined to help other young people, including those with disabilities. She wanted to teach others that “it’s ok to ask for help”. She said, “I’ve never been able to ask for help from anyone and I’m just learning how to do that now. And that’s pretty important”. Megan also wanted others to know that
despite all of the challenges she had faced because of her CP, she would not change a thing:

*People often ask me ... ‘If you had a magic wand and you could wish your disability away, would you?’ And I say ‘No’. When they ask why, I say it’s because my disability made me who I am. I’m stronger for it. It means that you don’t put up with the bullshit people dish out.*

### 4.5 Jessica’s story

Jessica’s plans were dominated by sport. They included representing Australia in swimming and wheelchair basketball, travelling overseas to study and train, and teaching physical education to young people with disabilities. She had recently transitioned into using a wheelchair and was determined to make the most of this new stage in her life: “this is only just the beginning of a new life for me now. It’s only the beginning.”

Jessica was 19 years old at the time of her last interview. She had recently completed her Higher School Certificate (HSC) and had commenced a degree at a private college. She had gained a scholarship at this college in recognition of her success as an elite competitive swimmer. Jessica was enjoying the college experience but had decided to change courses to better fit with her long-term plan of working with young people with disabilities. Jessica felt that she was an adult in some ways but not in others. She was feeling positive about the future and was determined to overcome any barriers she may face, just as she had in the past.

Jessica did not receive a formal diagnosis until the age of eight. However, she had struggled with fine and gross motor skills, and speech, from a very young age. She said, “I was always the one that was left behind”. Jessica considered herself to have “mild cerebral palsy”, spastic diplegic type, however her actual diagnosis was hereditary spastic paraplegia “or something like that”, which is an inherited condition that presents like CP. Her GMFCS level was II. Jessica experienced bullying throughout primary and the first half of high school, particularly because of her “funny walk”. This bothered her as a child, and she also felt awkward as a teenager.
At this age, fitting in, and being attractive to the opposite sex, was extremely important to Jessica. She decided not to tell people about her CP when she started high school, although she had always been open about her disability in the past. However, Jessica soon realised that others could tell she had a disability anyway: “I’ve never really hidden my disability. Maybe when I went to high school, because basically you didn’t want the boys to find out. But they all worked out that something wasn’t right”. As an emerging adult Jessica no longer tried to hide her disability and had learnt to cope well with the negative attitudes she faced. She said, “now it doesn’t even worry me, if a kid says something to me like ‘you’re a bit funny’ or something, I’m like ‘yeah, so be it’”.

Swimming had been a big part of Jessica’s life for a number of years. She began swimming competitively against other athletes with disabilities around the age of 13. She was very determined to do well and trained around eight times a week. She had competed in numerous titles at a state and national level, travelled overseas to compete in the Cerebral Palsy World Championship, and was hoping to train with the Paralympic program. Her travel had been funded through the Australian Paralympic Committee and Jessica was very pleased to have had these opportunities. In recent times she had experienced some training injuries which set her back for a time: “I just really had a really rough ten months. You think everything’s going great and then everything’s just turned back upside down again”. However, Jessica’s injury was healing well, and she was planning interstate trips for competitions. At the time of the study she was about to start playing wheelchair basketball also and was aiming to represent Australia at the Paralympics in one of her chosen sports; “swimming or basketball, I don’t care as long as I’m there”.

Jessica’s sporting commitments led to her completing her HSC over two years. This made it more manageable given the significant periods of time she had off school to train and compete. Jessica had a positive experience with her school: “[they were] excellent, I had so much support from there”. Although she was not a high achiever academically, Jessica successfully completed her HSC. She applied for and received reasonable adjustments for her exams, including extra time and a writer. Jessica
described her graduation as “the biggest relief of my life”; she was ready to leave school and move onto the next stage in her life. Also, a relief was finding out prior to commencing her HSC exams that she had received early entry into a private college to study a Bachelor of Sports Business. Her achievements in competitive swimming contributed to this opportunity, and she also received a scholarship. At the end of the study Jessica had nearly completed her first semester and was happy with the results of her assessments. However, she had also decided to change courses and her goal was to become a physical education teacher: “I was getting bored; I always wanted to get into teaching”. She also hoped to travel to America to study on a wheelchair basketball scholarship: “one of my dreams has always been to go over to America and do some study there. They [the College] said I can go and do that… I’ll probably end up going to Alabama”. Jessica’s long-term goal was to complete Masters level studies to enable her to teach physical education to young people with disabilities.

Jessica was involved in an intimate relationship during the course of this research project. The relationship was quite serious, and they had discussed plans for the future, including holidays and having children. Jessica’s boyfriend was accepting of her disability which was very important to her:

*He’s been excellent with me. I turned around to him when we were first going out [and said] “but are you going to be able to accept me and everything about me with even my CP and everything?” And he goes “yep”. And he has actually proved it to me because I’ve had a couple of major spasms and he’s looked after me so well.*

Unfortunately, this relationship ended for reasons that Jessica said were unrelated to her disability. She was very hurt by this and said it was a “shock”. She knew that in future it would take her time to trust new partners. She said, “I’ve been through too much shit; I’m not going to trust within a couple of minutes”. However, she was looking forward to a future that would include a committed relationship and children.

Jessica had recently made a transition into using a manual wheelchair for much of her mobility. Walking had become increasingly painful and difficult due to
deterioration in her legs, hips, ankles and lumbar spine, the presence of co-morbid scoliosis and arthritis, and increasing muscle spasms. It was hoped that using the wheelchair much of the time would reduce any further deterioration. While she mostly walked around home, Jessica used her wheelchair out in the community, at university, shopping and for sports. Physically she coped well with the transition to the wheelchair as she “already had the strength in my arms” from her swimming. Jessica also felt that she was “lucky” that she could get out of her chair to do some activities, and she was determined to remain independent:

I think in a way I’ve just learnt to do things. But I also still have the ability to get out of the chair. Like if I need to get anything out of the cupboards I can stand up. I get drinks and that. When I’m at uni I had to adjust to that, I just got used to it all. It doesn’t bother me, getting around home; if I’m in the chair at home it doesn’t bother me. I cooked dinner for myself in the chair the other day, I do everything for myself…. my sister will ask me if I need some help and I’m like “No”, my mum will ask me “do you want some help?” “No”.

Jessica “felt fine” about using the wheelchair. It was not unexpected, and she felt it was “just the beginning of a new life”:

I felt fine about it. I accepted it. Because I knew it was gunna [sic] happen sooner or later…I got told when I was younger that I would end up in a wheelchair by the time I was forty. I knew what the future held for me.

Most people close to Jessica were also supportive of her transition into the wheelchair. However, she did experience challenges due to negative attitudes and access issues in the community. Jessica found it difficult to go to some clubs with her friends because of poor physical access and she found navigating crowds difficult as “people just don’t move”. While waiting in queues, Jessica had also been pushed in front of, and ignored by staff:

She just ignored me, wouldn’t serve me. And one of the guys that was just in front, he turned around and said “excuse me, but there’s a young lady sitting here waiting to be served”… I was so annoyed at that...people are just so rude. I never knew how rude they were…I’ve seen the change. People aren’t as friendly as if you were walking.
Jessica had previously experienced negative attitudes in the community, even before she started using the wheelchair. She was particularly frustrated about a negative experience in a work environment. As a teenager Jessica worked for a large fast food chain and was “up front with them” about her disability. She felt that she was “discriminated against” by this company, forced to work in the drive-through section for what was described to her as “safety reasons”. This actually proved to be worse for Jessica, as standing still for many hours was difficult. Jessica left this job for this reason but chose not to make a formal complaint about her experience. Jessica then gained work as a swimming instructor, teaching babies and young children two days a week. However, at the time of her last interview she had recently left this position as it was affecting her own availability for swimming training. Instead, Jessica was about to commence part-time work at schools, educating students about spinal cord injuries and road safety. She was really looking forward to this opportunity, as it would provide her with experience relevant to her long-term goal of teaching young people with disabilities. It was also flexible and would allow her to meet her own swimming training commitments.

Jessica was determined to overcome the future challenges she knew she would face, and was feeling positive about the future. Her independence was important to her and she was very glad to be able to drive her own car without modifications. This helped Jessica to maintain an active social life and get to and from university and training. While she had considered moving out of home, Jessica was happy to remain living with her mum in the short-term. Her parents had recently separated, and she liked to be around to support her mum. Living independently, or with a partner, was however definitely part of her future. Jessica was confident she would manage future transitions as well as she had navigated those in the past, and she was passionate about helping other young people do the same. Through her work in schools, and her long-term goal of teaching young people with disabilities, Jessica hoped to promote safe and active participation in the community, particularly in sport. She had made lots of friends, and had lots of opportunities through sport, and she wanted other young people to have the same.
4.6 Lauren’s story

Lauren hoped to run a successful disability awareness business through which she could break down stereotypes and barriers, which she herself had faced, for the benefit of others with disability. Despite her significant disability, she was determined to achieve her goal, even if it meant having to review and refine her plans: “Even though it might take you a while to get your dream you can still aim for it...you might just have to look at your plan...and do little zig zags, detours, deviations...life is meant that way, nothing is a straight path. You’re always going to get hiccups”.

Lauren lived in a modest home in a regional city with her mum, who was still working, and her dad, Joe, who was her full-time carer. Lauren and Joe decided that Joe would be involved in most of the interviews, and some of his views are also included here. It was clear through the interviews that they shared a very close bond and that Joe would do anything to support his daughter. Lauren also had three older brothers who had all left home, and two nieces who she adored. Lauren had spastic quadriplegic cerebral palsy, GMFCS V. She utilised a power wheelchair for mobility, and needed assistance with accessing the community, and personal care. Lauren’s family attributed her CP to having been born 12 weeks early. Lauren turned 21 during her interviews and celebrated with a party at the local club. It was a great night with friends, family, food, music and drinks – lots of drinks! Lauren said “we kicked on to about 2am. [There were] a few sore heads the next morning”. Lauren occasionally enjoyed getting out to clubs and listening to music with a carer who was around her own age and with whom she shared common interests. Her dad did not mind getting up early in the morning to help her to bed. He said, “she’s getting out and enjoying life and we try to help her the best we can”.

Lauren had undertaken a lot of physiotherapy, occupational therapy, and had numerous operations as a child. She felt the success of a lot of these interventions had been limited: “all these different things they’ve done, tendon lengthening and things. But they haven’t really worked”. She had also had splints and most recently,
botulinum toxin injections in her wrist. She had some success with the botulinum toxin and was able to access the standard buttons on her wheelchair’s controller where previously she had had to use large switches. Despite her significant disability, Lauren considered herself lucky. A friend’s recent experience had cemented this:

One of my best friends from college had a car accident about a month after she was at my 21st and she’s only just come back from the brain injury unit. Whenever I hear things like that I think I’m very lucky. It will be harder for her because she’s been able to run around and do whatever she wanted. I know no different, but she will have a huge difference.

Joe also spoke about additional challenges faced by those people with CP who are non-verbal. While Lauren did have a speech impairment, she could speak fairly well and they counted themselves “lucky” as they could still “sit and have a laugh”.

Lauren had attended a primary school which had some mainstream classes but a significant proportion of support classes. While the family recognised some benefits of Lauren having attended this school, including “they had the swimming pool and they had the doctor and everything else”, overall, they had found this a negative experience. Lauren said “you only got integrated once a week. So you just interact with the other disabled people…you only get to know disabled people. You don’t get to know others…It was crap. I wish they didn’t have that school”. Joe also spoke about the impact of this environment on Lauren’s social opportunities, and about how much more positive her experience was when she moved into a mainstream high school setting:

What we found was the biggest problem was that kids came from all over town to that school, and then when the day was over, they all went home, then of course you have no friends. As soon as she went to the college she made friends with people who are all from the local area, which should have really happened from the word go.

Despite the positive social experiences, high school still presented a number of challenges for Lauren. It took the whole of her first year for a bathroom to be made accessible, leading to a significant degree of inconvenience for Lauren and those
assisting her. Lauren was keen to raise awareness of how long some adjustments take to be implemented and how important it was to request adjustments early. She said, “I just want to let other people know about possible pitfalls”. Lauren had a particularly bad experience of support in her last year of school, to the point that she eventually left. The difficulties related mostly to not having a consistent support person or people. Lauren described her experience as “a major mess and a major stuff up”, but regardless she felt leaving school led to a better outcome anyway. She said:

People like me need a constant person that knows what’s going on in their life so you don’t have to keep explaining what’s happening to 60 different people. I had twenty teacher’s aides in two years. I’m glad I left because I got a lot more opportunities when I left school.

Along with the practical issues around accessing support and adjustments, Lauren faced significant negative attitudes while she was at school. Those that had the biggest impact on her were the attitudes of teaching and support staff, not her peers. Lauren said:

I got told when I was at school ‘oh, you’ll never amount to anything’... I was down for a while because people had told me I couldn’t achieve... I felt in myself that I couldn’t achieve things but then once I made my mind up with what I wanted to do I surprised myself.

Staff, from both the school and later an employment agency, had suggested she could go into office work doing what Joe referred to as “menial tasks”. But Lauren was determined to pursue a path that would enable her to “help people”. Lauren spoke about how some of these same people now “couldn’t believe” what she had achieved, or even that she was “the same person”. She also made it clear that their low expectations had made her want to succeed even more – “positive things come out of negative things”.

Lauren had finished school three years earlier and since school had been involved in a Government funded post-school options program. She was about to do a presentation to other families about her experiences using this funding. Joe said, “the talk will be about how the post-school options funding helped her to get to
where she is now – that there is success”. Lauren was determined to do what she could to make sure other young people with disabilities and their families were aware of the supports they were entitled to, and of possible difficulties they may encounter. This followed her own experience of having missed out on receiving a particular Government benefit until an acquaintance happened to mention it to her – “no-one ever tells you about those things except through word of mouth”.

Lauren had recently started having paid carers attend her home twice a week to give her dad a break, and to prepare Lauren for a time when her dad could no longer care for her. They had experienced some initial problems with the staff but had found a company they were happy with. The carers were coming in at a set time however, which meant that Lauren wouldn’t be ready to start her day until after 10am. They were therefore looking at having to negotiate a new time that would allow Lauren to be ready earlier. Apart from these two mornings a week, Lauren’s dad was her primary carer. Lauren didn’t mind, saying “I’m used to it”. Lauren liked it more in some ways because Joe wasn’t worried about worker health and safety and would get things done more quickly than her carers. She found using a sling and hoist time consuming and frustrating and she spoke about the poor design of the sling in relation to female toileting:

*By the time you get into the hoist if you are busting it can be too late. And with the sling I’ve got, it puts even more pressure on you and makes you want to go even more.*

Lauren used a lot of equipment for her personal care, meals and accessing her computer. The family had found some of the products available for retail purchase to be unsuitable for Lauren, and Joe explained how he had developed quite a few custom pieces of equipment:

*I’ve made some things myself. I’ve made a joystick for the computer because her fine motor skills are not good, but she is good with the wheelchair control so I’ve made one that is the same to operate the computer...We made up a drink holder out of a pen holder. I made a new tray for the wheelchair because the ones that come with it are abominable. We’ve got one for computer use, and another Perspex one*
for meals, or when she goes to schools she can read stories or play games with the kids. We’ve really tried to work things out for her.

Joe had also recently purchased a second hand car that had been modified and enabled Lauren to travel in her wheelchair. Previously Lauren would have to rely on taxi transport, which had many shortfalls. The modified car enabled Lauren a degree of spontaneity, allowing family and others to drive her places she wanted to go, when she wanted to go, which was very important to her:

I don’t have to wait for taxis as much. They are so expensive, even with the subsidy. And they are not always available. Quite often you’ve got to wait. You can’t make plans to meet people at a certain time. To go from here to the other side [of the city] in a taxi costs $65, it costs us $5 so it makes a big difference. It’s been excellent, if I want to go somewhere I can just go, I don’t have to call up a taxi and wait 4 hours. It will also be good for my carer, if we want to go to the mall, or I need to go to the doctors, she can drive me.

Since leaving school, Lauren had utilised her flexible funding package to undertake a variety of education, employment and recreation focused activities. These included: purchasing and receiving support to learn to use specialised software to help her access the computer and build up her skills in word processing and developing presentations; having a person attend her home each week to assist her undertake activities in preparation for commencing her own business, for example, writing a business plan, developing invoice templates, developing presentations and marketing materials; and spending time with a young, female carer participating in social activities including shopping, watching movies and going to the club.

Lauren was just launching her own disability awareness business during the research. She received her first paid work during the study, presenting to a group of nursing students at a local training institute. She also spent significant time delivering disability awareness program on a volunteer basis at two local primary schools, and at one stage she was working in schools as much as four half-days per week. Lauren had located the schools interested in her program through “a lot of ringing around and a lot of going to schools and meetings”. They had also hand-
picked schools to a degree based on which ones were accessible and had suitable
facilities. These volunteer roles had allowed Lauren to develop, implement and
evaluate her disability awareness program, which she hoped to eventually take into
many schools in a paid capacity, with backing from the Education Department. Her
program included a range of games designed to simulate different disabilities, and
for older children, also aimed to explore and challenge assumptions they may have
about disability. Lauren also offered guest presentations, inspirational speaking and
a range of tailored presentations to families, educators, health professionals,
disability support staff and other interested groups. Lauren’s long-term goal was to
develop her business model and disability awareness program in such a way that it
could be franchised to other young people with disability looking to start their own
businesses. She “hoped to one day” expand into other states.

Lauren’s prices were modest; in fact her first paid job “didn’t even cover the costs
of getting there”. However, she hoped the demand would build up over time and
given that she also received the Disability Support Pension, the money was not
Lauren’s biggest driver. Lauren was prepared to take on volunteer opportunities
when paid opportunities were not available, and Joe spoke about a number of non-
financial benefits for Lauren which made it worthwhile even if she did not get a lot
of paid jobs:

*The idea of course is to try to get paid, but if you can’t you’re still
getting the satisfaction of the community work you’re doing, and
you’re getting out in the community not stuck at home. If you don’t see
anybody, you don’t get to know anybody.*

During the months Lauren was involved in interviews, the interest in her business
grew significantly. Just prior to her final interview, she had been successful in
receiving a grant from a youth foundation which she planned to use to host a
disability awareness day. She was aiming to hold it at a local school and bring in
people with a range of disability types and a range of equipment to help raise
further awareness. Lauren had also been offered a contract with a government
funded disability agency to deliver further disability awareness programs to schools.
This was still being planned, and Lauren would have to successfully complete a trial, but she was hopeful it would lead to two days per week work. Joe said, “we didn’t expect the business to take off as quick as it has”.

Through her business, Lauren wanted “to change people’s perspective [of disability]” and for people to learn to “treat people with disabilities how they want to be treated themselves”. She decided to pursue this career path as a result of her own personal experiences that made it clear that more awareness and acceptance of disability is needed. For example, people in the community would regularly stare at her, or speak with her parents or carer instead of directly with her. Even more frustrating to Lauren was when children would ask their parents questions about her, to which people would just “make stuff up” rather than ask her personally.

_I think people just see you differently, I think they think you’re some kind of alien, some sort of freak, I think they’re too scared to go up and ask questions because I think they think they will offend you. So they’re just happy to perceive you in whatever way they do, even if that’s not true, they are just happy to perceive you in whatever way makes them comfortable because I suppose they’re not going to get to know you. I think everybody that has some sort of disability has that same feeling, because it always happens. In my program I am trying to change people’s perceptions._

Lauren prided herself on being open and honest. She believed this was the most effective way to educate people, to break down stereotypes and build acceptance. She said:

_I’m willing to answer any of their questions...It’s really excellent the response I’ve had. One of the teachers asked me how I can do it, how I can open up about myself, but I’ve had to do it my whole life so I’m willing to do that because if you don’t answer their questions they will never know. If you aren’t open, it is just another reason to be mean to a person._

Joe was very involved in all of Lauren’s activities, and particularly in getting her business off the ground. A day working at a school could mean four trips for him to drop and pick up Lauren and to assist her with toileting. It was clear he was very happy to do this for Lauren, and very proud of her, even though he did joke that
“I’m running off my feet at the moment. I’m supposed to be retired and I haven’t stopped”. Joe was optimistic about the future, even if it meant reviewing Lauren’s goals over time:

The fact that she wants to work means a lot because a lot of other people say it’s too hard or they try and give up, where she has really persevered with coming up with ideas to be able to get out there and work. And if it doesn’t get off the ground we’ll try something else, just like anybody else.

Lauren too was determined to succeed: “Until you try you won’t know...the only way we’re going to find out is to give it a go... We just want people to accept that people with disabilities are exactly the same as everyone else, deal with all the same issues, and just some added issues”. Lauren felt that she was adult in some ways but not in others. She knew that moving out of home was not an option for her at that time, but was building her independence through starting to use paid carers. Lauren’s story did not include much mention of friends outside of family friends, or any mention of intimate relationships; she was focused on building her career. Lauren recognised that her goals might take her longer to achieve than it would others, and that she may need to review and refine them numerous times, but she was determined to keep going until she reached her goal of working successfully in the disability field: “You’ve got to make the best of whatever you’ve got. Life’s too short to sit in the corner and go ‘oh gee I can’t do anything’”.

### 4.7 Justin’s story

Justin’s aspirations included a PhD, living independently, moving overseas, and a successful career in his own business, through which he would help other young people. Justin was passionate about achieving his goals and happy with his progress: “I’m happy with my current path; I wouldn’t have it any other way”.

Justin’s first interview fell on his 19th birthday. He was in his first semester of university. Justin lived at home with his mum, dad and older sister, and he
described their relationship like this: “I’m really close to my family, sometimes they annoy me and I want to get away from them, but they have been amazing.” Justin credited the way he was brought up for his determination:

> When I was born the specialist told my parents I would be deaf and never walk and never talk and be in nappies for my whole life. So basically I’d be a vegetable. But my parents were always pushing me to do things for myself and I think that’s why I am who I am today.

Justin’s cerebral palsy was GMFCS level III. He got around using a walking frame for short distances or a manual wheelchair or electric scooter for longer distances. He found that he was walking less and less as he got older. He wanted to improve his fitness and endurance but found it difficult to prioritise exercise. Justin had not been involved with any specialist healthcare services since he was a child. Even then he only remembered doing some physiotherapy, occupational therapy, speech therapy and having one tendon-lengthening surgery. Justin did not even know what type of cerebral palsy he had, and he did not consider himself disabled at all. He said:

> I can do anything an able-bodied person can do – I walk, even though I have a walker, I walk, I drive, I stay home alone, I cook, I dress myself. So in my view I’m not disabled, I have an additional need. I prefer that term. I hate disability, I hate spastic, and it’s not just about being politically correct, it’s just a nicer way.

Justin’s experiences in education had greatly influenced his life. Justin moved between support units and mainstream classrooms several times during school. He started his first year of primary school in a support unit but was then integrated until year 7, his first year of high school, where he was placed into a support unit for “assessment”. This assessment process dragged out into a six month placement which made him “pissed off”. He said “they were just not organised enough to get me integrated”. When he finally moved into mainstream, Justin found it difficult to catch up with all the work he had missed and he was returned to the support unit, which “really hurt” him. He said, “I couldn’t handle the support class, the work was so basic...and the pace they worked at was really slow....it was really frustrating just
sitting there, I wasn’t mentally stimulated”. At the end of year 8 Justin demanded to “try again” and, with the backing of his parents, the school agreed to his move back to mainstream. He remained in mainstream classes throughout the rest of high school. Justin continued to receive some support; mostly practical help carrying his laptop and books between classes.

Justin’s teachers tried to convince him to reduce his workload for his HSC by completing it over an extra year, but he was determined “to do it like everyone else…. it was hard but it was worth it, I didn’t want to stay another year, thirteen years [of school] is enough!” He demonstrated his capacity to succeed within the mainstream setting through excelling academically, coming first and second in his grade for a number of subjects, and receiving a partial scholarship to university. Justin spoke passionately about how his future options would have been limited if he had been forced to remain in the support class and the effects that would have had on his self-esteem:

*They don’t even get a proper HSC, so I wouldn’t be here [at university] and I wouldn’t be talking to you right now. If I was still in the unit I probably would have ended up at TAFE somewhere doing a welfare course, but I wouldn’t have been happy there. I know that I would have felt like I’d given up on myself.*

Justin had always aimed to go to university to study social work and his hard work and determination got him there. The early weeks of university were not easy however, especially in relation to getting around campus. He said, “at the beginning it was horrible…I walked everywhere at school and I just assumed I could do the same at uni, but I couldn’t, it was too much”. Justin had not anticipated the physical size of the campus and a pre-semester visit to collect his text books left him in tears. He said, “on my first day my mum had to take the day off work and come with me because I didn’t want to come. I almost dropped out before I even started”. But he was resolute and with financial support from his parents he purchased a motorised scooter to enable him to get around campus. This made things “so much easier” and it meant that he could make his classes on time and not get so tired.
Justin received some support at university including note-taking support and extra time and a scribe in exams. There was none of the practical support he had had at school available though, which made the scooter even more vital. He felt like having to manage on his own contributed to his independence, and he was actually happy the practical support was not available as he felt that he no longer needed it. He said, “I need to stand on my own two feet, I’m really happy about the way things are here [at university]”.

Although social work had always been his goal, Justin “wasn’t too happy” with the course in his first semester and was considering the possibility of transferring into a digital art course: “my aim at the moment is to stick it out for the rest of the year and then if I still don’t like it I can transfer”. He was “in two minds” about which career path he really wanted to pursue; “I like both of them, I’m passionate about both and I know by doing social work I can help more people. But I’ve also always wanted to do something to do with web design and art”. By second semester, however, Justin had decided to stick with social work and was set on working with youth. He was “keeping on top of the work” and finding that his classes had “really opened up my eyes” to the possibilities ahead for him. Ideally, he was keen to integrate both of his passions into his career, but regardless of his eventual career path he had “big dreams” for the future and was determined to succeed:

I have high hopes, I want to get my honours degree, do a PhD and I either want to open up my own neighbourhood centre or move into private practice for youth, counselling...When I originally came into this course I was set on individual one-on-one counselling but now I’m starting to think about the community development side of things...It’s my big dream to open up my own [neighbourhood centre] and use my artworks to fund it.

Justin was a skilled artist and designer, particularly in the areas of digital art, photography and web design. He had developed his own website displaying his works and was actively seeking an art gallery to take on his works for an exhibition. He used his art as a forum to try to dispel “stereotypes” about disability, for example one series of works depicted parts of his body, with only the last work
including his full body and walking frame. He said, "I wanted to show that because I’m physically disabled I’m not different to anybody else". Justin had had quite a few "bad experiences" in the community in relation to people’s lack of awareness and acceptance of disability. These included people speaking to his parents instead of directly to him, and a person commenting to his mum "is that yours", referring to Justin. As a result, Justin wanted to do what he could to reduce "myths" that still exist around disability.

These myths may have played a role in the challenges Justin had faced socially throughout most of his schooling. Justin had spent a lot of time in school “sitting by myself” and had found it difficult to find people to “connect with, and talk about stuff with”. He blamed this partly on his own insecurities: “I guess it’s got more to do with me, I know this is probably wrong but I felt like people only spoke to me because they felt obligated or they felt sorry for me”. As he moved towards emerging adulthood, Justin said he started to “come out of my shell” and grow in “confidence” and “self-esteem”, which helped him to develop a couple of close friendships in his senior years of school who he knew were “genuine” and who he kept in contact with. He described this shift in his sense of identity like this: “I think I’m getting more confident about who I am. Like within myself. I’ve always been worried about what people think about me, whereas now I don’t really give a stuff”.

Justin was happy to only have a couple of really close friends in emerging adulthood but talked about having met new people at university and through online art forums too. These people were acquaintances rather than friends. Justin still did not feel very “comfortable” approaching new people and this was something he was working on. Justin emphasised that friendships with other people with disabilities were not something he sought out:

This might sound rude, but I don’t really like associating with other disabled people if that makes sense. I don’t see why I should have to be characterised, like I can only associate with people with disabilities. And I don’t have anything in common with them.
Justin had not yet had a “real relationship, whatever that is”. He had had a girlfriend at school for a number of years, who did also have a disability, but in hindsight he “wouldn’t call it really going out with her...it was more like I was there as a friend and that was it. It was like we were in a relationship but there were no characteristics of a relationship”. Justin was “fine” with not having a relationship at this stage in his life:

*I have different priorities, like at the moment I want to get through uni. If I meet someone, then that happens so be it, but if not I’m not going to go “why I haven’t I got anyone.*

Justin felt like he was an adult in some ways, but not yet in others. To him, moving into adulthood was about “greater independence and autonomy”, being “mature” and “not blaming other people for your stuff-ups”. Justin felt that he was “getting there, very slowly”. He had come a long way in increasing his independence, and this had been a key focus during his teenage years. He regularly stayed home alone, although not overnight, and was able to cook himself simple meals. His family had set up a bar fridge and compact oven in a way that was easily accessible which Justin said was a “big step for my independence”. He was able to manage most self-care independently but needed assistance of his parents getting in and out of the shower and putting on shoes and socks. He said, “honestly it was alright when I was younger, but moving into my 20s now, I wouldn’t say it’s really uncomfortable, but I would like to do it myself”. Unfortunately, major renovations would be needed to his family home to enable increased independence with showering, so this was a goal that Justin had for when he moved out of home. He was focused on achieving greater independence and knew he would succeed: “It would take a lot of time for me to get used to doing it myself but with time I could adapt, like with everything else I’ve had to do”. He had big goals for his future living arrangements:

*I want to eventually move out, but I need the finances to do that, because I can’t rent, because I’m going to need to do all the modifications...so I need to sell lots of artworks so I can move out. My ultimate dream would be to move right in the heart of the city, I’d love to live there.....I wouldn’t want to be too far away from my parents, not yet anyway, maybe in a few years. In the last year or so I’ve really*
wanted to move over to New Zealand and get work over there...[I’m going to] build up to it.

In the meantime, Justin didn’t mind “staying at home for a while” even though “it does get a bit much sometimes” feeling like his parents still had “authority” over him. He had at times had to push for his independence and this sometimes led to “a bit of conflict”. For example, his mum would sometimes lay out his clothes so Justin said he, “sat down with her and said, ‘look it really annoys me, let me make my own decisions about what I wear’”. While he worked towards a more independent life, Justin relished those opportunities he did have to be at home alone: “sometimes I just need time. I like to be by myself. I love it when I have the house to myself, I love it”.

Another important step in Justin’s push for independence had been to get his driver’s licence. It took two and a half years on his learner’s permit for him to build up the skills and confidence to get the provisional licence that would allow him to drive without a supervisor. The process was drawn out and expensive, requiring an occupational therapy assessment and lessons with a private instructor in a modified car. His parents supported him financially through this process and also bought him his own car fitted with hand controls. Justin had had his licence for seven months at the time of our final interview and was still trying to build up his confidence, only driving when it would be quiet and not on main highways. Justin still relied on his parents for transport a lot of the time, which sometimes meant having to wait around to be picked up, but he was determined to build up to complete independence in driving.

Justin was happy with where his life was at and where he was headed, and confident he would achieve all of the things that were “meant” for his life: “I am a believer that if it is meant to happen then it will, and if it’s not then it won’t”.

178
4.8 Jack’s story

Jack’s future goals included securing a permanent position at work, doing well in his career and representing Australia at the Paralympic Games. He was also keen to pass on life lessons to other young people with disabilities, including the importance of drive and determination. The “philosophy” he lived his life by was “there are no shortcuts to anywhere worth going”.

Jack was 22 years of age at his final interview, and he felt that he had reached adulthood. He had “always been a fairly mature person anyway” and believed that leaving school and commencing full-time employment was a sign of him having reached adulthood. He was working full-time as a customer service officer in local government, and in the process of applying for a permanent position after having successfully completed a traineeship. He was hopeful of a positive outcome and looked forward to continuing to work for this organisation into the future. Jack was also a successful sportsperson, having won multiple state and national titles in power lifting. Jack was feeling very positive about the future. He had overcome many challenges in the past and knew that with hard work and determination he would again in the future.

Jack was diagnosed with spastic diplegia at a young age, GMFCS level III. As a child he walked with callipers, and later with crutches. He attended a local public school as a young child, but in high school made the decision with his family to attend a special purpose school for students with disabilities. The challenges of navigating a large school to change classes multiple times a day, along with impending major surgery that would leave Jack in full leg plasters for many weeks, made this decision almost inevitable:

I knew [mainstream] high school wasn’t going to be an option as far as having to move around all day and you move from classroom to classroom and carry books and do all that sort of stuff. It just wasn’t an option and we knew we had to find something else, so I guess when I say it was a decision, it was a decision that was almost made for me.
Jack found the special purpose school met his needs well. He had very supportive teachers who were able to offer extra assistance and who “went beyond the call of duty” for their students. He was pleased to still have a wide subject choice for his HSC, including an opportunity to study a Certificate II in Business Administration at TAFE. Jack said his teachers were able to “tailor the subjects to fit my academic level and needs” and he successfully completed his HSC over two years. While Jack knew that special purpose schools were “not for everybody”, he was very positive about his own experience.

Jack also found his school experience beneficial in terms of his transition from school. He felt that his teachers were well placed to pass on knowledge about supports and services available in post-school settings. He left school aware of relevant employment services and funding opportunities. His experience was that students attending mainstream schools often did not have access to this level of advice, and were often left feeling that there was a “big black hole” after school. Jack felt that while there were gaps in services, a bigger issue was a lack of awareness of those services that did exist. Jack was passionate about helping other young people to learn about available support. As an emerging adult he volunteered to present to parents and young people at information evenings and events about his experiences, achievements and lessons learned. At these presentations, he learnt that many families were unaware of available services:

*I guess for people who are in the mainstream system, it is a lot tougher for them to find out what they can and can’t get access to, I guess…. a good example of that was only a couple of weeks ago when I did the presentations, and lot of people came up to us afterwards at both of them [and said] ‘we just didn’t know’. You just think ‘why, how, why don’t you know, how don’t you know’?*

Despite being aware of employment services, on leaving school Jack hoped to secure employment independently. He spent many months applying for positions, attending interviews, and being unsuccessful in securing a position. He felt that his disability contributed to him not gaining a job earlier, with both access issues at potential workplaces, and attitudes of potential employers, contributing as barriers.
Smaller companies did not have access to the resources to make significant modifications to the workplace, while Jack felt that others’ attitudes changed upon seeing that he used a wheelchair:

*I guess I thought it would be pretty easy. I tend to think “no it’ll all be good, it’s all pretty good, it’s all pretty laid back” ...but it was tough...there’s a big wide world out there that I didn’t sort of think was there. I don’t know exactly what I expected it to be but I just thought “oh well it will happen, I’ll be alright, other people can do it, I’ll do it”. But then we found that a bit hard to find a job... you would send in applications and that would all be fine and get your interview and that would all be good and everything, and then you’d sort of go away and they’d ring you up and say....well they’d never tell me it was because of my disability....they’d sort of say “we don’t want you here”......I’m not one that would take them to anti-discrimination boards or whatever, if they don’t want me then that’s their loss, cut your losses and [say] “see you later”...I don’t have time to go through courts or tribunals or whatever, if you don’t want me then that’s your problem.*

After around six months of job seeking independently, Jack decided it was time to “bring in the hired help”. He signed up with a DES provider, who “couldn’t have been more helpful”. Jack said he had to “swallow my pride” in order to ask for help; his goal had been to secure a job independently. In hindsight Jack was glad he asked for help, and said, “possibly now looking back I should have brought in the hired help a little bit earlier than I did”. He found the service provider very supportive, and they assisted him with job seeking and advocated on his behalf to potential employers. He said “[service provider] is one of those places that do really, really, really push employers, which is good”. Within six months, Jack secured a traineeship in business administration. He successfully completed his traineeship and took on additional Certificate IV studies in Business Administration. Jack was very pleased with the support offered by his employer. They had made all necessary adjustments quickly, including installing a small ramp at the building entrance. He said, “they have been a model employer, they’ve done everything they can...they have certainly been wonderful”. At the end of the study, Jack was feeling positive about securing a permanent position he had applied for, and he planned to continue his career in local government. He was determined to succeed, and was pleased that his current employer offered “plenty of opportunities for promotion”.

181
In emerging adulthood, Jack spent much of his time outside of work training for his chosen sport of powerlifting. He had taken up the sport only a few years earlier for general fitness, saying “I was gunna [sic] end up not being able to walk much, or maybe not at all. So we decided I’d have to do something about it.” He never expected to achieve as much as he had, earning several state and national titles. Jack trained at least four times a week with support from his dad and was determined to reach his next goal - representing his country: “I guess the main goal from here is to represent Australia...I never thought I would get there, never in my wildest dreams”. Jack had had the opportunity to travel interstate and internationally with a Paralympic development squad and got on well with other athletes with disability in the squad. He enjoyed the social side of travelling with the squad; getting “to meet people and have a good time”.

At the time of the study Jack was living at home with his parents and younger sister. He used crutches to get around home and for short distances, a manual wheelchair at work and for medium distances, and an electric scooter for long distances. He was able to get everywhere he wanted to go; choosing the most appropriate mobility aid depending on where he was going. Jack also had lots of help from his parents who would drive him to training and leisure activities. Jack was very close to his parents and sister and the family enjoyed activities on weekends together, especially watching football. He felt “lucky” that he had a “pretty active family that does stuff on the weekends and goes places”. Jack felt that his parents treated him as an adult and that he had “plenty of control” over making his own decisions. He said, “they don’t really treat me any different [to my sister]” and “sort of guide me without putting on the pressure”. Jack’s grandfather also lived nearby, and Jack stayed with him often. He considered his granddad his best friend, an extension of him being a key support during therapy and school activities as a child.

Jack was no longer accessing regular therapy or health services, despite having had lots of physiotherapy and some major surgeries on his legs during childhood. He had decided not to continue accessing regular physiotherapy in emerging adulthood.
as his cerebral palsy was fairly stable and as Jack said, “physio wasn’t going to make it better...if it’s not going to make it better and it’s not going to get any worse then we’ll let it go ...”.

Jack was looking forward to achieving his next goal which was to get his driver’s licence. He had previously been for a driving assessment which determined that he would be able to drive with hand controls. However, the financial costs involved in modifying a vehicle and having multiple lessons with a specialised driving instructor had been prohibitive. He was looking forward to having a permanent job that would enable him to commit financially to the costs involved in purchasing a modified vehicle and paying for the necessary lessons. Jack was looking forward to being able to drive himself to work. However, even without his driver’s licence, Jack said “I don’t miss out on too much now”.

Jack was happy to spend much of his leisure time with family and was not in a hurry to move out of his family home. Financially, and practically, Jack could “see no reason to leave” in the short-term. He knew his family would support him moving out “when the time comes”, but said, “it’s much cheaper and you do look at houses and things, but I’ll save a bit of money ... stick around for a while and see what happens ...”. Jack was also willing to wait and see what happened in regards to intimate relationships. Although he was open to having a relationship, Jack chose not to focus on it in the short-term:

If it [a relationship] happened, it’d be nice, you know, I wouldn’t say no. Obviously. But I’m not focused on it right now...I think just let it happen and let life take its course and when it happens, if it happens, you know.

At the time of his last interview, Jack was committed to his career and his sport. Between them, there was little time for anything else. He was ambitious and aimed to achieve great things in both areas, and knew that his hard work and determination would be worth the investment: “I see the light at the end of the tunnel, the long-term goal...It’ll be worth it in the end”.

183
4.9 Erin’s story

Erin’s focus was on actively making decisions and pursuing goals that would help her reach her maximum potential, despite having mild cerebral palsy: “It’s [the CP is] not a big deal, but yes, there is a difference...there is something and I have to figure out my life around that.”

At her last interview, Erin was 25 and felt she had reached the “beginning of adulthood”. She had recently started full-time work and her short-term goal was to focus on this for the next couple of years. Erin was very creative, and she loved drawing, sculpting and playing the cello. Erin still lived at home with her parents. She knew that moving out would be part of her future but said, “I don’t think I’d last a day out of home at the moment”. She was a bit worried about managing the demands of working as well as running a household. Erin hoped that one day she would have a relationship, but was not concerned that it had not yet happened. At the time of the last interview, she was happy to focus on what she had already achieved: “there are always things you have to do in life, there’s always the next step. But I’m not thinking about that right now. Save that for tomorrow but not right now.”

Erin had come a long way in her 25 years. As a child and adolescent, Erin’s story was one of “not fitting any boxes”; of not being “the same” but at the same time not being “disabled enough”. She was never told she had CP, only that she had a “motor problem” and was a bit “clumsy”. This was despite her having been diagnosed at age two with mild spastic diplegia, GMFCS level I. While she grew up in a supportive family with her mum, dad and older brother, Erin was bullied by her peers throughout primary and high school. Erin’s life at school was “a misery” and she attributed this predominantly to the emphasis put on sport within primary and high school. Her disability meant that she was very clumsy and uncoordinated and did not have the strength to complete some activities. Erin said, “I would like to meet one person who was the worst kid at sport who was popular as well”. Unfortunately though, Erin felt it was the lack of understanding of her physical education teachers
which led to her having such a hard time socially at school. She remembered frequently being called “lazy” and being “labelled as having a bad attitude”. She recalled one particularly awful experience in high school:

*I was yelled at, I was physically pulled from the back to the front of the class and she wouldn’t hear a word from me … I was trying to say “I can’t”, and it was “I don’t want to hear a word out of you”…they treated me like no person should be treated. The experience at school from the day I started to the day I finished in sport is a disgrace.*

Because Erin had “zip-all [no] understanding” of her disability, she “put a lot of pressure” on herself to perform the same activities, and to the same standard, as others. Throughout school she struggled hard to prove that she was “just as good as everyone else”. Erin did not understand that she had a “real” problem and did not think she had an “excuse” if her performance was different to that of others. She said “I was extremely driven, and I had ability, and I wanted to show that I had the ability”. During high school she became exhausted and experienced stress and anxiety, in the end “getting really-really sick”:

*I ended up driving myself sick …. I would work crazy hours – it took a lot longer to do my work than others and I knew it, but I didn’t want to let on because I thought it would show that I’m weak…..I felt like I had no option but to prove myself.*

When Erin started her HSC studies in year 11, her parents said, “well you have to get some provisions for doing the HSC”, such as extra time in her exams. At this time she “sort of took it as an insult” as she still did not believe she had a medical or other condition. Not long after, Erin found out about her CP by accident. She overheard her mum on the phone telling somebody that her daughter had cerebral palsy. Erin was 17. Her reaction was “what the fuck! You didn’t tell me that one”. At this time Erin was not really interested in learning the details of what cerebral palsy actually was. She found it helpful just to know that “it has a name…it was real and it wasn’t my fault”. Erin was also planning for her end of schooling, reflecting on her school years and realising that the school system had not been good for her. With hindsight she believed there was never a “level playing field” between her and her
peers. Although she had been doing well academically without special provisions, Erin knew her potential was even greater.

To reach her “maximum”, she decided to apply for special provisions to complete her final high school exams. Some of her teachers, however, believed that the provisions Erin was entitled to, including extra time and using a computer for exams, would give her an advantage. Erin experienced “teachers saying that they’re not going to support me because I do well. So people think you have to actually not do well in exams to get extra [time]”. Erin’s teachers did not understand her disability, could not see her disability, and did not believe how much extra effort she had to put in or how fatigued she became:

*It’s the first time in your life that you come out and say something [about your disability] and what you get is ‘oh well, what’s wrong with you?’ And it’s ignorance… but for me it … sort of invalidated my experience as such…teacher’s would say ‘well where is it’? I would say ‘I have mild CP, it’s a motor problem’…‘But which hand is it in?’ They wanted to see, they wanted to see something.*

This reaction from some of her teachers was a “blow” to Erin’s confidence and made her feel that her disability “wasn’t valid” and that she was not “respected”. Erin felt very alone at this time; she found it difficult that people did not understand her disability and that she was not aware of other people with similar experiences. She said: “I thought there was no one else on the face of the earth with mild CP like me”.

When Erin started university, although she knew that disability support services were available, she did not want to access special provisions. Her memories of reactions to the HSC special provisions she received were still raw in her mind. She did not want to put herself in a position where people might judge her and again invalidate her personal experience. She had decided “well if that’s the way I’m going to be treated, it’s actually better if people have no idea”. However, her parents strongly encouraged her to sign up with the disability service, to ensure that provisions would be available should she choose to access them in future. Erin agreed to this, but found the process a “bit weird”. Unlike past experiences, where
her parents had taken the lead in accessing services, this was the first time Erin had to independently acknowledge that what she had was a “disability”.

At age 19, Erin had an experience that changed the way she lived her life and significantly influenced her approach to disability. She learned that she was not alone in her experience. She was watching the opening ceremony of the 2000 Paralympics and the Australian torch bearer was announced as Katrina Webb, a young woman with mild cerebral palsy:

> Just seeing that there’s somebody else who had it and was open that ‘yes, I have mild CP’, it was just an amazing experience for me because I thought it was something that you can’t have or you have to hide...or no one would understand....I just couldn’t believe it and it made me feel like it wasn’t my fault, it wasn’t something I was doing wrong.

The experience of seeing another person with mild CP who was prepared to tell the world about her disability and was “proud of themself [sic]” was a validating experience for Erin. She said that learning that she was not alone was “liberating...it was the first time I’d felt this isn’t me, this is how it is”. It gave her the courage to start standing up for herself and taking control of her own experiences. For example, from that point on, Erin was able to ask for the provisions she needed and to say to the university, “it’s your problem, not my problem”. Erin describes this as “having the power...It was the first time in my life that I’d stood up and said ‘hang on a minute, let’s make it a bit fair. It’s not a big deal but I need a bit of a level playing field’”.

Erin now asked for the support she was entitled to as a person with disability. She still had to fight hard for support and at university again faced “invalidating” views and negative attitudes from staff who did not understand her mild disability. Erin fought for, and secured reasonable adjustments for her exams, although the process was slow and “like pulling teeth”. Erin did well academically at university, with much of her success due to her own determination and learning through experience what she needed as a person with CP. Although having mild CP was not “a big deal”, she had come to understand that there was indeed a difference
between herself and her peers. Erin had learned that she would have to “figure out her life around that [her CP]” because no-one else was going to do it for her. Erin learnt during her university years that no-one was going to seek her out to offer support, and that her own decisions, actions and determination would shape her future:

Adulthood I think is - you begin to be aware that you have to be actively making things in your life to suit you. And that can include things you weren’t worried about before because a) you couldn’t care less, b) you weren’t going to care less, and c) you left it for your parents to do.

Erin began to feel in charge of her own life. With this shift in responsibility and realising that she would have to manage her own disability, Erin actively took steps to “make it right” for herself. She sought out and accessed provisions she was entitled to, and chose to study a reduced load. Erin said, “[having CP] does change the decisions I make in my life – just the little things to make things easier.” This proactive approach continued when Erin was offered a place in the honours program at university. She actively searched out a supervisor who would be supportive, understanding and flexible. Having somebody “on her side” made Erin’s honours experience very positive. Erin successfully completed university and attained honours.

Having completed university, Erin’s next challenge was to find work. She was initially unsure of her career direction, joking in an early interview, “I still don’t know what I want to be when I grow up”. She was unsure if she would be able to manage full-time work and was worried that if she disclosed her disability she might face discrimination that would influence her chances of getting a job. She spent a few stressful months searching for a position without success. This was a “terrible time” and Erin cried a lot. She said:

I’m actually getting quite stressed out over this whole ‘what am I going to do now? thing! I’ve sort of decided that this whole emerging adulthood stage isn’t for me...I think I would like to regress back to the cocoon now.
In time, Erin used the same goal-focused and determined approach that had worked for her in the past to secure a job. She actively sought a position which she thought would suit her needs best – something flexible and varied. She knew she had skills to offer, sent an unsolicited email to a relevant organisation, and a job came up straightaway that was “a perfect fit”.

At the end of this research project, Erin’s job was going really well. Her hours were flexible, she was able to work from home on occasion, and she was coping with all her work demands without adjustment. Erin had not disclosed her disability to her employer. Initially she felt it was “stressful enough trying to start a new job, let alone trying to say something like that”. Over time Erin came to realise that in this particular role, her CP was not something that mattered. While she was open to disclosing her disability to an employer if she felt it necessary, in this job it was “irrelevant”. She had made an informed choice to seek positions for which she did not think her CP would “be a problem”. This was certainly the case in her current role.

Erin was feeling very positive about work and about what she had achieved. She also had a number of friends who she had met at university, and with these people her disability was a “non-issue”. Along with the overall increased maturity between school and university, Erin really believed that not having to participate in physical activities had made it much easier for her to make friends at university. She spoke about the changing reaction when people learnt of her disability:

*It’s not any more “oh, what a weirdo!” it’s “oh, that’s different, that’s interesting”, so it changes so much. It’s the same disability, I’m affected exactly the same way, but the different life circumstances totally changes my experiences because it changes how other people respond to me.*

While Erin knew in the long-term she would move out of home and she also hoped her future would include a relationship, she had chosen to concentrate on her work in the short-term and focus on enjoying life as it was:
I am feeling good and I’m enjoying it. I like the people and I like the work and I like to do it which is fantastic. Beyond fantastic. I feel like I got a lucky break, I feel very lucky.

4.10 Michael’s story

Michael’s goal was to live a fulfilling adult life that included a successful career, committed relationship and children. He was driven to overcome the societal barriers he knew he would face: “I don’t really see myself as different to anyone else; to me it’s just a limp. I’m doing all the same things that everyone else does…it’s really not stopping me from doing anything. The only way it does is in instances where other people make it...so it’s not actually the disability, it is society’s perception”.

At his final interview, Michael was nearly 23 years of age, and in his final year of an undergraduate university degree. He was living with his older brother, having just moved out of the university residence that he had lived in for the previous three years. He was looking forward to graduating from university, finding and starting full-time work. His short-term goal was to get “on my feet”, including finding a place of his own to live. He was in a new relationship that was going well and was excited to see “how things go” with this in the future. He felt that he was an adult in some ways but not in others, but he was confident that he would achieve his goals for adulthood. At the same time, he had learnt from experience that he would face barriers from society along the way.

Michael had been diagnosed with spastic diplegia as a toddler, GMFCS level II. Prior to this he had already defied the odds to survive being born three months premature. Both he and his mother were lucky to survive the traumatic birth, and Michael said that medical staff “didn't expect me to make it through the day”. He did make it through, and it was only when he was failing to reach his developmental milestones that his parents realised his difficult start to life may have had long-term consequences. A paediatrician confirmed that Michael had cerebral palsy, and it was “quite severe initially, in terms of the legs”. As an emerging adult Michael was
thankful to the doctors and surgeons who had enabled him to gain and maintain his mobility, albeit with a significant limp. He had seven orthopaedic surgeries as a child and adolescent, and extensive physiotherapy and occupational therapy. Michael said, “if I hadn’t had the operations I probably wouldn’t be walking today”. While he was grateful for what the surgeries had achieved, as an emerging adult Michael was also pleased that he was no longer involved in any significant ongoing medical care. He said “I just go to a GP when I’m sick, that’s all”. After his last surgery at age 16, Michael commented that “there was nothing else that could be changed which I was happy with because I’d had enough of hospitals and operations and stuff”. After so many years of significant involvement with health professionals, Michael just wanted to get on with life, a life that he hoped did not include doctors, therapists, surgery or stretching:

_I used to see a physio [therapist] every week. Like all the time, just because I had to do all my stretches and stuff, and electrical stimulation, all that kind of stuff. But that’s all stopped as well. Partly because I don’t feel that I need it anymore. I mean I know I should still be doing my stretches... and it should be a priority... but it just doesn’t seem to happen. I think after 22 years of doing it you just kind of get over it._

Michael grew up in a small rural town about 45 minutes away from the nearest large regional centre. He had lived with his mother and father, and a brother and sister who were both older than him. His family were “really supportive and encouraging” and he appreciated everything they had done for him as a child. He recalled his mum doing stretches with him every day and knew that all his therapies and surgeries had been very expensive. Michael had attended the local primary school which only had around 90 students. Here he had a very positive experience, with Michael commenting that the staff and students were “good, supportive, understanding...I was really lucky because there was really never any teasing or anything like that”. For high school, Michael travelled to a larger nearby town where he also had a very positive experience. He did not experience any bullying, only initial comments and questions from “curious” peers which he did not mind. He developed some close friendships and had an active social life as an older
adolescent. Michael was very pleased to be able to gain his driver’s licence without any modifications or restrictions. This was invaluable in assisting him to keep in contact with his friends, many of whom lived some distance away. He said:

*I’d be lost if I didn’t have a license, especially living in [a rural area]...we went to [a large regional centre] to go out...to go to nightclubs and stuff and I couldn’t do any of that if I didn’t have my license... it was a must... if I couldn’t have had that I wouldn’t have been happy.... it would have isolated me quite a bit...it takes that freedom away I guess to do what you want when you want, to rely on parents to drive you around and there’s no public transport out there... I guess to me it’s been very important.*

Michael decided around the age of 15 that he wanted to pursue a career in the health sciences, after having spent a lot of time with physiotherapists and occupational therapists as a child. He commenced his study at a small rural university, but said it “wasn’t what I expected... in terms of the social side of it, it was very quiet down there, there wasn’t much happening”. For this reason, Michael transferred after the first year to a larger metropolitan university, where he lived in the student residence. He was determined to do well in his studies, and he made friends and enjoyed the social environment. He said he was “always a bit apprehensive about meeting new people”, but here he found a group of close friends to whom his CP was “nothing”. Michael also liked the independence of living away from home, and he was paying his own way with support from a Centrelink allowance. In daily life Michael’s CP did not cause many difficulties other than some fatigue. He avoided some physical activities that he knew he would not be “good at”, like competitive sports, and instead swam, rode his bike or went to the gym. In terms of social activities, he mostly chose to ignore any limitations he did have in preference for participating fully with his friends, even if it meant experiencing some pain afterwards. For example, he remembered a day walking around the city that had left him in a lot of pain:

*I never consider it, I never factor in that I might need to rest or whatever, so I just do what everybody else does.... I don’t take the limitations that I do have into consideration. Like I’ll just get in there and do it and pay for it later.*
Michael found it exciting but also “a bit scary at first” when he left home at age 19, but he was pleased to experience living in another environment; “I was looking forward to it, I was a bit sick of the small town”. At the time of his initial interview, Michael’s aim was to finish his university degree and then move closer to his family for work, although not return to the small town where he grew up. However, his plan had changed by the final interview. He was in a new relationship and he had decided to find work and somewhere to live in Sydney close to his partner. He was really happy to have a partner, as prior to this relationship he had been worried about whether his CP would make it difficult to find someone who would accept him. He said, “it’s always in the back of my mind... can I find someone who doesn’t care about the fact that I have something [CP]?”. This concern had arisen out of a previous negative experience:

I was really good friends with a girl and I thought that it could’ve gone somewhere but it wasn’t...one of my other friends talked to her about it and she was like ‘well yeah he’s a great guy but I’d never go out with anyone with a disability’... so yeah it is an issue...that was the reason, [be]cause she was worried about what other people would think of her going out with someone who had a disability.

Michael was very pleased that his new partner did not share this negative view and accepted him as he was. He said, “my CP is not an issue at all; it wasn’t even ever brought up really”.

Michael hoped that he could similarly find an employer to whom his CP did not matter, however he was again concerned about negative perceptions he may face. He had experienced negative attitudes in the past, including from a health professional on a clinical placement, and another time when he applied for a part-time job in a liquor store:

...the guy out the front had taken me through to the manager’s office and I sat down, so when the manager came in I was sitting. He was looking at my resume and everything and we were just chatting, everything was going fantastic like [I was] really getting a good vibe, and then he said ‘ok, I’ll just show you around’. And yeah so I was walking, and he said ‘oh have you hurt yourself’? And I said ‘no I have slight cerebral palsy’....and he just goes ‘oh’ and I knew instantly that
Michael hoped that he would not face this negative view again in the future, but knew that it may happen. He said, “it makes you think if they’ve got that attitude then maybe so do lots of others and obviously that will affect getting a job. I mean you don’t like to think of it, but it could”. Michael knew however that he was in control of his own response if he did again face these negative attitudes, saying “if an employer has a negative reaction then I don’t want to work for them anyway”. Michael felt that overcoming previous negative experiences had forced him to develop this protective attitude and a positive self-concept:

I think it’s something that you have to. I think if you didn’t develop that attitude you would have a very different outlook on things, like internalising everything, and feeling unaccepted. I think if you don’t need them [other people] that is the best approach.

As Michael planned for his life after university, he was determined to take this attitude and strength and use it to overcome any barriers he may face in the future. To Michael, adulthood was “starting to live your life the way that you want, to be more independent, gaining more responsibility, moving off and sorting out your own life.” He was well on his way.

4.11 John’s story

John’s plans included going to university, travelling independently overseas and forging a career in the information technology field. He refused to be defined by his disability and was determined to overcome any barriers he faced: “There’s the disability, then there’s me. The disability is part of who I am but as much as possible I don’t let myself be limited or I don’t think about it. Most of the time I just do what I do and if I hit some kind of barrier then so be it”.

John was 18 years old at the time of his last interview, and in the process of completing his HSC. John lived at home with his parents and younger sister in a
rural, coastal town around five hours drive from the nearest capital city. John had spastic quadriplegic cerebral palsy, GMFCS level III, although his legs were significantly more affected than his arms. He got around his house and short distances using crutches or a manual wheelchair. As a young child he had not been able to walk, but major surgery on his legs around the age of eight gave him the independence to walk short distances. John’s family had “always had to travel for most of the medical stuff”, including significant interstate travel for specialist appointments and surgery. John said this added challenge of growing up in a rural area “was a bit of a drag…but it’s just something that needs to be done”.

John had accessed a lot of therapy, medical, and equipment services as a child. However, he had a poor experience of transitioning into adult healthcare as an emerging adult. He felt there was no planned transition between paediatric and adult services, and also found service providers’ tendency to speak mostly with his parents rather than himself frustrating. He said:

As soon as I turned 18 the children’s hospital didn’t want to know about me really... it wasn’t really handled all that well... It was even before I was 18. It was probably when I was about 16 actually. And I mean at that age you’re not a kid anymore. They can talk to you and tell you what’s going to happen and what that means to you...we did get that kind of information in the end but I feel like they should deal with me directly at least some of the time...By 18 you should be given a choice whether you want to have your parents help you with that kind of stuff.

Apart from his general practitioner, dentist and occasionally a private physiotherapist, John had now disengaged from the healthcare system. Services were difficult to access, and he had other priorities as an emerging adult.

John had attended mainstream schools throughout his childhood. He had managed quite well, and his family had always sought out the support to which he was entitled. The family ensured they were up to date and aware of study options, assessment accommodations and reasonable adjustments he was eligible for, and proactively sought them out. John’s mum had initiated his transition to high school three years before he started, knowing that extensive modifications at the school
would be required and that this would take time: “they’ve done things like put ramps in and put covered walkways in... they’ve done all that stuff”. John recommended this early planning and a “proactive” approach to other families and students with physical disabilities:

Make sure they have so much warning there is no way they can avoid being ready... because as all bureaucracies go, it takes them a long time to get stuff done.... the school definitely needs a lot of advance notice to be ready.

John was funded to receive support from a teacher’s aide throughout most of his schooling. He particularly needed this help in earlier years, commenting that “I was moving from room to room to room so I needed help with getting packed up, getting unpacked and set up for any practical things like science lessons”. He did not need this assistance for his HSC: “I’ve got less subjects and I’m not moving around classes ... [and] it’s all on the laptop”. While handwriting was slow and difficult for John, he was able to type “pretty fast” so it was helpful for him to use a laptop in class. John also accessed special provisions for his exams, including using a laptop, separate supervision, extra time and rest breaks. He recommended that people with disabilities take advantage of the support for which they were eligible:

When you go for special provisions try and get everything you think you need. Even though it is a bit embarrassing to get all that stuff as someone with a disability, you’re entitled to all that - rest breaks and extra supervision and separate supervision and extra time definitely. It just takes a bit of the stress off.... even though there’s a hell of a lot of paperwork, it is worth it.

John found it frustrating that he sometimes had to justify his support entitlements to other students, who had accused him of “cheating” in the past. He had experienced some bullying, and this worried him “a lot” in the earlier years of high school. However, he had a few close friends who supported him and was more able to deal with the taunting as an emerging adult. John felt this shift in his own reaction to bullying was an important part of becoming an adult:
...now I don’t care, they can say anything and I won’t care...There are a few idiots at school that hassle me. It’s taken me a long time to get used to the taunts and whatever, but I will either ignore it or say something really quickly back. I’ve turned into a bit of a smart arse actually....as I say I don’t care anymore. I’m not sure if it doesn’t get to me, but I don’t let it visibly affect me anymore....That’s part of growing up, part of being more mature....You can call me any name in the book, I’ve heard them all; every taunt you know I’ve already heard so it doesn’t affect me anymore.

John was also aware that bullying and negative attitudes were the result of a lack of acceptance and awareness, and that “unfortunately” he would always face people who treated him differently. However, he refused to let this get to him, and recognised that people with other “differences” were also treated in this way:

If people can tell you have a disability, then unfortunately there are some people who are going to act differently because of it. They’re not going to treat you directly like a person. They are going to treat you like a person with a disability. And some people for some reason still can’t tell the difference between intellectual and physical disability either.....You can replace disability with race, gender, sexual preference; whatever...It is people that are different. People don’t deal with people that are different.

John had chosen to complete his HSC over two years instead of the usual one, in a program known as Pathways. He was in his final year at the time of the study. John chose Pathways because of the fatigue he experienced as a result of his CP, and also as it gave him time to focus on other activities in addition to school: “I get worn out easily ... because I burn more energy getting around, just moving around is harder... and I like to have lots of time to do other things”. While he sometimes found it frustrating to be “sitting at school for another year”, John generally felt he had made the right decision and that all young people with CP should be aware of the option to complete their HSC using the Pathways program:

It depends on the day but in general, yes, it was a good idea to do Pathways. I would recommend it to anyone with CP who has difficulty keeping up or is getting tired out. I wouldn’t go as far to say that if you have CP or another disability do Pathways. I mean I’m sure there are people with CP who have done it in one year but it’s an option.
John was looking forward to finishing up his school studies so he could focus on his longer-term plans. He was bored at school and did not find it relevant to his future goals. He said:

*I mean it’s interesting enough but school’s just started to lose its interest a bit..... For a long time I haven’t seen the relevance of school...[my goal is to] get rid of this wall called the HSC and then just continue on. Do the interesting stuff afterwards.*

John had thought carefully about life after school and knew that both the physical limitations resulting from his CP, and negative attitudes he may face from potential employers, would make it difficult for him to find competitive employment in his local area. He spoke about how not being able to do “normal” part-time work had led him to pursue self-employment and set up his own computer technical support business:

*Getting a job here as a person with a disability is almost impossible... I had to create my own basically. Anyone able bodied who really needed money could go and work at [supermarket]...or work behind a bar once you’re 18 ... and do all those kind of normal jobs that you do as a teenager...But as someone with a disability in a rural area...I mean there are a lack of jobs at the best of times so I had to go and make a job...that resulted in me becoming a registered business after a while...*

While John’s business was registered, he had not yet started to advertise, and it operated mostly through word-of-mouth referrals. His skills were self-taught through having spent “far too much time on the computer” but he had recently commenced the first subject of a university computer science degree via correspondence, even while still at school. John stated that his business in its current form “wouldn’t be enough to sustain myself” to live independently. However, he hoped to continue this part-time work while pursuing further training and employment after school. He had made an informed decision to pursue a career in information technology because “there is no manual labour involved and my disability doesn’t really restrict me”. John had identified various options for the future, including full-time university study, a cadetship in information technology with a Government Department, and an overseas exchange, but was not sure what
order he would pursue them. He said, “I’d definitely like to go to uni at some stage, but it may not be the first thing I do”.

John’s parents really wanted him to go into full-time university study after school, and John’s indecision was a “point of contention”. John felt that his HSC marks would be the deciding factor in where he went directly after school. He mostly got on well with his family, but would sometimes argue with his parents around issues related to his independence. John felt that they were keen for him “to become more independent because it’s less of a burden on them”:

Oh, my dad and I have our arguments; mum and I have our arguments, like any family. Just our arguments change a bit. Me not doing enough exercise or me not doing the stretches I have to do, or something that I should be doing to get independent that I’m not, or something like that.... [Having a disability] changes the family dynamic a bit if you know what I mean but it doesn’t really get in the way of me getting on with my family... my family are quite supportive.

John felt he was an adult in some ways but not in others. He agreed that adulthood was about “independence” and was aware that he would need to further build his independence before he could move away from home to study or travel. He said:

I’ve got to really work on my independence...what I want to be able to do is go over there [overseas] and not be limited too much in what I can and can’t do. I need to be completely self-sufficient and that is gonna [sic] be the biggest challenge ever.

John needed assistance to put his shoes on, and had not “learnt how to cook yet”. He knew that he would need to build these sorts of skills, and get his driver’s licence, if he was to become truly independent. He said that while it was not a priority while he was still at school, “it’ll become a priority”.

John was able to get around his local community independently. He used a motorised scooter which he found made a huge difference to his community access: “A few years back I got a motorised scooter which was a big boon for my independence; I use it to get around town and to school and back”. For slightly longer distances, John would use the local taxi company who knew him well and
“have been really good”. While John was able to get around home, school and his local community independently, travelling longer distances was more of a challenge:

I can get around town just fine and it’s only just started to become an issue. I mean since I’ve been in high school I’ve wanted to get around a bit more. Go and see friends. Go out. So I can use my sticks for short distances, wheelchair for longer distances, and then a motorised scooter for longer distances still ... but that’s only around town.... It’s difficult to travel longer distances.

As an emerging adult, John wanted to venture further away from home but faced multiple barriers that usually made it “more trouble than it was worth”. He had recently missed an opportunity to go to a concert in Sydney because of problems organising and accessing suitable and affordable transport, accommodation, and personal support:

Because I’ve got a pension card the bus would only cost $35 but that’s not the problem really. I mean getting to Sydney isn’t hard. I’m mobile enough to get on and off a bus. So the problem is once I get to Sydney what do I do, because the taxi companies in Sydney will charge me more than the local company does, so I’m already burning up a lot of money just getting from the [bus station] to wherever I stay. And then where do I stay? I know one of the youth hostels is set up for easy access but still I’m going to need a little bit of help but I don’t really have anyone to turn to up there...So when I was looking at going up to Sydney I looked into getting I think it’s called temporary care and that’s just phenomenally expensive...it just cost too much. And as I said, for an able-bodied person it would be fine. They would be just able to go... to travel up on the bus or whatever, or drive the car, or have a friend drive them up, or fly up...and then they could take a train or a tram or whatever to their accommodation. They could stay in a youth hostel if they were doing it on the cheap and that would be really easy for them, but I don’t really have that option. It’s feasible. It is just so difficult it’s not worth the trouble for a couple of days in Sydney.

While John found experiences such as this frustrating, he chose not to dwell on them. Instead, he was focused on finishing school, his business and university studies, and his plans for life after school. John felt confident that his
“stubbornness” would help him achieve his goals for the future, just as he had in the past. He said, “I just need to stick with it and focus on it”.

4.12 Rina’s story

Rina’s goals were in line with those of other emerging adults – to finish university, get a job, move out of home, and develop close friendships. While she was confident hard work would allow her to achieve most of these things, she was cautious about whether this strategy would work when it came to the thing she wanted most – a relationship: “I’ve learned that I can get things if I work for them; I can get almost anything. I just have to work a bit longer and maybe a bit different and I can get what I want. But this is different”.

At the time of her final interview, Rina was 21 years old and lived at home with her parents and two younger sisters. She enjoyed “music and movies and reading” and also loved swimming. Rina had severe spastic quadriplegia, GMFCS V, some uncontrolled movements and reflexes, and her speech was challenging to understand at times due to dysarthria. At the time of the study, Rina felt that she was adult in some respects but not in others. She associated adulthood with “maturity and independence”, but knew that her own level of independence would be different to other emerging adults. She said, “I can’t do things by myself, but I have to become a manager, a manager of my supports, and that will be a big step towards me being an adult”. She also associated starting work and earning her own money with adulthood: “I think that getting a job will be a big milestone, because it’s about financial independence which I think is a feature of adulthood”. Rina was making important steps towards adulthood, but wondered whether she would achieve all her goals.

As a child and teenager, Rina had always attended mainstream schools and had little contact with other people with disabilities. She attended private primary and high schools where she felt like a “square peg in a round hole; it just didn’t work” because “everyone was the same...they had the same background”. She said, “I felt
ignored, I learned that ignoring is a form of excluding...I just remember not having friends, not being teased, but feeling ignored and not fitting in, in a place where everyone fitted in”. For her final two years of school, Rina moved, by her choice, to a selective public high school for girls which she “loved”, stating that “because everyone was so diverse...I just had my own diversity”. Here she found friends, commenting that she “felt like I belonged somewhere, which was the first time that had happened for a long time”. Rina was pleased that she had proactively sought to remove herself from a negative environment, and took this lesson with her into emerging adulthood: “the move was good, because it showed me that if there’s something wrong in your life and it’s quite external, you can change it. It can be better; life doesn’t have to be shit”.

Rina used a power wheelchair to get around home, university and the community. She could access the community independently using accessible taxis, but had experienced them being at times unreliable, and she found it frustrating that so few taxis were accessible. This often increased her waiting time: “will I be waiting for two minutes like my elderly aunt who can catch any taxi, or will I be waiting for two hours?” Taxis were also much more expensive than the other forms of public transport accessible to most people, regardless of being entitled to half-price fares. Rina’s parents would often drive her places she wanted to go, but this required them to be available, and also required Rina to fit into their schedule. Rina found it frustrating that her friends and sisters had “spontaneous” lives that she associated with being young. They were able to drive, jump on a bus, or get a lift from friends whenever they liked, but for Rina it was different. All activities involved detailed planning in terms of timing, access and facilities. Rina felt that she did not have the freedom that other young people had to do whatever they want when they want; it was not possible to “just hop in a car and go and forget all about it”. She felt disappointed that she would never have the opportunity to drive, to “work at a boring casual job”, or to participate in team sports.

Rina’s parents both had successful careers, and this had enabled them to provide significant resources for Rina. She had had little contact with the public health care
system or community-based therapy services, instead receiving regular private physiotherapy at home. Rina felt that public services needed to be “much more efficient” and she felt “lucky not to have to rely on services, like public services”. Rina had a “good relationship” with her parents and felt they had made “sacrifices” to ensure they were available for her, for example by working from home. She felt she had “a lot to thank them for”, however did find certain family dynamics difficult because of the extensive assistance she needed. She said:

_I have to have more contact with my parents than my friends do, and because of this I get frustrated with them more easily...I think as a family we need to move the way we see each other, to realise there are four adults living here now, and I don’t think we’ve quite reached that point yet._

Rina also found it upsetting that her sisters’ lives were very different to her own, especially because they were younger than her. They both had “a great amount of freedom” and one had recently travelled overseas for a ‘gap year’. A year working or travelling after finishing school and before starting tertiary studies is not unusual for young people in Australia. Rina would have loved to have the choice to have a ‘gap year’ and travel overseas alone, but she knew it was unrealistic. Rina felt that her sisters had very different lives because they were able to have “secret lives” that their parents did not know about. For example they could choose not to give details of where they had been or who they spent time with when they were outside the home. In contrast, Rina had “no secrets”; her parents had to know about her life, they were part of every aspect, including her personal care. She said, “I just feel my parents know an unhealthy amount about me”. Rina also found it “demeaning” that she constantly needed her parents to help her, stating she could not even “stay mad at my parents for a sustained amount of time...I can feel so angry, so angry, but I still need them”.

Rina was working towards gaining greater independence by getting attendant carers to assist her with personal care. She felt that, at times, her parents forced her to be more dependent than she needed to be:
I want to have more independence than I currently do. I’m going to have to make the transition sometime between being supported predominantly by family to predominantly by attendant carers. And now is a good time to start it I think.

Unfortunately, gaining access to attendant care funding was very difficult unless you were “in crisis”, and Rina was “clearly not”. She remained on a waiting list and was doubtful whether she would be able to secure government funding while she still lived at home. She felt “lucky”, however, that her family was in a position to be able to advertise for private attendants, and she had recently started advertising in the local paper. It had taken some time for her to negotiate with her parents and for them to understand how important this increased independence was to her. She said, “I’ve come a long way in getting my parents to agree to that and support that so there’s been some sort of shift”.

Moving out of home was something Rina wanted to do in the future, but this was not a priority while she was still studying full-time at university. Rina knew that moving out of home and being supported solely by attendant carers would bring a whole new set of challenges, but it was something she was determined to work towards in the future. This was despite others being sceptical about whether it would be possible:

Assistants are good, but they are not perfect. That’s why moving out of home scares me, because everything will be so routinised. For example, I really like sleeping in...my definition is not sleeping late, but not knowing when you’ll get up. And sometimes I resent that when I move out that will just go... the lack of flexibility really scares me, the concept of being so dependent. It’s quite scary but I don’t think it’s scary enough to make me not want to move out....it’s something that I know that will happen for me, but I don’t know if my friends think it will happen...they seem sceptical.

Rina was studying the third year of a challenging full-time university degree. She was doing extremely well in her studies and had found that hard work, planning, perseverance and financial resources allowed her to achieve most things at university. Rina had to work very hard to complete the academic demands of her university course. She received extra time and a scribe for exams, as well as a
practical assistant on occasion at university. Rina also required “clerical” assistance to complete her assignments, and her family paid for a private scribe. She wished it were possible to be more independent in this area. Rina knew that many people with physical disabilities utilised voice recognition software to improve their independence in using computers. Unfortunately, however, she had not had success with assistive technologies due to her dysarthria. Relying on assistance from others to complete the physical tasks of preparing her university assignments made Rina feel “constrained”. She said, “I need to be ready at a certain time...I need to be ready in advance, I have to have done enough reading to write...this is very stressful for me”. She was frustrated that her disability meant she could not do anything at the last minute, as she knew many of her peers did:

I have to be more organised than the average person; you [the interviewer] are probably organised, but it’s a choice for you. I can never do an all-nighter...it makes me different from my friends, who just do stuff the night before. My friends told me I should just try it, but I can’t.

Rina had been told by academic staff at her university that she should study honours and get into research. She wondered whether this was because she had outstanding academic ability or whether it was because academic staff did not believe she would be able to succeed in her career because of “barriers in the workplace”. Rina worried whether she would be able to gain graduate employment that matched her intellectual ability because of the severity of her physical disability. She believed that if she did struggle to find employment, her “disability will have quite a lot to do with it”, in terms of employer’s negative perceptions. Rina thought that potential employers would expect her to prove herself more, just to be offered a chance of employment:

I feel that even though I have a better transcript deservedly [than a peer without disability], that if we went for a job together...employers would look at me going “well she has to prove more”...there’s still that pre-judgement that people have before they get to know you...like I guess “is this person even worth getting to know, there are so many people out there, why them?”. I have to be even better than other people who don’t have my obstacles.
Should she be successful in securing a position, Rina knew that her day-to-day work life would also be challenging. She said, “I do know that I’ll have barriers in the workplace...and I feel confident that I will develop the strategies to overcome them. I just don’t know what those strategies will be”. Her experience during a short internship made her realise just how challenging her work life may be. Although she “loved the experience”, she found it very stressful and would spend time at home catching up on tasks because they took her a long time to complete. While she found having to “compensate” in this way frustrating, Rina thought it would be worthwhile if she had a job she loved.

The strategies of hard work and organisation which had paid off in the areas of study, work experience and at home, had not worked as successfully for Rina in the areas of friendships and intimate relationships. While she had some friends who did not have disabilities, and participated in some leisure activities like occasional movies, music and parties outside of her family, she wondered whether these relationships were truly “reciprocal”. She said, “I have people that value me, but they don’t need me...they like me a lot, but they are still more important to me than I am to them”. She wanted friends who were her equal and felt like she “needed” her friends more than they needed her. Rina was frustrated that she had to rely on friends for practical support when they went out together. This made her feel “inadequate” and she wondered, “how can I prove that I’ve got something to give, because of my disability?”.

When Rina commenced university, she was “very very excited, very positive” as she thought diversity at university would be welcomed and that she would have opportunities to make new friends, including with young men, who had not been at her school. Unfortunately, Rina’s experience was different and she continued to face challenges in forming close friendships. She felt the physical layout of her university lecture theatres contributed to this, as she could only sit in accessible areas and could not choose to sit close to her peers. Rina even joined a number of
university social and volunteering clubs trying to meet people and find a “magical connection”, but found this both “exhausting” and unsuccessful:

I just found it not so easy to make friends at uni as I thought it would be...this was a big disappointment in first year...I do have friends I just don’t have the close connections...I’ve found people very stretched. They all have to study and they have to work. They have their own friends, keeping old friends, trying to make new friends, relationships, everything. Everybody is not as time rich and free as I imagined them to be.

Rina “began to feel something was missing” and wished for contact with other people who “could understand what I’ve been through”. She attempted to connect with other people with disabilities through organised social forums. However, she found this experience disappointing, both because the forums took place so rarely that it was difficult to form “meaningful connections”, and she did not meet people who shared her goals. She said:

I was really disappointed. I found that people didn’t seem to share my dreams and aspirations, [they] didn’t have high aspirations for themselves... I just felt that they didn’t want the same things out of life that I did.

Rina was keen to see more opportunities for young people with disabilities to connect with each other in an “informal way” which mirrored what “any other person that age would want”. She had observed a local disability service provider trying to set up social opportunities, but felt they had focused on financial, practical and support “barriers”. Rina believed that while organisations continued to focus on such “barriers”, well-meaning plans would not turn into actual outcomes: “nothing is going to happen”.

Rina really hoped her future would include an intimate relationship. However, given how hard it was just to form friendships, she wondered whether this would ever happen for her. Her lack of a previous or current relationship had become very apparent to Rina since starting university, as the majority of her peers had experienced relationships. She believed the Internet may hold promise for helping people with disabilities to form relationships, but unfortunately had experienced
disappointment in the past when an online friend she had feelings for did not reciprocate those feelings. She felt this was because of her disability, and wondered whether “only a person with disability would accept me”. Rina faced a constant internal battle to not let her lack of a relationship get her down:

*I thought that if I tried my very best, I would get what I wanted. It might be a longer path, but I’d get there. You just learn different ways. Until uni my life was like that – it might have taken longer, it might have been different, but I could still get there. Uni was the first time I realised just how hard it would be, and there are some things that I don’t know how to find a way..... It’s very hard to tell yourself you don’t want it [a relationship], but you almost have to, just so that your whole life won’t be kind of wasted. There are so many opportunities in life but you’re just hankering after this one thing which you may very well not get... There’s no point wasting your life. So starting off last year, and a bit more this year, I’ve tried to just not concentrate on it as much. It’s really hard, but it’s the only way to live a full and happy life.*

4.13 Hayley’s story

Hayley’s aspirations included opening her own art gallery, overseas travel, marriage and children. However, she was hesitant about whether she would be able to achieve any of these things. She had faced many barriers in the past, and knew that she would continue to face them in the future. Hayley was trying to stay positive about the future, but it was wearing thin: “I will always have it [CP], so there is no time to get upset about it and there is no time to sit and think ‘oh poor me, how hard my life is’.... this life is always moving on and it won’t stop just because you have got CP... [I have to] move past it. [But] that is a very hard thing to do”.

At her final interview, Hayley was 23 years old, and had recently commenced post-graduate study at university. She lived at home with her parents who were both successful business people. They lived in a large home in an expensive suburb. Hayley was an only child and said that “it got boring being the only child”. She generally got on well with her parents, although sometimes they would “nag” her. They would spend leisure time together as a family, for example shopping, going
out to dinner, to the pub, or to a movie. She said that they were “so proud of me and so supportive of me”. She had always tried to do her best in her studies because she said, “if I don’t then I think that I am letting them down”. Hayley talked with her parents about the decisions she was trying to make about her future, but she felt that ultimately she would make the decisions herself. Hayley felt that she was adult in some ways but not in others. She said her mum treated her like an adult, while to her dad she would “always be his little girl”. Hayley’s future goals included moving out of home, a relationship, overseas travel and children. However, she was cautious about whether she would achieve these milestones and knew she would face many barriers along the way. Not the least of which being negative attitudes from society which had limited her opportunities in the past.

Hayley had athetoid cerebral palsy, GMFCS III. She experienced significant involuntary movements which affected her balance and coordination. Hayley attended private physiotherapy regularly along with a physical skills group at a local disability organisation, funded by her parents. Despite these therapies she was facing the possibility of surgery to try to maintain her mobility. Hayley also had severe dysarthria making verbal communication very time consuming and difficult to interpret. Her personal choice was not to use an augmentative communication device, although she had one. She also had a telephone typewriter that would allow her to communicate over the telephone. However, she found this very tedious and rarely used it. Hayley preferred email communication, and following the first face-to-face interview, chose to complete the remaining interviews using email.

Hayley hoped to move out of home within a few years, however knew that this was unrealistic in the short-term. She needed assistance with cooking, cleaning, washing, and also dressing, and was not yet in a financial position to be able to support herself. While Hayley walked short distances and around her home, she had an electric scooter which she used for longer distances at university, and in the community. She mostly travelled around the community with her parents or by taxi, which her mum would arrange. Hayley had experienced difficulties with taxis being unreliable and not arriving on time, or at all, for scheduled pickups.
Hayley had some learning difficulties and struggled throughout primary school, not learning to read until the age of eight, and then worked hard to complete her HSC over two years. At high school, she struggled socially as well, changing schools after her first year to escape bullying from peers at her private girls school, saying “school was hell for me...girls can be little bitches”. Upon leaving school, Hayley received funding to attend a post-school program funded by the state government. However this funding would only enable Hayley to attend a “day program with [people with] intellectual disabilities”, noting “that is not what I want to do”. Because Hayley wanted to go to university, she was not entitled to keep this funding. Her family were in a financial position that she could forego this funding and they were able to support her to attend university. Hayley completed her undergraduate degree in visual arts and had just commenced a graduate diploma in the area of creative arts administration. She was considering whether to convert to a Master’s degree because she thought it may help her to get a job. Hayley’s dream was to one day open her own art gallery. She was worried about spending another year at university though, and said she was “totally over studying”, having been studying continuously for 18 years.

Hayley was proud that she had never failed a subject at university and studied very hard to get her assessments completed on time. Her parents funded the assistance of a private scribe to help her prepare assignments during university, because her severe athetoid cerebral palsy made typing quite slow, and she also got some help with her grammar and spelling. She had experienced challenges when other students felt this placed her at an advantage and they had raised it with teaching staff. At one point, she had to justify the role of her private scribe to the Dean of her course.

Hayley also received adjustments from her university, including alternative assessments to exams, and scribes for note-taking in class. However, she found some teaching staff less helpful than others. Hayley changed majors at one point because “the lecturer was giving me hell because it was all too hard for him”. She
Hayley wished that she would be treated “like the other students, not a special student”. Physical access at the university was also poor and she had to be innovative to access classes and materials. For example, the library was inaccessible, so she would travel to another public library to research instead, and used online resources where possible. Hayley felt that she had not received much support from the disability service at university, saying “they do nothing but make problems”. Examples of the “many problems” she experienced included difficulties accessing note-takers and her classes not being organised in accessible rooms in a timely fashion. Hayley stated that she had to spend a lot of time “organising myself and the uni…all that stuff that I hate to do but have to do”. Hayley worked very hard to do well at university, and faced extra challenges because of her disability. Despite the amount of effort she put in, she felt frustrated that those people employed to help her did not seem to put in similar effort.

Hayley’s negative experiences of service provision continued into the area of employment. She had been involved with a DES provider for over two years, and still not had any paid work or volunteer work experience arranged through them. The places they had approached for work experience did not eventuate because they saw Hayley as an Occupational Health and Safety (OH&S, now known as Work Health and Safety in Australia) “risk”:

*Nobody will employ me because I do fall over a lot of the time... it is great being an OH&S risk...NOT!... I think that the law about OH&S should be changed because people are so worried about it they are forgetting about people like me who are an OH&S risk but who have got brains.*

The DES provider had also asked her to consider a supported workplace, or community day program, instead of open employment, which made her “really mad”. She said, “both places that I went to have intellectual disability people working there and it was not for me”. The only work Hayley had ever done was with a family member, assisting with filing and book-keeping for short periods over her university breaks. She did not enjoy this work. Hayley found it difficult to “not have
anything to do” and “depressing” that other young people had jobs while she did not. She said, “if they can do it I can do it too”, and so had started to take things into her “own hands” and apply for jobs and work experience without the assistance of the Disability Employment Service. She was unsure, however, about whether her proactive approach would lead to an opportunity, as she had been “knocked back” so many times in the past:

I want to get a job in the art world, but I need to have a key to get into the art world. I have written many emails and letters off to many galleries. I need some work experience but I can’t get any, I will even do some volunteering work.

During emerging adulthood, Hayley also had some difficult experiences in terms of friendships. She had come to realise that people who she believed were friends were not true friends. She had some friends from school “leave me behind”, and others where she had to “do all of the hard work” to maintain the relationship. Hayley tried to meet new friends at university, but said that it was “like a ghost train for meeting people”. She found it difficult, noting that “people judge me” and while “I can see past my CP, other people can’t”. She had even had peers at university say to her “why are you here?” Hayley really wished that she had some friends “to just hang out with”. She said, “I wish that I was not an outcast with people my own age - to make friends rather than being so lonely”. Hayley had one friend who also had a disability who she would see occasionally to watch a movie with, however much of her leisure time was spent with her parents or watching DVDs.

Hayley was especially focused on finding a boyfriend, and said that she was looking for someone who was “husband material”. She also wanted to have children “before I am too old to look after them”. However, Hayley wondered whether a relationship and children would ever be part of her life; she realised how hard it was to meet people and said, “I probably will never get married and have children”. This was something that Hayley found particularly difficult to cope with, and so she stated that she “hides behind studying”. Hayley believed that “society looks down on people with disability” and thought that people who do not have a disability
avoid those that do. She said, “it is like we are sick and other people don’t want to get our illness from us….society needs to change their perceptions of people with a disability”.

Hayley had aspirations for her career and personal life, however, she again wondered whether these goals were achievable as a result of factors outside her control. She knew that other people and circumstances would influence the choices and experiences that she would have in the future, and not often in a positive way. Hayley stated that she was determined to keep “fighting for my rights” and trying to achieve her goals despite the barriers she knew she would face: “I am learning that people will always put me down but I have to rise above them…I have to make my own path through my life because nobody will do that for me”.

### 4.14 Daniel’s story

Daniel’s goals included gaining full-time employment, moving out of home and perhaps some independent travel. He was cautiously continuing to pursue these goals, but had faced many barriers and knew these would continue into the future. Daniel had been searching for full-time work for many years without success, and hoped that a postgraduate university qualification may increase his chances of being offered a position. Daniel had cerebral palsy, Asperger's Syndrome, and speech and communication impairments which he felt “definitely” created barriers in the workforce. Even so, Daniel felt that he could only keep trying to reach his goals, and “wait and see what will happen”.

Daniel was 26 years old at the time of his last interview and considered himself to be adult in some ways but not in others. He defined adulthood as “taking responsibility for your own actions and having good work”. Daniel was an only child and lived at home with his parents. Daniel looked forward to moving away from home “one day”, but staying in the same area as his parents. He “hoped” this would happen soon, but was unsure about whether this goal was realistic. Daniel needed assistance from his parents to do some personal care tasks, including doing up
buttons and shoelaces, and they also looked after all household duties. However, he was able to manage his own money and to travel independently on public transport. This was a fairly new thing for Daniel, as up until the age of 22 his parents had driven him everywhere he needed to go. He said, “they worried about me, but now my parents let me go by bus”. He enjoyed the independence this brought, and also liked not having to “rely as much on my father”. Daniel generally got on well with his parents, but stated he was “closer to my mum than to my dad”. Daniel particularly enjoyed travelling overseas with his parents each year to visit family. He hoped that “one day” he would travel independently. Daniel had mild cerebral palsy, GMFCS level II, but he did not know what type of CP he had. Daniel also had Asperger’s Syndrome and speech and communication impairments. He found expressing himself difficult, and mostly used short sentences in response to specific questions posed.

Daniel attended a support unit within a mainstream school during the early years of his schooling, but was “integrated” into mainstream classes in later primary school which he found “wonderful”, because “you’re treated like any other student”. Daniel said that when he was in mainstream classes he “felt really good about myself”. Daniel went to a “pretty normal high school” where he received assistance from a special education teacher who he stated “helped me to organise note taking and someone to help me carry my laptop computer”. In the main, Daniel felt that he was treated like other students without disabilities at school, although he did experience some bullying which “really annoyed” him.

Daniel continued his studies at university and graduated with an information management degree two years prior to his interviews commencing; he was a “qualified librarian”. Daniel received assistance from the disability service at his university and said they were “excellent” and “very good to me”. He received help from note-takers in all his classes and was given alternative assessments instead of exams.
Despite successfully completing the course two years previously, Daniel had not yet managed to find full-time work in the area. He said, “it’s so hard for me to get a full-time job, I’ve applied for so many jobs that I haven’t been successful...there is a lot of competition”. He had been to “lots” of interviews, but with “no success”. For this reason, Daniel returned to university part-time to study for a Master’s level qualification, saying “I hope it will be easier to find work because I’ll have more skills”. It was Daniel’s mum’s idea that he return to university, but Daniel was initially “hesitant”. He “didn’t know whether it would be worthwhile”, which he equated with whether it would actually lead to him finding employment. Daniel was frustrated that he had not yet been able to secure full-time work. He had decided to pursue an accounting role instead of a librarian role in future, because he thought that his speech difficulties had “definitely” played a role in him not having been successful in gaining work earlier. He said, “library takes a lot of communication. It does, it really does”. It was very important to Daniel to find full-time work and he was still pursuing this goal, but he also knew that he would continue to face barriers, the largest being the challenge of finding an employer willing to give him a chance.

While studying part-time, Daniel also worked one day a week at a non-government disability organisation that he had been involved with since he was a child. His work involved updating a website for youth with disabilities. Daniel also worked one day a week at his local newsagency, where he entered stock orders onto the computer system and did newspaper returns. Daniel had got both jobs with support from a DES provider. He also knew people at both the disability organisation and newsagency prior to starting work with them, which he thought had helped him to secure the positions. Daniel generally found the employment service very helpful and was pleased that they had let him make his “own decisions”. However, he was becoming frustrated that even after having been involved with the service for five years, he was yet to gain full-time work. Daniel continued to attend the service one day a week, where he would do practice interviews, call potential employers, and prepare job applications, with the assistance of an employment officer. While he enjoyed both of his part-time jobs, Daniel had “nothing much” to do for the rest of
the week and wished for full-time work that matched his qualification level. He stated that he wanted full-time work so that “my time would be occupied, less empty hours”.

Daniel spent much of his free time walking around the large capital city near his home. He said, “I’m a city person”. He would travel into the city independently by bus and frequent coffee shops, where he would get to know the staff and they knew him by name. He would also meet up for lunch or a movie with a friend from high school. Daniel wished that he could see more of his friends, “but they are busy with work”. Daniel was also involved in some supported leisure activities for young people with disabilities. He attended a local dance class for people with disabilities which he said made him “happy...I get to dance with a lot of nice girls...everyone says I’m a star”. Daniel had also recently started attending a “social group for young people” with Asperger’s Syndrome. The group would go out for meals together and visit local attractions. Daniel enjoyed being involved with this group; especially noting that it gave him “the opportunity to meet new people”. However Daniel wished that there was a social group closer to his home, as he had to travel quite a distance to participate, which meant he could not attend as often as he would have liked. Despite these supported activities, Daniel still spent much of his leisure time alone or with his parents. He would listen to music and use the internet to keep up to date with news and current affairs. He also went to the gym with his mum, although he did not enjoy this. He said he only went “because my mum asks me to...she says it is good for me”.

Daniel really wanted a future that would include full-time work, moving out of home, and perhaps some independent overseas travel. It was clear from some of his comments that he also wanted an opportunity to have a relationship and family of his own, although he did not feel comfortable speaking in detail about this. Daniel was unsure about whether he would achieve his goals for adulthood, having faced so many barriers in the past. For the time being, Daniel had decided to keep working towards them and “wait and see what will happen”.
4.15 Mitchell’s story

Mitchell’s aspirations included finishing his HSC, further travel, and gaining work. He knew he would need assistance to move into a career and was cautious about whether services would provide him with the help he needed – past experiences of education services had been inadequate. Even so, Mitchell was willing to continue pursuing his goals, and trying not to worry about the barriers he knew he would face: “I’ll deal with it as it comes...I have to...because if I got stressed about everything I’d be a mental bag by now”.

Mitchell was 19 years old at his final interview. He lived at home on a small rural property with his mum and two brothers, one younger and one older than himself. His older brother spent much of his time away from home studying at university, only returning during summer and winter breaks. Mitchell’s parents had recently separated, however his father lived close by. Mitchell and his family lived in a small community about an hour by car from the nearest regional centre and about nine hours from the capital city, Sydney. His family were well known in the area, as his dad was the local general practitioner. Mitchell liked the rural lifestyle and people: “people in the country are more laid back and not in such a rush”.

Mitchell got on well with his family and they spent a lot of time together; he had never been treated differently because of his CP. They had travelled a lot as a family, both in Australia and internationally. Mitchell’s mother felt that travel was an important educational experience. She said “travelling is worth so much more than sitting in a classroom anyway”. Mitchell said “my parents have shown me the good life of travelling”, and he was keen to travel more in the future, probably with his brother. Mitchell was aware that his parents had provided him with experiences that were beyond the reach of most Australians. Mitchell and his family also enjoyed fishing, and playing pool, board games, chess and cards. Mitchell thought that being an adult meant “becoming mature”. When asked if he thought he had reached adulthood, his response was “yes and no”.

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217
Mitchell had spastic quadriplegic CP. His GMFCS level was III and his legs were more significantly affected than his arms. At the time of the study Mitchell walked using a walking frame, after having had hip surgery a year earlier to relieve pain in his hip joint, which also dislocated regularly. The surgery was successful in reducing his pain, but was not as successful as he and his family had hoped in improving his mobility. He spent many months using a wheelchair, which he said was “annoying, because I didn’t have much independence”. Mitchell thought he would probably need the walking frame as a permanent mobility aid to “give me a little bit of support”. Without the frame, Mitchell would have frequent falls: “sometimes I can go for a couple of weeks without falling and one day I can fall five to ten times”. He found the frame gave him some independence and was pleased that he now only needed to use a wheelchair for long distances.

In an attempt to further improve his mobility following surgery, Mitchell continued to see a physiotherapist twice a week. Mitchell had had a “pretty ordinary” experience with the health care system: “when I was young I was in and out of hospitals a lot to try and figure out what I had exactly [his diagnosis]”. Mitchell recalls that he had significant health problems as a young child that led to him developing CP. Mitchell explained it like this: “my brain sort of poisoned itself … and so the message from here to here doesn’t get there properly”. While there was a local physiotherapist who was able to come to their property, Mitchell found it frustrating that his family usually had to travel very long distances to access health and other services: “living in this rural area we are far from any major city so if we want help from health services, we have to travel down to Sydney...they don’t exist around here”. As a result, when he was a young child, his family was separated for long periods. Mitchell spent significant periods of time in hospital and his mother would stay in charity accommodation nearby, while the rest of his family stayed at home.

Since childhood, Mitchell and his family had been involved with the local Scouting group. He was very proud to have recently received a Queen’s Scouting award; the highest youth award achievable within the Scouting movement. This award was
presented by the Governor General, the Queen’s representative in Australia, and was only awarded to around 30 other people in NSW in that year. Mitchell spoke of having to do outdoor adventure, leadership, personal growth and community activities totalling over 300 hours, and meet the same criteria as “able bodied” people to receive the award. He enjoyed adventure activities including white-water canoeing, abseiling and rock climbing. Mitchell said, “I really like Scouting because it teaches you different skills for life, like determination, loyalty and other skills... I like everything about Scouts and everything it stands for”. Unfortunately, he had recently had to leave Scouts as he had reached the upper age limit for Venturer Scouts, and Rovers, the Scouting group for 18-25 year olds, was not active in his area.

Since leaving Scouts Mitchell said he had time for “more study”. He was studying the second year of his HSC, having completed half of his subjects the previous year. Mitchell decided to complete his HSC over two years instead of the usual one because of the significant amount of time off school required while he was recovering from surgery. Mitchell received some adjustments during his exams, including extra time, a scribe, and the option of completing each exam in two sections on two different days. He found it difficult to work with the scribe, because “it takes too long... by the time he’s finished I lose concentration or my train of thought”. Overall though, Mitchell stated his school was “pretty good I have to admit, but as every school it has its ups and downs, most of the teachers are great and are really nice”. He had however experienced barriers in getting access to support in the past, and remained cautious about whether support would be implemented when it was promised:

*When I first started school the teachers thought that because I had a physical disability that I also had a mental disability and so they just stuck me in the corner. I have had so much promised to me over the years by schools and then never seen [that I] have lost count. So if you say that you are going to do something, do it! Don’t say that you are going to do something and do nothing.*
Mitchell had been involved in lobbying for additional support for students with disabilities within the education sector while he was at high school. Some of his key recommendations were to work with each student “as an individual”, and to make changes to the curriculum so that all students can “get involved”. He had presented to teachers, funding bodies and other education professionals about how “they could make things better for the average disabled person”. This opportunity was organised by one of Mitchell’s previous school teachers who also taught and conducted research at the nearest university. Mitchell felt it important to be involved in these sorts of activities when opportunities arose, as he did not want other students to have to wait for help as he had in the past. He said, “[I do it] so people after me don’t have to deal with the issues I’ve had to deal with. Otherwise it gets nowhere, it just keeps happening over and over and over...” Mitchell hoped that his involvement in pushing for better educational services had led to some changes “for the better not for the worse”, but his own previous experiences had made him wary about whether positive changes would be implemented.

One example that was typical of Mitchell’s experience was when he had waited “two to three years” to receive a laptop which he had been “promised”. He only received the funding for the laptop after coincidently presenting to the NSW Department of Education staff responsible for the funding at a forum:

_Luckily the person who gives out the funds was there and one of my points was “if you’re going to promise funding, then actually do it”. And then she came up to me afterwards and said, “here’s my number”. If you get the school to give the paperwork in, I will get it done”, but the school still took like two or three weeks to get the paperwork in ... they did it eventually and then I got a brand new laptop._

Mitchell used the laptop for note taking in class and found it very helpful. He said: “my typing speed is two or three times faster than I can write”. However, the laptop remained the property of NSW Department of Education. Mitchell was required to hand it back when he left school, leaving his family to fund the purchase of a personal computer. The laptop also generated criticisms and questions from his student peers at school as they questioned why he got to use a laptop or got to have extra time in his exams. This “annoyed” him greatly, as “even with the benefits
of a laptop or extra time] it doesn’t outweigh the disadvantages [of having CP]”. He said, “they see me working on my computer and they say ‘you’re lucky’, and I say, ‘Do you want to swap bodies? I’ll swap bodies without hesitation’”.

Mitchell was also frustrated by mobility and access issues in and around his rural township. Despite the local Council having an access committee whose role was to promote physical access improvements, Mitchell and his family had seen no positive changes over a long period of time:

We’ve been here for 10 or 12 years and nothing has changed...even the disabled toilets...it’s just got an ordinary door... you can’t even get a chair in there and there’s definitely not enough room to get in and turn around.

The access problems extended to moving around the community on public transport, which was very limited in the area:

It’s always a problem trying to get public transport around here; it pretty much doesn’t exist... [There are] buses, but they are not reliable and they only come a couple of times a day. Taxis, but they cost a fortune.

Mitchell was entitled to half price taxi fares, which he said was “good for short rides, but it still costs a fortune if I have to go to [other suburbs] every day to go to work or shopping or something like that”. While he used taxis on occasion to get around locally, more often than not Mitchell said, “Mum drives me around or Dad”. Mitchell said that he would “eventually” like to try to get his own driver’s licence and he had explored the process: “well first I have to get a medical to see if I can or not ...”. Mitchell was cautious not to get his hopes up and was aware that he may not be able to drive due to his startle reflex: “when something startles me... my hand will go off the wheel and my right foot goes down which doesn’t help...”. Mitchell was not “really” concerned if he could not drive and said that he would “deal with it as it comes”.

Mitchell had started considering his options for life after school, however had not made any firm decisions. He had been told about a NSW Government funded Transition to Work program, and was planning on being assessed for possible entry
into this program. Mitchell described the program as “the Government supports me for two years looking at different options”. He was considering possibly working in a bank in the future, or as a travel agent. Mitchell was also interested in computers, however did not think he would like a career in this area: “I like computers, but I’m a very social person too, so I can’t see me stuck in front of a computer all day... that’s why I’m thinking banking or travel agency where you actually talk to people”. Mitchell was cautious about whether the Transition to Work program would be able to assist him to achieve his goals, although he hoped it might help him get some work experience and make a clear decision about his future. His family were unsure how the Transition to Work program was structured. His mother said, “we’re still trying to get a grip on how the whole system works...There are obviously boundaries and they’re not very clear on what they can and can’t do”. Their previous experiences of service delivery had made them wary of expecting significant outcomes from this program.

Mitchell was considering the possibility of going to university sometime in the future, however was not sure what he would like to study. He said, “that’s why I’d like to do Transition to Work first to see what I want to do”. Mitchell also knew that he would have to travel a distance to do this. He said, “all the universities around here are on the side of the hill... so that is not very accessible”. Mitchell also knew that finding work in his local area may be difficult; “there’s not much work around here”. He was open to moving to a large regional centre about five hours away from his home sometime in the future, either for work or to study at TAFE or university. He said he “could never live in the city”, having loved the rural lifestyle of his youth. Mitchell thought he would be happy to live in share accommodation when the time came to leave home, and that he would be capable of living independently. He said, “I’m pretty good with everything except hot liquids”, having experienced a couple of significant burns in the past. However, Mitchell was in no hurry to move out of home, saying “then I’d have to cook and clean and do my laundry”.

Mitchell was frustrated by the impact of his CP on his ability to participate in activities with friends and peers. Mitchell had not experienced significant bullying at
school, except for the taunts about him receiving adjustments. He recognised that many students with disabilities are bullied and said, “I’ve been lucky”. However, he felt that he was less and less able to participate as he got older and this made him feel “different, sad and angry”:

*I find the most annoying thing about having CP is that when your friend says “let’s go play a game” of something, no matter how much you want to join in you know that you can’t.... I have spent so many PE [physical education] classes sitting on a bench watching people playing sport that I was unable to play. [I] felt left out, forgotten, or back to the big picture, so different, that I was unable to join in with my classmates and friends ... When I was younger I was able to partly join in. But now, no matter how hard I try to act normally they still react to me differently, even my oldest friends.*

While Mitchell communicated with some old friends by email or phone, he only “caught up with” one friend who was still in the local area. As he got older, Mitchell was feeling more and more isolated by his CP, especially as most of his friends had already left school. He hoped for a future that would include more travel, friends and a job he enjoyed. However, he was feeling unsure about whether he would be able to achieve all his goals.

4.16 Paul’s story

Paul did not really have his own goals for emerging adulthood and he was ok with that. Rather he was happy to be following a routine that was directed by other people; in particular his parents and service providers. Support was available to assist Paul to participate in work and leisure activities, and these activities took place in structured environments with other young people who had disabilities. To Paul, this was just fine: “I’m happy where I am”.

Paul was a month short of his twentieth birthday at the time of his last interview but believed that he was not yet an adult. He thought other people treated him “sort of” like an adult. Paul lived at home with his mother and father, and his only sibling, a sister who was two years older. Paul “got along alright” with his parents. He usually got on well with his sister, however did say “she’s the annoying one...
bosses me around all the time”. Sometimes their parents would go away and leave Paul and his sister to look after themselves. Paul enjoyed this, saying “I get to have fun with my sister”. He felt comfortable being at home with his sister and also stayed at home by himself for short periods of time in the afternoons when his dad was working late. Paul said his dad would often call “to check what I’m doing”. At home, Paul spent a lot of time watching television and DVDs, particularly surfing DVDs. He also enjoyed computer games and would spend many hours playing them.

Paul had spastic hemiplegia, GMFCS II, which significantly affected his right arm and leg. He found the severe spasticity in his right hand particularly frustrating: “That’s why I have trouble, I need to try to find out what’s going on with it, it’s very difficult to stretch”. Paul also had an intellectual disability which contributed to his interviews being quite structured, with little detail in his responses. He also had epilepsy.

Paul had attended the local public high school, where he was in a support class with other students with disabilities. Paul did not enjoy school and particularly disliked English and Maths. He was very happy to finish “stupid schoolwork” and start working fulltime. Straight after leaving school, Paul started working full-time at an Australian Disability Enterprise – a supported workplace for people with disability hosted by a not-for-profit disability organisation and receiving funding from the Australian Government. Here Paul was responsible for packaging and processing tasks. Paul enjoyed helping his colleagues at work, saying he liked to help people out “anytime they need it”. He got on well with his colleagues and was involved in a lot of friendly banter with them. Paul had also done some work experience for a fast food restaurant in the past which he enjoyed, and he was hoping to do some more work experience there in the future. Paul had also completed a TAFE course one morning a week, learning computer skills. He enjoyed the course and going to TAFE. However, he had no plans to do further study and was very happy to stay in his current workplace in the long-term. Paul said, “yes I want to stay working here”, at one point emphasising that he would like to keep working to 100 years of age.
Outside of work, Paul’s leisure time was spent either with his family, or with groups of young people with disabilities in supported environments. His dad was teaching him to surf, which he enjoyed, and his family had recently returned from an overseas holiday where they had surfed at many different places. Paul was also a keen ten-pin bowler. He played in a ten-pin bowling competition for people with disabilities every second weekend which he loved. He was proud to have come first in the doubles competition. Paul had some friends from school who were also in this competition and he liked catching up with them at bowling. Paul was also a keen football fan, and sometimes went to games to support his team with his family. He had an in-depth memory of his team’s results over several years and was looking forward to the start of the new season.

Paul also attended a conductive education group for young people with disability one afternoon each week. Here he was involved in a mixture of physical therapy and leisure activities. The group had attended dance parties, sports matches and other outings together. Paul had quite a few friends in this group and said, “I get along with everyone”. Paul rarely spent time with his friends independently outside of these organised social activities, or at work. He was excited that he had recently had an opportunity to see a movie with a friend and catch the bus back to his friend’s house without another adult present. When asked if he wished he got to see his friends more often on his own, Paul’s response was “yes, sometimes I do”. In general, however, he was satisfied with his routine participation in supported leisure activities.

Paul was working with a service provider to improve his independence in some activities of daily living, including cooking and money management. Each Friday afternoon a support worker from a local community service came to his house to help him organise a meal for his family. They would make a shopping list, go to the store and purchase ingredients, and then prepare the meal at home. Paul liked that this gave his mum and dad “a break from work”. He liked the opportunity to help others, especially his parents. He said, “mum and dad do it all the time… I’d like to help them out around the house”. He washed his family’s car for them, and watered
the garden. He was looking forward to learning other domestic skills, including washing and washing up, however the spasticity in his right hand made these tasks difficult. Paul enjoyed the opportunity to contribute at home, but had no plans to move out, saying he would “not really” want to. He did not speak with his parents about the future. Paul was happy with the supported work, leisure and life skills activities that others had arranged for him, and he had no plan for a different future: “I’m happy where I am”.

4.17 Simon’s story

Simon’s goal was to reach similar milestones as other emerging adults, but he knew that he would need ongoing support to achieve this. He wanted to continue his work in a supported environment, move out of home into supported accommodation, and hoped to meet a girlfriend through supported leisure activities. While he knew he would always need support from family or service providers, Simon wished for more independence and to feel less “restricted”: “my parents always want to be with me…they’re my bodyguards”.

At the time of his last interview, Simon was 21 years old and felt that he was an adult in some ways, but not in others. He thought that being an adult meant “being responsible for yourself”, which included “doing the right things all of the time” and “not behaving badly”. He said that he was only responsible for himself “sometimes”. Simon required support to participate in most activities, including work, travel, self-care and leisure. He had cerebral palsy; GMFCS level III, although he did not know which type. Simon also had a mild intellectual disability. He was aware of his need for support and happy to accept assistance. However, he hoped for a future that would include similar milestones to his peers without disabilities, including moving out of home and finding a girlfriend.

Simon lived at home with his mum, dad and younger brother and sister. He was not close to his siblings, saying “I don’t really talk to them that much”. He generally got on well with his parents, although he sometimes “got in trouble” from them,
particularly for swearing. Simon could walk short distances, for example around his workplace, using a rollator frame with forearm support. He also had a manual wheelchair and had recently received an electric wheelchair that he could use for longer distances. Simon could independently use the electric wheelchair, but had to rely on others to push him in the manual chair. He was very pleased with the electric wheelchair and how it helped him to get around large places like shopping centres independently. Although he always had a support person with him, it meant a lot to Simon that he no longer had to be pushed around.

Simon required a lot of assistance with personal care. He relied on his parents for all domestic tasks, including cooking, cleaning and washing and he also needed assistance with showering from his mum or dad. His bedroom at home was upstairs and he would either crawl up or his father would help him. Simon said that it was not important to him to be able to do these types of things more independently. He did however wish that he could participate in more leisure activities without his parents as he sometimes felt a bit “restricted”:

One thing I do not like is going out with them [my parents]. I would like to go out with my friends more... I'm at the stage where I don't like to go out with them, you know sometimes it would be good to go out with friends...sometimes they want to take me to the movies but I don't want to go. Out for a drive...but I do not want to go.

Simon had completed his schooling at a local special school, designed for students with intensive support needs. He finished his HSC, but completed Life Skills courses, a modified program of study for students with special learning needs. Simon did not like school; “I got bullied which is why I didn’t like it”. While at school, he began working with a DES provider. They arranged for him to do some work experience at a local Australian Disability Enterprise – a supported workplace for people with disabilities. He enjoyed the work experience and was able to get a position at the same workplace after school. Simon found the transition from school to be quite well organised and smooth. It was also a “relief...because I didn’t like school at all”.

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227
At the time of the study, Simon was working three days a week. He was involved in packaging products and enjoyed the work, particularly the variety; “yeah it’s good here”. Simon saw himself remaining in this workplace in the long-term. He was aware that his disability limited the type of work he could do, and felt that societal perceptions would limit the possibility of him moving into open employment. Simon had thought a lot however about what he would like to do if not for the barriers associated with his disability. While at school he did work experience at a local community radio station. He said, “I love doing radio, actually I would do it for a job if I wasn’t disabled...most people don’t hire people with disabilities to work on radio”.

While Simon was accepting of his need to work in a supported setting, and was happy in his current workplace, he did wish that he could make some more friends at work. He found it difficult to talk with some of the other employees, because they were “a bit too old”. He wished that he was seated with other younger people to make friends as he said he was keen to make “friends my own age”. Simon thought they would have similar problems and experiences and it would be helpful to have someone to talk to. To date he had not had much success in making friends at his workplace; “I try to get some [phone] numbers of people here at work but they don’t seem to want to do that”.

Meeting people and making friends was very important to Simon. He was involved in a range of supported leisure activities. These activities had been identified and arranged by his DES provider and parents. He was in a theatre company for people with disabilities, and had recently performed in a production. Simon greatly enjoyed this but identified that there were limits on what he could achieve in acting because of his disability. He said, “I would like to do more acting but unfortunately my disability is holding me back...I had trouble remembering my lines for that play that I was just in and it’s because of my disability”. Simon was also involved in a social group for people with disabilities. Each Saturday he went out with this group, for example to see a movie or out to lunch. He had one friend in this group, someone who he also worked with during the week. Simon really enjoyed these outings and
found it “boring” to stay at home; he would rather be “going out and meeting people”.

Simon was very keen to “find a lady”. He desperately hoped that one day he would get married and live with his “lady”. He did not have many female friends, which he thought was a “pity”. He said, “I’m single; I wish I wasn’t, but one day it will happen”. Finding a girlfriend and having an intimate relationship were very important to Simon, stating that “I want to know what it feels like”. He sometimes felt upset about not having had experience with relationships. He said, “it gets depressing at times you know, because a lot of women don’t find you attractive when you have a disability”. Simon was seeing a counsellor to help with these issues and found this “very helpful”. He also found it supportive to have a friend in similar circumstances. Simon had maintained a friendship with one young man from his school days. They would meet up “whenever me or him [sic] has a chance”, usually at the local shopping centre. His friend also did not have a girlfriend and was “looking, like I am”. At the shopping centre, Simon stated they would “try to find a lady…but it’s not all talking to ladies, I like to buy things there as well”.

Simon was on the Disability Support Pension, and also received a productivity-based wage for his work at the Australian Disability Enterprise. Simon had “no idea” however about how much money he earned, because his parents looked after his money. While Simon had his own bank account, his parents would withdraw “little amounts” of money for him to spend, mostly on DVDs and CDs. Simon was happy with this arrangement and was not interested in managing his own money, stating “I’m not good at maths”. Simon had a large collection of DVDs and CDs, particularly comedy DVDs. At home, he enjoyed listening to music, watching DVDs, and watching cable television. He also spent much of his leisure time on the internet, talking to people online, particularly young women. He enjoyed talking in chat rooms. Simon was aware that this could be dangerous, saying “you have to be careful because most people, they don’t act who they really are”. Simon’s dad had told him that chatting with people online was “dangerous” and had asked him to take his picture off his online profile. Simon did take his picture down, but
continued talking to people online. Simon would tell people only a little about himself, including his age. Simon would ask young women “whether they have a boyfriend or not”. He had recently met an adolescent girl online who he would speak to regularly, and really enjoyed this.

The two days a week when Simon was not at work, he attended a community-based, not-for-profit organisation where he was involved in artistic and recreational activities. This community service was specifically for adults with disabilities. Simon “hated it there”. He spent much of his time painting, which he did not enjoy. Simon’s mum had organised for him to attend this service, as he was not able to stay at home alone during the day, and both of his parents worked. Simon’s parents and DES provider knew that he did not like it, and had arranged for him to start working four days a week the following year. He was looking forward to this, as it meant he would only have to go to the arts centre one day a week. Simon did not have any plans to stop attending the centre completely; despite how much he hated it. He seemed resigned to having to attend as it was what his parents had arranged for him.

Simon found it frustrating that he was not able to travel independently around his community. Simon travelled to work with other people from his workplace in a taxi. He was picked up from home and dropped off again in the afternoon. Outside of work, he also did not go out by himself. He relied either on his parents or a service provider to take him places. Simon was not able to use public transport independently, and the cost of using taxis was prohibitive. Simon was aware that he was entitled to half price taxi fares for social trips, just like for travel to work. Even so, he said, “they’re expensive; I wouldn’t recommend them...that’s how you lose all of your money”. In addition though, Simon felt his parents did not encourage his independence because they wanted to protect him. He said, “my parents always want to be with me...they’re my bodyguards”.

Just as Simon would have liked to be able to travel independently, he also wished that his parents allowed him to stay home alone more often. He felt that sometimes
his parents treated him “like a child”. He said, “I do tell them that I’m old enough to stay at home and do other things [but] they say there is nobody to look after me”. Simon said, “I’m quite independent on my own” and said he liked staying home alone so “I can do whatever I want to”. Simon’s parents did leave him at home alone on occasion, but only about once a month and for short periods of time. Simon thought that one way of gaining some more independence would be to move into a group home with other young people with disabilities. He said, “I quite like that idea”. Simon thought this would be good because he “can be with people my own age there...and just maybe I could find a girlfriend there”. Simon’s parents, however, were “against that idea”. Simon “didn’t really care” that his parents wouldn’t let him move into a group home at that time and was happy to stay at home for a while longer. He did however hope that this would be part of his future. Simon knew that it was likely most aspects of his life would take place in supported settings in the long-term. He accepted that his life would include numerous service providers and often be led by other people. But he desperately hoped that within this modified context his future would still include similar milestones to other emerging adults.

4.18 Scott’s story

Scott summed up his life experiences to date as “my disability sets me back”. He particularly emphasised the challenges he had faced trying to fit in socially. His main goal was to find a relationship, as he felt this was the means to finding true happiness. He had experienced significant depression and was very “lonely”. Scott had put any other plans he may have once had for adulthood on hold and instead “dedicated” most of his time to an online community as a means of gaining “respect” from others.

Scott was 21 at the time of his interview. He lived with his mother, who was a sole parent to Scott, an only child. They lived in a modest home in a regional area, and Scott had no plans to move out of home. Scott had spastic diplegic cerebral palsy, GMFCS III, which mainly affected his legs. His story also included many examples of
challenges with social interactions and restricted interests which indicated a possible comorbid Autism Spectrum Disorder, although this was not disclosed.

Scott walked short distances around his home using crutches. He had a three-wheeled bike which he used to get around his local community – to his work, the local shopping centre and TAFE. He would pedal up to half an hour each way, but sometimes used a wheelchair when he was going to be travelling long distances, for example around large shopping centres. He was able to travel on public transport independently and often used buses; he thought the bus network in his area was “pretty good”. Because Scott was able to walk for short distances he was able to use any bus rather than wait for one that was accessible. He would ask the driver or another passenger to lift his wheelchair into the bus, and climb on himself. He had never had a problem getting someone to assist. Because he was on the Government disability support pension he could travel for a very small fee and “go anywhere I want to for the whole day”. Scott had previously begun the process of obtaining his driver’s licence, and had held a learner’s permit. However, he said “it was difficult for me to drive”. He found driving very stressful and “sometimes made mistakes”. After a few near misses, Scott decided that it would not be safe for him to drive: “it was best for me to stop before I was seriously injured or worse”. Scott was not worried about being unable to drive as he felt he was able to get anywhere he wanted to go using his bike or public transport.

Scott had been very involved in performing arts until age 20. He enjoyed singing and had been in his school choir, a state choral music program for school students in NSW, and also performed at the Paralympic Games Opening Ceremony. He said this was a “great honour”. Scott had also been involved in drama classes for many years and performed a lead role in a local youth theatre company production. He had a “sharp memory” and felt that his ability to remember lines and perform was improved because of his physical disability. He said, “they say when one sense dies on you the others improve. My physical side failed me but my mind increased”.
Scott was no longer involved in performing arts, saying “I guess I’ve kind of retired now”. He said it would be “nice” to perform in another production but “I doubt I’ll get in, my disability sets me back”. He recalled vividly a comment from a past drama teacher: “he said I would be a famous actor if I wasn’t disabled. I didn’t know whether to feel proud or feel hurt”. Scott had at times been asked to perform duties such as selling programs instead of performing on stage. He said, “my disability stopped me there and they got someone else”. In addition to these external barriers, Scott spoke of a “history” of difficulties with interpersonal skills which affected his participation. At one time he offended other students and was asked to leave his drama class. He said, “I have a history...whenever I find something good like an acting class, I always do something to screw it up and I usually get kicked out”. He started at a new class but had to leave after less than a year because the fees became unmanageable. He said, “mum couldn’t afford it so I had to leave. I was very sad. I was really enjoying myself and the other cast members had a lot of respect for me”. Being respected was of great importance to Scott.

Scott found a new interest after having to stop drama classes which he said gave him back the “respect” and enjoyment that he had liked about drama. Scott was passionate about a children’s television and book series and spent many hours finding and collecting memorabilia from online auctions, and was involved in an international online forum for fans. Here he chatted with other adult fans, wrote stories, and developed multi-media productions, doing character voiceovers and narration. Scott was very “dedicated” to this forum and spent much of his time online working on productions and communicating with other members. He had made friends with people from many countries through this forum. He also met face-to-face with a small group of forum members in his local area. They would share a meal, chat and watch DVDs together. Scott enjoyed being a part of this forum very much and it was the activity he liked to talk about the most. He had made some new friends and felt that he was “respected” by most members of the forum. He had, however, again struggled socially within this environment, having been given a warning from the forum’s moderator for making comments that were
perceived to be rude. Scott thought it was just a “mix up” and really hoped he would not get banned, as this would make him “very upset”. Involvement in this forum was extremely important to him, as was the television series and what it represented to him. Scott viewed the main character of the series as his “hero”. He said:

He reminds me of me. He succeeded despite all obstacles. Not because I’m acting as a kid but because when he has troubles they don’t last long and he’s able to get back up and back to normal life. That’s really inspiring.

Scott found it very important to have something to focus on and provide him with inspiration. He had experienced a history of severe depression, even contemplating suicide as a high school student. He was bullied a lot by his peers and said, “high school was very, very bad...a lot of the students teased me”. He also struggled with the workload and felt that this, in combination with the bullying, led to him having two “emotional breakdowns” while at school. Scott felt that he had only been “happy” during drama class, and during a lunch time meeting once a week with a Christian group. He said:

There was a Christian group that got together on Wednesday during lunch time. I went to the lady and spoke to her. She was very kind and I joined the group. I’m not a Christian, I just went along because I enjoyed it and I became a popular member...[it was] one of the only times that made me feel good.

Despite the bullying, Scott worked hard during school to make friends and be nice to those around him, even the students who bullied him. He remembers fondly a time when he helped a person who had bullied him, leading to them becoming friends. He said:

We started out as enemies, but I think I did something to change her mind about me...I think she learned that I like to help people, even my enemies, and we became friends...she started out as a bully but eventually she became a kind and loving person. Sometimes I think that was because of me.
Scott felt this experience had a profound impact on his life, even in the present. He said, “one of my goals in life... [is] if I can change the world for at least one person I’ll die a happy man. I think I’ll die a happy man now”. At school though, these positive experiences were few and far between, and not enough to keep him there. Scott left school after completing his mandatory education in year 10, saying “I decided I had to go before things [the bullying] got worse...I got a school certificate and high tailed it out of there”.

Scott had been studying at TAFE for four years since he left school. He had done multiple courses, recently completing a business studies course. Scott thought he would do at least another year at TAFE and was planning on enrolling again the following year, although he did not have a firm interest in any particular course. Scott’s reason for continuing at TAFE was because otherwise “Centrelink cuts my pay”. Scott’s only work was to deliver the paper in his local area, and at the time of the study, he did not have plans to start further paid work in the future.

Scott had a desire for a relationship and really hoped he would find a girlfriend. He was quite absorbed in this goal as he felt it would make him very happy. He had never been in a relationship, felt very lonely, and found it hard to observe other people in relationships. When two members of his online forum began dating, Scott commented “[I] was a little upset because sometimes seeing people in love reminds me of how lonely I am”. Scott said that he “had been in love three times” with girls from his drama group. He had had some very upsetting experiences and “bad memories”, recounting times when “girls decided to play a trick on me, like pretend to be in love with me just for fun”. This was extremely upsetting for Scott, and he recognised that he was quite “vulnerable”. Scott felt the lack of a relationship was the one thing missing from his life that was stopping him from being truly happy. He said, “all I’ve got to do now is find a girlfriend...and my happiness will be restored, and my depression, which isn’t as strong now, will go away”. Scott seemed to have put any other plans he may have once had for adulthood on hold while he focused on trying to find happiness.
4.19 Chris’ story

Chris only planned to take each day as it came and to “make the best” out of each situation. He had severe cerebral palsy and faced many barriers to participation. While he hoped for a future that would eventually include paid work and a relationship, he had put these goals on hold. Chris was careful not to focus on, or want, things too much. He knew there was a chance he would not overcome the many barriers he faced, and therefore not achieve some of his goals. So for him, focusing on the here and now was “a lot easier to deal with”. He said: “It’s best not to worry about things. I’ve found that life generally sorts itself about, whatever will be, will be…Que Sera Sera”.

Chris was 24 at the time of his interview and he lived at home with his parents and younger sister. He also had an older brother who had moved out of home. Chris had severe spastic quadriplegia, GMFCS V. He used a power wheelchair for mobility, and required assistance with most activities, including personal care. He received assistance from his mother, his sister, and also Government funded Home Care Services. He also had an assistance dog who was both a great help, and great company for Chris. Chris relied on assistance from other people to get out of bed, shower and dress. He said, “my lifestyle right now is pretty regimented…like a whole military style operation”. He relied on other people’s availability and service schedules. Consequently, spontaneity was not, and could not, be part of Chris’ lifestyle. While this was frustrating, he had learnt how important patience and persistence was to his life,

I’ve had to be very patient, with everything in my life, otherwise I’d do nothing. Because everything takes me a long time…I have to be patient to get up in the morning, get dressed, otherwise it would never happen…I can’t do things in five minutes. Five minutes doesn’t exist for me, five minutes turns into two hours…[but] this is my life and this is what I’ve got to work with.

An example of Chris’ patience was having completed his HSC over four years, instead of the typical one. He found this “kind of hard” but emphasised that for him
it was about “persistence – I did it. That is the most important thing”. He successfully completed his HSC and commented he “did quite well actually” but acknowledged that he “got a lot of help”. He also faced and overcame many barriers while at school. At the end of year 10, he and his family had to make the difficult decision to leave his private school and transfer to a local public school. This was the result of a significant change in staff and peers that led to a previously supportive environment becoming an unsupportive one. He said his mum ended up getting “sick and tired” that “the help just wasn’t there anymore”:

...everyone around me just left...teachers left, my aide that was there left and people that came in really didn’t know me or understand what my problem was... and the old principal left. The old principal said, “if there’s anything you want help with, just ask”. The new principal that came in at that time just didn’t want to know [about me]. I was just a serious complication.

At the private school he had also faced a lot of bullying from his peers. They teased him because he was not good at, or interested in, sport, and also because of the assistance he received. They thought the assistance he received placed him at an advantage with his assessments, and accused him of “cheating” when he received good grades. Chris attributed these negative attitudes to “immaturity” and a lack of “understanding”. Whatever the reason, it was enough to make Chris’s experience in the middle years of high school awful. In particular, he became very angry when bullies would invade his personal space:

I used to get hassled a lot...especially when I was going along in my chair. They’d start playing with my [electric wheelchair] control. I used to get really pissed off about that. “I don’t touch your personal things, I don’t invade your personal space, please don’t invade mine”. That is a big thing with me. I like my personal space. I don’t really have a lot of it in my life but what I do have I like people to respect.

In the end, the change of school for the final years turned out to be very positive for Chris, both in relation to receiving the support that he needed, and socially. Chris found his peers at his new public high school to be much more accepting:
I’m actually sad that I didn’t go there [new public school] from the beginning because I would have had a lot easier time….when I went to [the new school] I got into a whole group of kids and I thought that was great and I wish I could have done that from the beginning… I actually think public schools are better because you’ve got everybody [students with many different experiences], unlike private schools… at [private] school I found there was this whole mentality – if you didn’t play sports, if you didn’t do certain things, you didn’t fit in.

Although Chris made friends at his new school, they all went “in different directions” after school and Chris did not keep in contact with them. Chris did have a few close friends he had known since early childhood. He said:

*I’ve got one or two good friends and that’s all I need basically…I think some people, the more friends they have the more it makes them feel validated…I don’t need that validation…I’m not in a rush to make any more [friends]…I’d rather sit with one or two people and have a good conversation than a whole room full of people and try to spend 10 minutes with every person.*

Chris was also happy to stay at home and “hang around” with his mates, rather than go out. This was mostly due to the effort required to arrange transport and assistance. He said, “because it takes so much effort to go out and do something I end up hating doing it…it feels like a chore”. Taxi transport was unaffordable, and public transport was “a waste of time” in Chris’s experience, so he mostly relied on his mother for transport. Although Chris received half price taxi fares, the cost was still prohibitive, especially for long distances. In addition, Chris had experienced taxi drivers refusing to take him on short journeys, because the reduced fare made it unprofitable. This was despite refusing short trips being against the taxi industry regulations in NSW: “they’re not going to be bothered because it is only five minutes here and five minutes there. What are they going to get out of it?”

Chris was frustrated by the lack of support, especially financial support, available to assist families with members who have disabilities. Chris said, “I wasn’t allowed to get any financial assistance or any help up until the age of 16… Before that, it was like the Government didn’t want to know. I have a big issue with that.” Inaccessible transport options were one issue, in addition to a lack of funding for specialised
equipment, home modifications and personal care. Chris’s parents had to purchase most of his equipment themselves, and had also accessed charity support from community groups for his wheelchair and hoisting equipment. Chris knew his dad in particular, was uncomfortable “putting his hand up” for charity, but they were left with no other option. Home modifications were only made possible because Chris’s grandparents had bequeathed him some money. Chris felt it was important that the Government initiate a fund to support the families of children born with disability: “When a child with disability is born, the Government should have funding for that child. Some sort of fund for that child, like a private fund, just to help the parents”. Since the time of Chris’ interview, the Australian Government has trialled, and commenced a National roll-out of such a fund, the NDIS.

Chris had put plans for work and study on hold at the time of the interview, although he had been involved with a DES provider for some time. He found the people who worked at this service “lovely”, but they had so far been unsuccessful in securing him work. Chris also had an issue with organisations designed to “separate” people with disabilities from the rest of society. He felt disability services focused on a person’s disability, while his preference would be for the focus to be on “the rest of you… when you separate that person [from their disability] then you can actually appreciate the whole person”. Chris felt that narrow societal perceptions towards people with disabilities would influence the opportunities he had in the future, and this made him “less ambitious” than he might otherwise be. He said that some people might “call that just a defeatist attitude….but unfortunately I’ve got to learn to live within that world”. Chris had come a long way towards accepting his disability and the barriers he faced, and had worked with a psychologist on these issues for a time, which he found very helpful. Chris had experienced periods of depression as an adolescent when he wondered what he would be able to manage in the future:

*I used to think ‘if I can’t take care of myself, how am I going to be able to do anything else?’ If you can’t take care of yourself you can’t do anything else...how in the hell am I going to do any work?...[but] I’ve really turned a corner about it all....*
Chris now hoped that he would one day be able to find employment. He was particularly interested in the music industry and the area of audio engineering. “I’d like to get some sort of job in the music industry, hopefully something to do with music because that’s where my real passion lies”. He had taken up guitar lessons as an emerging adult, which he enjoyed despite his progress being slow. But he was not actively pursuing this goal of getting work in the music industry; he knew he would have to overcome many barriers to achieve this. Similarly, Chris hoped for a future that might include a relationship, children and a home of his own. However, he had learnt not to focus too much on such goals, but to take his life one day at a time. He had put his goals on hold, as it made his daily life “easier to deal with”:

Eventually I’ll sort things out and the life I’m supposed to have will happen, no matter what. I mean, whether that includes the traditional, you grow up, you get a job, you have two kids, a house in the suburbs, whether that’s going to happen for me I don’t know. Don’t get me wrong, I’d like that someday, certainly wouldn’t hurt...but if it doesn’t happen, then that’s fine. I’m not a guy that says, “I must have a legacy”. I’m like if it happens for me then it happens for me, great. If it doesn’t, it doesn’t. I’m cool with it. Like I said, what will happen, will happen. What won’t happen won’t happen. At least that’s the way I look at my life.

4.20 Synopsis

This chapter has presented the stories of the eighteen emerging adults who participated in this research and generously shared their experiences, hopes and goals. Their stories were constructed through narrative analysis. They include many direct quotes from participants, giving voice to a group of young people who have rarely been heard, and in doing so, answering the first research question: what are the stories of emerging adults aged 18-25 years with CP? The stories are all unique and reflect the varied experiences of young people who were in different places on their journey through emerging adulthood. They reflect differences that stem from variances in age, disability, family life, financial status, roles, past experiences, character and future goals. However, there are also many commonalities of experience, and common challenges, barriers and opportunities that can be
identified within these eighteen individual stories. These were identified through paradigmatic analysis of narratives, which led to the development of 15 themes from the stories. These themes are presented in Chapter Five.
Chapter 5. Journeys of emerging adults with CP: Story themes and theoretical connections

5.1 Introduction

This chapter presents the findings of the paradigmatic analysis of narratives and in doing so answers the second and third research questions. Inductive analysis of narratives was utilised to answer the second research question: what themes can be developed from the stories of emerging adults aged 18-25 years with CP? Deductive analysis of narratives allowed insights to be gained in relation to the third research question: are emerging adulthood and ICF theoretical constructs reflected in the themes developed from the stories of emerging adults aged 18-25 with CP? Both forms of analysis are presented concurrently with the theoretical constructs highlighted within the text of each theme and also summarised in table format.

Within this chapter, each theme is also discussed in relation to existing literature and research. Discussing literature pertaining to each theme allowed a depth and specificity of discussion pertaining to each theme after its presentation to relate each theme to the wider body of knowledge related to that theme. The combined presentation of results and discussion has previously successfully been utilised within narrative inquiry research in similar areas, for example in a study of adolescents with CP regarding their aspirations for the future (Cussen et al., 2012). This combined results and discussion approach has also been identified as “common practice” within broader qualitative methods (Anderson, 2010, p. 5; Sutton & Austin, 2015). While each theme is discussed individually in this chapter, a broader discussion consolidating the key contributions of this research and links with prior knowledge is presented in Chapter Six.
5.2 Summary presentation of themes and theoretical connections

Arnett (2015) has previously referred to the journey of emerging adulthood as a “winding road”. This concept of the journey, with differing paths and roadways was clearly evident in the data and as a result is reflected in the theme titles. Each theme is represented by a conceptual label chosen to reflect various aspects of the journey of emerging adulthood. Within the presentation of each theme, the experience of participants is explored, compared and contrasted, highlighted by examples from the data, and discussed in relation to prior knowledge. Inductive analysis of narratives facilitated the development of fifteen key themes within and across the stories of emerging adults aged 18-25 years with CP. The fifteen themes, providing the answer to the second research question, are introduced in Figure 2 below, and discussed in detail in section 5.3.

|-----------------------------------------------|--------------------------------------|----------------------------------------|------------------------------------------|------------------------------------------|

Figure 2: Themes within emerging adults’ collective stories, identified through inductive analysis

Concurrently, deductive analysis of narratives was utilised to identify and explore whether a number of constructs relevant to the theory of emerging adulthood as previously outlined by Arnett (2004; 2015), and the ICF (World Health Organisation,
were reflected within these themes. Constructs examined included the five features of emerging adulthood: identity explorations; possibilities; instability; self-focus; and feeling in-between. Also considered were the domains of the ICF: body structure and function; activities and participation; and the contextual environmental and personal factors. This process provided the answer to the third research question. Each theme was deductively mapped against these theoretical constructs to identify the extent to which they were present within the themes. A summary of how the theoretical constructs were reflected within each of the fifteen themes is presented in Table 7 below. In addition to the table below, the theoretical constructs within each of the themes are highlighted in detail in section 5.3, and presented in a more detailed tabular format in Appendix J.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Emerging adulthood concepts</th>
<th>ICF concepts</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>The journey to find myself: Identity exploration</strong></td>
<td><em>Identity exploration</em> is core to this theme and was inherent within participant stories. <em>Instability</em> is also experienced by those young people who experience worsening mobility and have to redefine their identity during emerging adulthood.</td>
<td><em>Body structures and functions</em> were rarely mentioned, and many participants knew little about their CP. This is significant to this theme in its absence. <em>Worsening mobility</em> (<em>activity limitation</em>) caused challenges for some. <em>Personal factors</em> including self-concept and confidence influenced exploration of identity.</td>
</tr>
<tr>
<td><strong>Dealing with roadblocks: Resilience</strong></td>
<td>The varied views of participants in relation to their <em>possibilities</em> are central to this theme. Many participant stories reflected high hopes for a future filled with possibilities. Others were more tentative, and a minority demonstrated a resigned view that possibilities were outside of their control.</td>
<td>Clear goals for education, work, domestic life, relationships and social life were present (<em>activities and participation</em>), along with numerous challenges to participation. <em>Environmental barriers</em> including physical and attitudinal barriers influenced possibilities, as did <em>personal factors</em> including levels of (or lack of) resilience, positivity and determination to overcome roadblocks.</td>
</tr>
<tr>
<td><strong>Supporting others’ journeys: Altruism</strong></td>
<td>Stories of participants with positive views of <em>possibilities</em> often reflected a passion to support other young people with disability. These demonstrations of altruism reflected a high level of <em>other-focus</em>, in comparison to <em>self-focus</em>.</td>
<td>Many participants were involved in altruistic <em>activities</em>, including volunteering, mentoring and sharing their story with others with disability. This was a representation of certain <em>personal values</em> and character traits.</td>
</tr>
<tr>
<td>Theme</td>
<td>Emerging adulthood concepts</td>
<td>ICF concepts</td>
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</tr>
<tr>
<td><strong>Inductive analysis</strong></td>
<td></td>
<td><strong>Deductive analysis</strong></td>
</tr>
<tr>
<td><strong>It’s a hard road:</strong></td>
<td>This theme relates to the sometimes difficult process of identity exploration. Challenges experienced by some participants contributed to mental health problems or mental illness.</td>
<td>Personal factors including self-esteem, coping styles, depression and anxiety were present within this theme. Body functions were affected for participants with diagnosed depression and/or anxiety. Education workloads (activities and participation) and bullying (environmental barrier) also contributed to mental health problems.</td>
</tr>
<tr>
<td>Mental health problems</td>
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<tr>
<td><strong>Telling others about my journey:</strong></td>
<td>Making important decisions about whether or not to disclose their disability formed part of some participants’ identity exploration. This was particularly the case for those with milder CP.</td>
<td>Disclosure was particularly an issue for those with less noticeable body structure and function impairments. Disclosure was an issue at school, university and work (activities and participation). Participants held concerns about attitudes, stigma and discrimination (environmental barriers). This at times led to a personal choice to not disclose, despite implications for access to services (environmental facilitators).</td>
</tr>
<tr>
<td>Disclosure</td>
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<tr>
<td><strong>Finding my place:</strong></td>
<td>Participants’ identity exploration included making decisions about friendships and the qualities sought after in friends. Some were concerned about the possibility of developing true reciprocal friendships.</td>
<td>Environmental barriers including bullying and exclusion in the past had made participants cautious about choosing friends, and impacted on the self-esteem of some (personal). Most had a small number of genuine friendships (participation). Those who did not (participation restriction) attributed this to the negative attitudes and ignorance of others (environmental barriers).</td>
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<tr>
<td>Friendships</td>
<td></td>
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<tr>
<td><strong>My journey is limited:</strong></td>
<td>A lack of instability in regard to relationships was identified, in contrast to typical experiences during emerging adulthood. For some, the lack of possibilities in this area caused much distress as they faced the possibility of a future alone.</td>
<td>Most participants had never had a relationship (participation restriction) despite a desire to do so. Previous negative experiences (personal) made some young people concerned whether others would accept them (environmental barrier). Many put in place coping strategies to deal with the distress they felt, however self-esteem was impacted for many (personal).</td>
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<tr>
<td>Romantic relationships</td>
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<tr>
<td>Theme</td>
<td>Emerging adulthood concepts</td>
<td>ICF concepts</td>
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</tr>
<tr>
<td><strong>Inductive analysis</strong></td>
<td><strong>Deductive analysis</strong></td>
<td></td>
</tr>
<tr>
<td>Changing direction and help with navigation: Education pathways</td>
<td><em>Instability</em> was reflected in some stories through multiple changes in study direction. Examples of <em>possibilities</em> and reduced <em>possibilities</em> were also present, often linked to availability of support services.</td>
<td>Both school and tertiary study experiences (<em>activities and participation</em>) featured heavily in stories. Contrasts in service provision within educational settings were evident; some viewed services as an <em>environmental facilitator</em> but for others they were a <em>barrier</em>.</td>
</tr>
<tr>
<td>A bumpy road: Finding the right job</td>
<td><em>Instability</em> during the challenge to find the right work path was evident in some stories. Others reflected a concern that employment <em>possibilities</em> would be negatively impacted by their disability.</td>
<td>Experiences of employment (<em>participation</em>) and unemployment (<em>participation restriction</em>) were emphasised within stories. <em>Environmental barriers</em> to work were clear – including discrimination, and ineffective Disability Employment Services (DES). For one participant, DES was an <em>environmental facilitator</em>. For another, a flexible work environment was an <em>environmental facilitator</em>.</td>
</tr>
<tr>
<td>Controlling my journey: Negotiating an adult relationship with parents</td>
<td><em>Self-focus</em> for some participants was restricted by overprotective parents. Establishing a more adult relationship with parents was important for participants to gain a sense of independence and control.</td>
<td>All participants except one were still living at home, in contrast to most emerging adults (<em>participation restriction</em>). Personal factors including finances and ongoing dependence (<em>activity limitations</em>) contributed to this, along with a decision to focus on other activities first (eg completing study). Some stories expressed overprotective parents as an <em>environmental barrier</em>.</td>
</tr>
<tr>
<td>My crew: Personal care and health services</td>
<td><em>Self-focus</em> was demonstrated through independent decisions to access health services in emerging adulthood or not. <em>Self-focus</em> was restricted for some participants as a result of inflexible personal care services, which reduced opportunities for the spontaneity and freedom that are common during emerging adulthood. Inflexible services also affected <em>possibilities</em>.</td>
<td>Accessing health services (<em>environmental</em>) was not a priority for most participants. Poor transitions and a lack of flexible personal care services were identified as <em>environmental barriers</em> to <em>participation</em>. Some participants relied on personal-care services for their daily <em>activities</em> (<em>environmental facilitator</em>) due to disability related impairments (<em>body structure and function</em>) but services were not ideal and restricted spontaneity.</td>
</tr>
<tr>
<td>Theme</td>
<td>Emerging adulthood concepts</td>
<td>ICF concepts</td>
</tr>
<tr>
<td>------------------------------------------------</td>
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<td>------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Inductive analysis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The open road or a traffic jam: Transport options</td>
<td><em>Possibilities</em> were greatly impacted by availability, or lack of, transport. <em>Self-focus</em> was more easily demonstrated by those who could drive and had a car, and limited for those without independent transport options.</td>
<td>Inconvenient, unreliable and expensive taxi services were identified as an <em>environmental barrier</em> which significantly influenced opportunities for <em>participation</em>. Many participants relied on their parents for transport (<em>environmental facilitator</em>) due to severe functional impairments precluding capacity to drive (<em>body structure and function</em>). Five participants were able to drive (<em>participation</em>) and had access to a car (<em>environmental facilitator</em>), which facilitated personal freedom and independence.</td>
</tr>
<tr>
<td>Funding my journey: Opportunity costs</td>
<td><em>Possibilities</em> were impacted, positively or negatively, by families’ access to financial resources. Opportunities were facilitated through a capacity of families to provide financial support.</td>
<td>Being able to finance (<em>personal</em> <em>environmental facilitators</em>) including private therapy, professional driving lessons, a modified vehicle, and/or private assistants significantly increased the possibilities available to some participants. Limited finances were a barrier to <em>activities and participation</em> for others.</td>
</tr>
<tr>
<td>Off the beaten track: The limits of a rural location</td>
<td><em>Possibilities</em> to access services, education, employment and the community were influenced by the geographical location in which participants lived. Rural locations limited some opportunities.</td>
<td>The geographical location of participants influenced the availability of services (<em>environmental facilitator</em>), education, employment, transport and community participation options (<em>participation</em>). Predominantly, opportunities were restricted in rural areas (<em>environmental barrier</em>).</td>
</tr>
<tr>
<td>Are we there yet?: Clarifying what it means to be adult</td>
<td>The majority of participants felt <em>in-between</em> adolescence and adulthood, in line with other emerging adults. They faced the challenge of accepting that their adulthood may look different to that of their peers without disability.</td>
<td>Participants believed <em>personal</em> traits were most important to being an adult, including taking responsibility, making independent decisions and maturity. Some also included working full-time, moving out of home, and managing their own supports as criteria for adulthood (<em>participation</em>). Functional capacity (<em>body structure and function</em>) enabling physical independence was not viewed as necessary to being an adult.</td>
</tr>
</tbody>
</table>

Table 7: Summary of theoretical constructs reflected within themes
5.3 Detailed presentation and discussion of themes and theoretical connections

This section details each of the fifteen themes in full, highlights the theoretical constructs present within each theme, and discusses the themes in relation to existing literature and research. For ease of identification, theoretical constructs are highlighted in italics within each theme, and superscripts are used to identify which construct each phrase relates to. An explanation of the superscripts utilised is provided in Table 8 below.

<table>
<thead>
<tr>
<th>Superscript code</th>
<th>Theoretical construct represented</th>
</tr>
</thead>
<tbody>
<tr>
<td>EA</td>
<td>Features of emerging adulthood: identity explorations; possibilities; instability; self-focus; and feeling in-between.</td>
</tr>
<tr>
<td>BS/F</td>
<td>ICF body structure and function</td>
</tr>
<tr>
<td>A/P</td>
<td>ICF activities and participation: A - communication, mobility, self-care, domestic life, relationships, social and civic life, education and work; P – these activities in the context of a life situation</td>
</tr>
<tr>
<td>E</td>
<td>ICF environmental factors: support, relationships, attitudes, services, systems, policies, physical environment, products and technology</td>
</tr>
<tr>
<td>P</td>
<td>ICF personal factors: social background, coping styles, past experiences and character</td>
</tr>
<tr>
<td>ICF</td>
<td>Broad ICF domains: activities, participation, environmental factors, personal factors</td>
</tr>
</tbody>
</table>

Table 8: Superscript codes used to identify theoretical constructs within themes.

5.3.1 The journey to find myself: Identity exploration

Participants’ stories reflected that emerging adulthood was a journey of identity exploration$^{EA}$. Deductive analysis within this theme identified two emerging adulthood concepts: identity exploration$^{EA}$ and instability$^{EA}$. The ICF concepts of body structures and functions$^{ICF}$, activity limitations$^{ICF}$ and personal factors$^{ICF}$ were also recognised as relevant within this theme. Many participants viewed their disability as being very separate to their identity. For some, however, physical progression of their disability during emerging adulthood led to instability$^{EA}$ and actually triggered a redefining of identity.
The stories of participants highlighted that at this time of life it was important to discover who they were and what was important to them. For many, this was a journey to ‘find myself’. Rachel stated that emerging adulthood was a time of becoming “in control of your own destiny”. This is reflective of other stories, as a number of participants spoke of having reached a point of being able to confidently make decisions and be in control of their own lives. A central part of participants’ identity exploration as emerging adults was developing an acceptance of their disability, and of who they were as a person separate to their disability. Rachel spoke of a “complete understanding and acceptance” of her disability, while John made the distinction clear between his identity and his disability when he said “there’s the disability, and then there’s me. The disability is part of who I am but as much as possible I don’t let myself be limited”. Similarly, Michael said “I don’t really see myself as different to anyone else; to me it’s just a limp, I’m doing all the same things that everyone else does”. Hayley’s view was “I will always have it, so there is no time to get upset about it and there is no time to sit and think ‘oh poor me’”. She was determined to “make my [her] own pathway through life”. These examples represent the young peoples’ self-concept and sense of worth outside of the presence of their disability. Most participants, during emerging adulthood, showed signs of a healthy self-concept. This is in-line with other research with adults with CP which has also demonstrated that the majority do have a positive self-concept, regardless of disability severity (Gannotti et al., 2011; Magill-Evans & Restall, 1991).

Many participants spoke very little about the physical implications of their cerebral palsy during interviews; their physical impairments were barely mentioned. A few recognised they probably should acknowledge the physical components of their disability more, and take active steps to maintain their mobility, for example through doing exercises that had been prescribed. However, it just was not a priority to them during emerging adulthood. Megan simply said, “I can’t be bothered”, while Michael said, “it just doesn’t seem to happen. I think after 22 years of doing it (exercises) you just kind of get over it”. This finding is consistent with previous literature which has emphasised that modern service delivery must
look beyond body structure and function issues and contribute to preparing young people for all aspects of adult life (Doyle et al., 1994). Similarly, the risk of becoming ‘burned out’ in relation to healthcare has been previously identified in qualitative focus groups with young people with chronic illness or disability. This is particularly the case if previous experiences of healthcare have not been positive (Patterson & Lanier, 1999).

Somewhat surprisingly, some young people not only did not think about the physical implications of their disability in daily life, they also had very little knowledge about CP. While the presence of CP in general had influenced their identity exploration, the specifics of their impairment were often not considered. A number of participants did not know what type of cerebral palsy they had. Megan said, “I didn’t know there were types of CP! That was news to me”. For others, a lack of knowledge about their disability led to challenges in developing a sense of identity. Erin was not told until age 17 that she had CP, instead being told she had a “motor problem” and was “clumsy”. This led to her putting “a lot of pressure” on herself at school to prove she was “as good as everyone else”. When Erin found out her condition had “a name...it was real and it wasn’t my [her] fault” and that there were other people with similar experiences, it was a great relief. Her life to date made sense and it was “liberating” for Erin to get to a place where she felt she could ask for support. Having finally gained knowledge of her disability helped her understand, and accept, who she was. An increase in knowledge of disability has been shown in other research to improve resilience, capacity to articulate strengths and disability-related needs, and confidence to self-advocate (Ganguly et al., 2015; Stewart et al., 2010; Stewart et al., 2014). The lack of knowledge displayed by some participants about their disability therefore could be of concern, particularly if this correlates with lower levels of resilience, as resilience has been linked with successful transition outcomes for young people with disability (Stewart et al., 2010; Stewart et al., 2014).

Despite a number of participants having very limited knowledge of the specifics of their disability, more generally, there was a noticeable shift during emerging
adulthood in the sense of identity^{EA} of some participants in relation to how they felt about being a person with disability. Justin said: “I’m getting more confident^{p} about who I am. Like within myself. I’ve always been worried about what people think about me, whereas now I don’t really give a stuff”. Megan talked of a similar experience of having to overcome a desire “to be the same as everyone else” and instead learn to like herself as an individual. Nathan too, had come to be proud of his disability^{p} and his achievements. He was very “comfortable” with his CP and even said that “he wouldn’t have it any other way”. Nathan felt his disability had given him many “opportunities” that he would not have had if he did not have CP, especially in relation to his competitive swimming^{Ap}. There is some limited evidence from previous research that supports this apparent increase in self-esteem during emerging adulthood for young people with disability. The capacity of young people to separate themselves from negative past situations in emerging adulthood, along with an increasing ability to separate their self-esteem from negative environmental perceptions, are possible contributing factors (Magill-Evans & Restall, 1991).

For some participants, emerging adulthood was a time of instability^{EA} as the functional impact of their CP worsened^{BS/F}, leading to changes in mobility^{Ap}. Other longitudinal research has also provided evidence of gross motor declines during the transition to adulthood, particularly for people with GMFCS Levels III-V (Hanna et al., 2009). For participants in the current study, declines in motor function subsequently led to further identity explorations^{EA}. Rachel spoke about her journey to find herself after transitioning into using a wheelchair, saying, “I didn’t know who I was”^{p}. Megan too, experienced a worsening of her mobility^{Ap} during emerging adulthood, including severe and disabling hip pain^{BS/F}. There was a time when Megan was unsure if she would have to use a wheelchair^{Ap} and this was a cause of much anxiety^{p} and worry. She said “I was very angry and incredibly depressed^{p} ... I was very emotional and very up and down. Because you think ‘am I going to lose my mobility^{Ap}?’” The significant emotional impact of a decline in gross motor function has been previously identified (Bottos et al., 2001), and the current study adds qualitative evidence of this impact.
In sum, this theme “the journey to find myself: identity exploration” reflects that the emerging adulthood concept of identity exploration\textsuperscript{EA} was inherent within young people with CPs’ stories. This is consistent with the experiences of all emerging adults. This life stage is now viewed as the time of life when the most intense identity exploration occurs (Arnett, 2014), and this appears no different for emerging adults with CP.

### 5.3.2 Dealing with roadblocks: Resilience

Participants’ stories reflected a lot of exploration around character\textsuperscript{P} and personal traits that would help them respond to roadblocks that could take them off the path to their adult life. Participants dealt with the obstacles and barriers they faced in different ways, with many demonstrating high levels of resilience\textsuperscript{P} and a determination\textsuperscript{P} to overcome challenges. Others were more tentative about whether they could overcome certain barriers they faced, and still others displayed a resignation to just accept the cards they were dealt in some aspects of their lives. Deductive analysis within this theme identified close links with the emerging adulthood concept of possibilities\textsuperscript{EA}, with participants demonstrating varied perceptions of life’s possibilities. The ICF concepts of activities and participation\textsuperscript{ICF}, environmental barriers\textsuperscript{ICF} including physical and attitudinal barriers, and personal factors\textsuperscript{ICF} including character, personality, resilience and the influence of past experiences, were influential on experiences.

The stories of the majority of participants reflected a view of possibilities\textsuperscript{EA} that was in line with Arnett’s (2015) description for emerging adults in general. Emerging adulthood is seen to be an age of “high hopes and great expectations” (p. 15), when many different futures remain possible and little has been decided for certain. Many participant stories reflected these high hopes for a positive future. Justin, for example, spoke of having “big dreams”. A majority of participants were able to articulate clear goals, and had a determined\textsuperscript{P} attitude towards reaching them. These young people were either already engaged in, or looked forward to a future where they would have a successful career in open employment\textsuperscript{A/P}, live independently\textsuperscript{A/P}
and have an intimate relationship. They had recognised that a persistent, positive, assertive, determined, and hard-working character would assist them to overcome barriers and achieve their goals, and they displayed high levels of resilience. Resilience is the capacity to cope effectively with adversity, and to deal with it proactively rather than reactively (Mannino, 2015). Traits like assertiveness, enthusiasm, drive and a positive attitude are protective during times of challenge, and utilising these protective factors contributes to a positive outcome. There is evidence that resilience is a good predictor of overall satisfaction with life in emerging adults with disability (Mannino, 2015), confirming the ongoing relevance and importance of this theme.

There were many examples within participants’ stories of protective traits and resilience. While participants had faced countless roadblocks along their journeys, many were able to deal with such challenges effectively, and bounce back from adversity. Nathan felt that his own positive attitude was instilled in him by his parents who taught him “there is no such word as can’t”. He took this to another level by being determined to prove wrong anyone who suggested otherwise. This sense of determination to prove doubters wrong was also identified as a common response of 18-20 year olds in previous Canadian qualitative research (King et al., 2000). Nathan saw his current job as a “stepping stone” for future positive career moves, and despite the barriers he had faced, he even saw that having a disability had created additional possibilities for him. He said, “I’ve just been given so many opportunities”, including opportunities to teach children with disability to swim, and opportunities to be involved in leadership activities through Rotary.

Rachel’s story also reflected her resilience, positivity, and determination. She recognised that she had a choice in how to respond to roadblocks in her life, and she tried to always respond with a positive attitude. She demonstrated a high level of resilience when she said “something can be the absolutely worst experience you can possibly have but you do have the capacity to turn it into a positive. It’s just up to you whether you want to or not”. A key example was her decision to make the most of new possibilities created by her transition to a wheelchair by getting
involved in competitive *wheelchair sports*. This was despite initially finding it extremely difficult to accept that she needed to use a wheelchair. Rachel’s previous *success* in overcoming roadblocks contributed to her feeling positive about the future: “there will always be challenges because of my CP, but I have overcome all of them thus far and will continue doing so in the future”. She had chosen to “accept the disability and move forward with it” because otherwise she felt she would risk missing out “on all there is that life has to offer”.

Jack and Lauren had similar *determined* and *resilient* views of pushing to succeed in life despite the hard work required and roadblocks encountered along the journey. Jack described his approach as “there are no shortcuts to anywhere worth going”, while Lauren said, “you’ve got to make the best of whatever you’ve got”. Justin too spoke of many *possibilities* he saw in his future, including *owning his own business*, *completing a PhD*, *moving into the city*, and even *moving overseas*.

Not all participants’ stories reflected the levels of *resilience and determination* detailed above. In contrast, other participants’ stories reflected a more tentative view of their *possibilities*. These young people had the same hopes and goals as their peers. They wanted a *career* that would enable them to make a *valued contribution* to society. They hoped for a future where they would *live outside of their parents’ home* with *support*, and have reciprocal *friendships* and a *relationship*. However, although these young people wanted all of these things, their goals were tempered by a realistic appraisal of the many *barriers* that restricted their *possibilities*. They were *ambitious, but cautious*. They were unsure whether hard work and perseverance would be enough to allow them to overcome all of the roadblocks they faced. Many of these *obstacles were imposed by society*. Some of them were *physical*, but by far the most significant were *attitudinal*. These tentative emerging adults hoped people would see past their disability and give them a chance - in *work*, in *friendship*, and in *love*. But all had *negative experiences in their past*. They had faced numerous physical and attitudinal roadblocks along their journey, and were finding it difficult to keep
bouncing back from ongoing challenges. They knew that no matter how much they wanted something, or how much effort they put in, they still may not have the same possibilities as others in all areas of their lives. For example, Rina, Megan and Hayley all worried they would not have the chance to experience an intimate relationship, because people could not see past their disability. Michael, Jessica, Jack and Rina were all tentative about their possibilities in employment as a result of past direct discrimination and what Rina termed “pre-judgement”.

Finally, in comparison, other participants demonstrated lower levels of resilience and a more resigned view of the possibilities before them. Two young men had a painful awareness of the possibilities other young people have, but they did not see such possibilities for themselves. They had given up on a lot of their previous goals and plans and had chosen to focus instead only on each day as it came. These young men had both faced many roadblocks, challenges and obstacles along their journey. They seemed to have lost the desire to overcome such challenges and mostly tried not to think about the future; it had become too overwhelming. They had instead adopted a resigned approach to life’s possibilities. They no longer seemed motivated to push past roadblocks and work towards a future of their choice. Scott’s view was that his disability “sets me [him] back”. In particular he felt that his possibilities to make social connections and develop relationships were limited. Chris clearly articulated his understanding of the “traditional” possibilities available to most emerging adults and indicated a level of desire to have these too. However, he had adopted a passive character and believed that whether he would have similar possibilities was not in his control. Chris used the Spanish phrase “que sera sera” [whatever will be, will be] to describe his stance on life.

In sum, within the theme “dealing with roadblocks: resilience”, many participants demonstrated high levels of positivity, determination and resilience, regardless of how many roadblocks they faced on their journey. Others, though, demonstrated a more tentative view of life’s possibilities, wondering if some barriers would be too difficult to surmount as a result of external factors. Lastly, others’ stories reflected
lower levels of resilience and a level of passivity and resignation. For these participants, significant external barriers\(^E\) and roadblocks faced in the past had led them to believe they had little control over their future.

Positivity, determination, and resilience have been identified in other literature, cited above, as being present for many young people with CP. However, this study contributes additional qualitative evidence suggesting that there is significant variation in the level of resilience displayed by emerging adults with CP, along with varied responses to dealing with life challenges. Positively, the qualitative findings of the current study suggest that despite the presence of disability, the majority of emerging adults with CP in this study held a positive perspective of their future possibilities\(^{EA}\) and their ability to move through roadblocks on their journey. This is similar to the broader emerging adult population, where 89% agree with the survey question “someday I will get what I want out of life” (Arnett, 2014). The challenge remains to effectively support those emerging adults, including those with CP, who would currently disagree with this question and whose experiences with barriers have left them with little resilience to continue to explore future options.

5.3.3 Supporting others’ journeys: Altruism

This theme highlights the desire of many participants to support the journeys of other young people with disability, at a personal level, or through broader advocacy pursuits. While not all participants were demonstrating this desire, it was a common theme, particularly for those who felt their own journey was progressing well. Highlighted through deductive analysis, this theme was closely linked to the emerging adulthood construct of possibilities\(^{EA}\) and to the activities\(^{ICF}\) in which participants chose to participate\(^{ICF}\). It also reflected personal factors\(^{ICF}\), in particular a strong sense of altruism.

Many participants took their positive view of possibilities\(^{EA}\), highlighted in the previous theme, to another level through a passion to also make a difference\(^P\) to the lives of others with disability. As they entered a more mature stage of life, they wanted to share their journeys so that other young people with disability could
recognise the possibilities available to them. They played an active role in supporting others’ journeys and facilitating these possibilities. Participants demonstrated altruistic character traits and were passionate about giving back to others. They did this through work, community involvement, and mentoring, or through otherwise working to break down societal barriers and reduce negative attitudes toward disability. They wanted to help other young people to develop the resilience that they themselves demonstrated and support others to overcome roadblocks along their journey.

The young people had varying motivators for their decision to actively contribute to the lives of other young people living with disability. Nathan said, “I want people to have the same opportunities I’ve been given”. For Megan, however, it was about “validating” the experiences of marginalised young people because she did not “want anyone to go through” the negative experiences she had faced. Lauren’s focus was on changing “people’s perspective” towards disability and on telling her story to help other people with disability recognise “that there is success”. Jack volunteered, presenting to groups of young people with disability and families, about his own experiences, achievements, and support available. He knew, from his own past experiences, that families sometimes struggle to “find out what they can and can’t get access to”, and he wanted to help facilitate these connections. Rachel volunteered to mentor young students with disability at a local school and was in the early stages of planning a local support group. These activities arose out of Rachel’s own experience during adolescence of feeling that she did not “fit in” and her desire to connect with other young people who were having similar experiences and to support their journey.

The finding that many emerging adults with CP display a high level of altruism is consistent with evidence from a growing body of research (Kim & Kang, 2003; Mannino, 2015; Read et al., 2015; Yeung et al., 2008). For example, a participant in Mannino’s (2015) research expressed a very similar view to that shared by participants in the current study: “my first goal would be making life, or trying to make life easier for everyone else, especially the younger kids with disabilities,
'cause I remember what that's like” (Mannino, 2015, p. e137). More broadly, many participants in the current study were actively demonstrating what Arnett discussed about the broader emerging adult population; that they place a high value on community, and are more likely than previous generations to participate in community service and volunteering (Arnett, 2014).

5.3.4 It’s a hard road: Mental health problems

Participants’ stories reflected that their journeys were not easy; they had faced a hard road growing up with cerebral palsy. For some, this hard road contributed to short and long term mental health problems, or the development of a diagnosed mental illness. Deductive analysis within this theme identified close links with the emerging adulthood concept of identity exploration\textsuperscript{EA}; in particular the challenges arising through exploration attempts. The ICF concepts of body structures and functions\textsuperscript{ICF}, in relation to diagnosed mental illness, personal factors\textsuperscript{ICF}, including self-esteem, the challenges associated with participation\textsuperscript{ICF}, and environmental barriers\textsuperscript{ICF} including bullying were all relevant to this theme.

While the identity exploration\textsuperscript{EA} that is undertaken during emerging adulthood is often exciting, it can also be confusing. Trying to figure out who you are and what you want to do with your life can be overwhelming\textsuperscript{P}. Rates of depression\textsuperscript{BS/F} and anxiety\textsuperscript{BS/F} are high during emerging adulthood (Arnett, 2015; Slade et al., 2009), even for people without the added challenge of disability. This study did not set out to compare the rates of mental health problems between emerging adults with and without CP. However, it is clear from the narratives that mental health problems affected many participants. These problems seemed to begin for most during adolescence, and for some, emerging adulthood was the time they began to implement strategies to improve their mental health. Rachel experienced depression\textsuperscript{BS/F} during her transition to a wheelchair. Her self-esteem\textsuperscript{P} plummeted and she began disengaging\textsuperscript{P} from family and friends. She began to see a psychologist\textsuperscript{E} to help her come to terms with this major change, which she found very helpful. Interestingly, Rachel attributed the “maturity” of emerging adulthood as influencing her recognition that she “needed to go speak to someone”, 
something she had vehemently avoided in the past when it had been suggested to her.

Megan too struggled with low self-esteem, depression and anxiety throughout adolescence that was closely tied to her CP. She said, “I basically hated myself...I thought that I wasn’t worth anything. I felt that having a disability made me like nothing”. Megan was still “trying to work through” these feelings in emerging adulthood but felt she was “coming to terms” with things and learning to “like” herself. Chris also experienced depression in adolescence and had spent significant time working with a psychologist trying to accept his disability and the barriers he faced. As an emerging adult he felt he had “turned a corner”. Erin experienced stress and anxiety as an adolescent as she pushed herself to achieve at the same standard, or better, than her peers. She said, “I ended up driving myself sick...I would work crazy hours...it took a lot longer to do my work than others and I knew it, but I didn’t want to let on...”. Scott too found the school workload difficult to keep up with, and coupled with significant bullying, he experienced severe depression to the point of contemplating suicide as an adolescent. As an emerging adult he continued to face depression, although it was not “as strong”, and he felt he would only ever be truly happy if he was able to find a relationship. This qualitative evidence adds to the existing limited body of knowledge in this area. Other research evidence has identified high proportions of young people with CP experiencing anxiety and depression (Galambos et al., 2008; Krakovsky et al., 2007; Young et al., 2011), and the current study reports similar findings.

To summarise, this theme, “it’s a hard road: mental health problems”, reflects that the challenges associated with the emerging adulthood concept of identity exploration were important within participants’ stories. Anxiety and depression were disclosed by a number of participants. This is consistent with both anxiety and depression being common within the general emerging adulthood population (Arnett & Schwab, 2012; Twenge, 2013b). Within Australia, greater than one in four (26.4%) 16-24 year olds experience a mental disorder, with the most common being
anxiety and depression. This rate is higher than in any other age group (Slade et al., 2009). This research has also added new insight into some of the factors emerging adults with CP believe contribute to their mental health problems. These include low self-esteem, the pressure of trying to keep up with workloads despite their disability, and bullying.

5.3.5 Telling others about my journey: Disclosure

Participant stories, particularly for those with milder CP, reflected decisions they needed to make about disclosing their disability to others. Deductive analysis within this theme revealed close links with the emerging adulthood concept of identity explorationE; in particular whether young people with milder CP were happy for others to know about their identity as a person with disability. The ICF concept of body structures and functionsICF was relevant to this theme, in relation to people with more noticeable physical disabilities not having a choice about disclosure. Personal factorsICF, including a decision to hide disability to try to avoid environmentalICF barriers including stigma and discrimination, were also of interest. In addition, activities and participationICF, particularly in education and work, were a focus of stories, as participants revealed having to make decisions about whether to disclose in order to access environmentalICF supports like reasonable adjustments.

For some participants, decisions around disclosure of their disability formed part of their identity explorationE. While the majority of participants had physical impairments that were quite noticeableBS/F, those young people with less severe CP had to make informed decisions around whether, and to whom, they would disclose their disability. Megan had chosen not to disclose her disability to her universityA/P in order to seek reasonable adjustmentsE, because she did not want to risk being “stereotyped”E. A decision of non-disclosure meant that Megan was not able to access the adjustmentsE she would have otherwise been entitled to under the Disability Standards for Education. Megan weighed up the risks associated with disclosing and decided it was not worth it, even to access support. She said, “that’s my choice [not to access services], because I don’t like being labelledE. I never have….I feel I’ve done good enough on my own”.

260
Erin, by contrast, disclosed her disability at school and university in order to receive reasonable adjustments like extra time and the use of a computer in exams. However, this resulted in her facing negative reactions from educators who thought the adjustments were giving her an unfair advantage rather than enabling her to reach her potential. These negative experiences made her less inclined to disclose when it came time to seek employment; she was concerned about discrimination. Erin was hesitant to be labelled as a person with disability and instead focused on securing a position that would not be impacted on by her disability. She said that it was “stressful enough trying to start a new job, let alone trying to say something like that [I have a disability]”.

Jessica’s views on disclosure changed as she matured through adolescence and emerging adulthood, especially in relation to disclosing to her peer group. As a 19 year old she was happy to disclose, saying “it doesn’t even worry me”. However this had not always been the case. Earlier in her adolescence, when commencing high school, Jessica had tried to hide her disability “because basically you didn’t want the boys to find out”. Fear of not fitting in or being accepted within her peer group had prevented her from disclosing, although in the end “they all worked out that something wasn’t right”.

In summary, this theme “telling others about my journey: disclosure” reflects important and personal decisions made by participants with milder CP around whether or not to tell others about their disability. No other research could be located which specifically explores the experience of, and decision making around, disclosure for emerging adults with CP. The current study adds to this gap in literature and raises concerns that young people may be avoiding disclosing because of the risk of, or actual past experience of, negative implications and discrimination. Research across a broad range of disability types and age groups has identified similar concerns with disclosure, particularly in the workplace (Stanley, Ridley, Manthorpe, Harris, & Hurst, 2007). More research around disclosure for emerging adults with CP is needed, particularly given that non-
disclosure means young people cannot access the reasonable adjustments\textsuperscript{E} they are entitled to in education and employment settings.

5.3.6 Finding my place: Friendships

The stories of participants reflected the journey of finding their place within their peer group. For some, the journey to develop reciprocal and meaningful friendships was a difficult one, marked by a history of bullying and alienation during younger years. Participants’ experiences around friendships were deductively linked with the emerging adulthood concept of identity exploration\textsuperscript{A/P}, and inherently related to the ICF concept of activities and participation\textsuperscript{ICF}, in particular interpersonal interactions and relationships, and the major life area of school. Friendship experiences were also influenced heavily by environmental barriers\textsuperscript{ICF} including bullying, exclusion, negative attitudes and ignorance, which in turn contributed to impacts on personal factors\textsuperscript{ICF} including self-esteem.

Participants’ identity exploration\textsuperscript{EA} during emerging adulthood extended to consideration of the qualities they looked for in people they chose to associate with. This is common within the broader emerging adult population, when young people explore what kind of person they want to be, and the kinds of relationships they want to have (Arnett et al., 2014). Past negative social experiences had made participants very cautious as emerging adults when choosing friends\textsuperscript{A/P} and associates\textsuperscript{A/P}. Almost all participants had experienced significant bullying as children and adolescents. This experience negatively impacted their self-esteem\textsuperscript{P} and their feeling of fitting in with others. Predominantly, the bullying\textsuperscript{E} involved derogatory name-calling, exclusion from activities, and having low expectations. Megan spoke about being “teased constantly, every day, like ‘cripple, retard, spastic, freak’” and this had a significant negative impact on her self-esteem\textsuperscript{P}. Jessica, Erin, John, Hayley, Daniel, Scott, Chris, and Simon had also experienced similar teasing and name-calling. Scott said, “high school was very, very bad” and described the bullying\textsuperscript{E} as one of the major factors in his decision to leave school\textsuperscript{A/P} after year 10: “I decided I had to go before things got worse...I got a school certificate and high tailed it out of there”.
For Rina, her experience was less about verbal taunts and more about exclusion. She said, “I learned that ignoring is a form of excluding...I just remember not having friends, not being teased, but feeling ignored and not fitting in, in a place where everyone fitted in”. Unfortunately for Hayley, Rina and Chris, their experiences of bullying and exclusion were significant enough to force them to change schools during high school. Interestingly, all three young people made a point of mentioning that they were private schools they left. Rina spoke about how the diversity within public schools contributed to her finally feeling like she “belonged somewhere”: “everyone was so diverse so I just had my own diversity”, in comparison to the private school where she felt like a “square peg in a round hole”.

The findings of this study in relation to bullying, a lack of acceptance, negative attitudes and social exclusion are in keeping with a growing body of knowledge. Unfortunately, environmental barriers to developing friendships have been identified and emphasised in a number of research studies with young people with disabilities (King et al., 2000; Kramer et al., 2012; Morris, 2001; Vlachou & Papananou, 2015; Yeung et al., 2008). The evidence is clear that much more needs to be done to try to break down these barriers and improve the experiences of emerging adults with disability in relation to social participation and friendships.

Most of the bullying participants in the current study experienced was from peers, but sadly sometimes it came from people in positions of power, including teachers. For example, Lauren was told “you’ll never amount to anything” by one of her teachers, while Erin was belittled by physical education teachers and labelled “lazy” and with a “bad attitude” because she could not keep up in sport. Nathan had experienced teasing and verbal “taunting” from his peers, but the experience that had the most significant impact on him was when a parent on the edge of a soccer field said “that kid there shouldn’t be playing soccer! How bad must his parents feel”. This is not the first study to identify environmental barriers arising from people in positions of power. Other research with people with CP has cited barriers in education settings, including teachers having low expectations, poor levels of
understanding of adjustments required, and even accusing students with disability of receiving an unfair advantage when adjustments are implemented (Freeborn & Mandleco, 2010; Lindsay & McPherson, 2012). The current study adds additional evidence of these barriers, and supports the need for greater levels of education of teachers and others in relation to the capabilities of young people with disability, and of their rights by law to access appropriate adjustments and supports where necessary, to help them reach their full potential.

Despite the often devastating experiences of bullying and a lack of acceptance having had a big impact on participants’ childhood and adolescence, emerging adulthood was a time where many had come to the realisation that they had the power to pick their friends carefully in order to facilitate positive experiences. For example, Rachel said that people who could not see past her disability were “not worth knowing”. Nathan said, “if they are up themselves they can go and get screwed, because everyone’s equal”. At the time of interview, most participants had established a small number of close friendships and were satisfied with this. Within these friendships, which Megan labelled “genuine”, the young peoples’ CP was irrelevant. Nathan said, “they know I’ve got CP but they don’t treat me like I’ve got CP”, while Rachel described her friends as “the kind of people who see me and not my disability”. Rachel recognised that as she moved through emerging adulthood she was becoming more aware of what she looked for in others and was better able to assess people’s motivations: “I guess as you get older…you can see when people are really genuine and if they’re not I just don’t have time for that”.

For some participants, by contrast, the challenge to develop reciprocal friendships was ongoing. Hayley desperately hoped that her future would include some close friendships, but she was worried about whether this would happen, as her previous experience was that people “judge” her and could not “see past” her CP. Lauren felt frustrated by negative attitudes displayed even by strangers. People would stare and make assumptions rather than initiate a conversation with her: “I think they think you’re some kind of alien, some sort of freak…they’re just happy to perceive you in whatever way they do, even if that’s not true…in whatever way
makes them comfortable…”. Rachel eloquently described similar experiences in this way: “There’s a lot of ignorance in the world and there are a lot of misguided people in the world and unfortunately I meet more of them than other people”. This ignorance was seen to be a significant contributor to the struggles some participants faced forming friendships.

In summary, this theme “finding my place: friendships” has explored the significant environmental, particularly attitudinal, barriers faced by many participants in forming and maintaining friendships. While for some, emerging adulthood was a time where they had secured genuine, reciprocal friendships, for others this was an ongoing challenge. This finding is supported by other research which also identified challenges for young people with CP in forming friendships (Bjorquist et al., 2014). In keeping with the findings of existing research, young people within the current study with more severe disabilities, and those who could not walk independently, seemed to have the highest levels of difficulty forming friendships (Boucher et al., 2010; Morris, 2001; Palisano et al., 2009). The stories of those who could walk independently and had a driver’s licence included more examples of participating in social activities with friends.

Previous Australian narrative research has confirmed the importance of friendships to young people with CP; they wish to participate actively in social and leisure activities in line with peers without disability (Cussen et al., 2012). The participants in the current research also emphasised how important friendships and social participation were. They wanted to find their place and to fit in. The ongoing challenges faced by young people, as demonstrated in previously cited research, and the current study, provide clear evidence of the need for additional efforts in this area. Attention on building the capacity of young people in regards to forming friendships, and on breaking down environmental barriers they continue to face, is needed.
5.3.7 My journey is limited: Romantic relationships

Participant stories highlighted the challenges experienced in developing romantic relationships. The presence of CP was seen by many to obstruct this important part of their journey towards adulthood. A link between the experiences of participants in relation to romantic relationships and the emerging adulthood concept of *instability*<sub>EA</sub> was identified through deductive analysis. However, unlike other areas, where participants’ stories indicated some similar experiences to other emerging adults, in this case participants’ experiences were in contrast. While *instability*<sub>EA</sub> and frequent changes are common in the broader population of emerging adults, including in *relationships*<sup>A/P</sup> (Arnett, 2014; Arnett et al., 2014), this was not the experience of the majority of participants with CP. Experiences were also deductively linked to the emerging adulthood concept of *possibilities*<sub>EA</sub>, again in an adverse sense. A number of participants felt their *possibilities*<sub>EA</sub> around relationships were limited by *environmental*<sub>ICF</sub> barriers including a lack of acceptance by others, and this had significant impacts on ICF *personal factors*<sub>ICF</sub> including self-esteem and coping styles.

The majority of participants in this research were yet to experience the *instability*<sub>EA</sub> that is customary in emerging adulthood in relation to *intimate relationships*<sup>A/P</sup>. Only Michael and Jessica were in *relationships*<sup>A/P</sup> during their involvement in the study, and Jessica’s *relationship*<sup>A/P</sup> ended prior to her last interview. Nathan spoke of two previous brief *relationships*<sup>A/P</sup> with young women who also had a disability, but the other fifteen participants had never experienced a *relationship*<sup>A/P</sup>, let alone the numerous relationships which many emerging adults experience as they evaluate and re-evaluate what they are looking for in a partner. For many young people this was a source of much *sadness and disappointment*<sup>P</sup>, and weighed heavily on their *self-esteem*<sup>P</sup>, as they recognised their disability as the major obstruction influencing their lack of relationship experience.

Rina was very upset by the thought that she would not have the *possibility*<sub>EA</sub> to experience an *intimate relationship*<sup>A/P</sup>: 

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266
I thought that if I tried my very best, I would get what I wanted...it’s very hard to tell yourself you don’t want it [a relationship], but you almost have to, just so that your whole life won’t be kind of wasted.

Megan struggled with the same feelings that “people haven’t been that interested in me...they’re not going to want me because the first thing they’re going to see is my disability”. Michael, despite having a partner at the time of the study, still felt that previous negative experiences meant that it was “always in the back of my mind” whether he could truly be accepted. Hayley also worried that she “probably will never get married and have children”, but desperately hoped that these experiences would be part of her life journey.

These emerging adults had to reappraise what they wanted and how they would respond to goals that remained unmet. Simon said, “it gets depressing at times you know, because a lot of women don’t find you attractive when you have a disability”. Participants employed various coping styles to try to deal with these difficulties. Rina “tried to just not concentrate on it as much”; feeling that choosing not to focus on it helped her to live a “full and happy life”. Hayley responded to the same situation by “hiding” behind her ongoing studies, which she found easier than thinking too much about what she was missing out on. Many had adopted a self-protective response or attitude toward their not having a relationship. For example, Rachel said, “if it happens it happens, if it doesn’t it doesn’t”, while Megan’s view was “if anyone is going to be that shallow I don’t want them in my life”. Still, the majority of participants hoped that their future would include a genuine, loving relationship, with someone for whom their disability was irrelevant.

This is not the first Australian research with emerging adults with CP to provide evidence of poor outcomes in respect to intimate relationships. In one recent study with 335 participants with CP, only 20% had ever been married or had a partner, in comparison to 70% of a population control group (Reddihough et al., 2013). There is however clear evidence that emerging adults with CP do have the same level of desire in relation to romantic relationships and sexual activities as their peers (East
& Orchard, 2014; McCabe, 1999; McCabe et al., 2000), and this was the case for the young people in the current research. Their current lack of experience in this area had a significant negative effect on many of the young people. It is clear that much needs to be done to break down the barriers faced by emerging adults with CP in forming romantic and intimate relationships.

To conclude, the area of romantic relationships is an area where the experiences of participants in the current study were in stark contrast to those of emerging adults as a whole. Most participants had not been able to embark on this leg of their journey. Participants’ experiences did not reflect the instability$^{EA}$ and possibilities$^{EA}$ reflected in the relationships of most emerging adults. Participants felt their possibilities$^{EA}$ were limited by environmental$^{ICF}$ barriers including, in particular, a lack of acceptance by others. Challenges in this life area had significant impacts on ICF personal factors$^{ICF}$ including self-esteem and coping styles for many of the participants in this study.

### 5.3.8 Changing direction and help with navigation: Education pathways

Participants’ stories around education and training pathways reflected changing directions for many, and highlighted varied experiences with accessing help to navigate these journeys. Participants’ experiences were deductively linked with the emerging adulthood concept of instability$^{EA}$. Some participants had experienced numerous changes in schools, institutions, and study directions, as is common within emerging adulthood (Arnett, 2014; Arnett et al., 2014). Study experiences were unpredictable, in particular in relation to possibilities$^{EA}$. Some participants felt their possibilities$^{EA}$ were in line with those of most emerging adults, while others felt they were quite limited. Feelings around study possibilities$^{EA}$ were in most cases linked to the quality of services received.

Participants’ experiences in educational settings$^{A/P}$ were significantly influenced by the quality of service provision$^{E}$ they received from those responsible for helping
people with disability navigate education and training. Participants’ narratives reflected a number of examples of the ways that educational possibilities had been influenced either positively or negatively. Stark contrasts could be identified between positive experiences of services which facilitated possibilities and successful achievement of goals, and negative experiences that created barriers and reduced possibilities. This was the case both in high school during adolescence, and tertiary settings during emerging adulthood. Experiences in both settings are discussed below, as participants emphasised how education experiences during adolescence had significantly influenced their current experiences and opportunities.

Nathan experienced teachers “bending over backwards” to support him and provide access to reasonable adjustments at school, and Jack too believed his support staff “went beyond the call of duty”. Unfortunately, Lauren’s experience was less positive, waiting a whole year for a bathroom at her high school to be modified to make it accessible, and then experiencing a significant lack of consistent support: “people like me need a constant person that knows what’s going on in their life so you don’t have to keep explaining what’s happening to 60 different people. I had twenty teacher’s aides in two years”. This was a significant factor in influencing Lauren’s decision to leave school and she felt that her possibilities and “opportunities” increased only once she left. Chris too experienced many teaching and support staff leaving: “and people that came in really didn’t know me or understand”. In the end this was a catalyst for him having to change schools. Justin too had a negative experience of support at school, being shifted between support and mainstream classes numerous times. The difficulties schools face in attracting and retaining staff who are qualified and experienced in supporting students with disability has previously been identified (Winn & Hay, 2009). The current study provides additional evidence that inconsistencies in service delivery have a significant impact on a large number of young people with CP during high school.
Service delivery within tertiary environments was also inconsistent. Many participants’ ability to succeed in tertiary education was facilitated through access to disability services staff and reasonable adjustments, including extra time, scribes, note-takers, alternative assessments, and access to assistive technology. Daniel found the support “excellent”. For some, studying at university would not have been a possibility except for the availability of these adjustments. Some though still encountered significant barriers that needed to be overcome. Hayley felt she had to do a lot of the “organising” of adjustments herself when they were not implemented in a timely fashion. She also experienced a lack of awareness of actual teaching staff in terms of implementing adjustments, and physical access barriers. The current research provides additional evidence in support of another Australian study, with university students with a range of disabilities, which reinforced that nearly all barriers to academic success are environmental (Ganguly et al., 2015). Existing literature has also identified the lack of inclusive education practices training for academic staff within universities as a challenge for students with disability. While academics are experts in their topic area, they may not have any formal teaching qualifications or have received any training on inclusive education for students with disability (Järkestig Berggren et al., 2016). The current study reinforces that this barrier negatively impacted on some participants’ experiences at university.

In line with most emerging adults, some of the young people in this study had made numerous changes of direction in relation to their study and career, and many were planning further changes in future. Megan demonstrated a high level of instability as she explained her struggle to find her study and career “niche”:

I left High School in Yr 10 and started a hair dressing apprenticeship. That went down the gurgler. I hated it. Went to TAFE, started a course, hated that, it wasn’t what I wanted. Then I had a bit of a mental health crisis, took some time off, went back and did [another course] at TAFE, which was brilliant... I didn’t really know what I wanted to do...I kept going from one thing to another, and in the end my parents sat me down and said ‘You’ve got to finish Years 11 & 12’, because I was going for jobs but no one would employ me...In the end I went back to get Yr 12, after much kicking and
screaming. Started HSC at TAFE then left that, then went back six months later and did my TPC [Tertiary Preparation Certificate]. I got work\textsuperscript{A/P} in a childcare centre, was there for 18 months, and I knew then that I wanted to work with children – but I also knew I didn’t want to be in a child care centre for the rest of my life....

Jessica too had commenced one university\textsuperscript{A/P} course only to decide within her first semester to change to a different course to fit with her developing career goals\textsuperscript{A/P}. Justin had also seriously considered changing university\textsuperscript{A/P} course and remained hopeful that he could eventually combine his goal of opening a neighbourhood centre with his passion for digital art. Scott, by contrast, had undertaken numerous TAFE\textsuperscript{A/P} courses still without developing a strong interest in any career\textsuperscript{A/P} area, and was planning at least another year of study\textsuperscript{A/P}. However, the motivation behind this instability\textsuperscript{EA} was related to staying engaged in the tertiary education system so as not to lose his income support benefits: “otherwise Centrelink cuts my pay”. At the time of the study he really had no career goals\textsuperscript{A/P} attached to his area of study\textsuperscript{A/P}.

Starting university\textsuperscript{A/P} is often a stressful time for emerging adults. However, the impact of having a disability can add another layer of complexity and challenge to an already unpredictable time. Rachel found the idea of starting university\textsuperscript{A/P} “overwhelming” as it involved not only a new education environment, but also “moving out of home\textsuperscript{A/P}, meeting new people\textsuperscript{A/P}, [and] learning to function in a different environment\textsuperscript{A/P}”. She spent significant time exploring various courses and universities, and learning about supports available to help her navigate the journey, before making a final decision on the direction she wanted to go. Learning to navigate her university campus and student residence as a wheelchair user, and learning to be completely self-reliant\textsuperscript{A/P}, provided additional challenges for Rachel compared to those experienced by her first year university peers without disability. However, Rachel was confident\textsuperscript{p} in her ability to succeed during this new time of instability\textsuperscript{EA}, having overcome previous challenges\textsuperscript{p} and developed a high level of resilience in the process: “If I can get through what I’ve been through over the past 18 months [transitioning to wheelchair]...I don’t think I have a lot to worry about”.
In summary, participants’ experiences of education and training reflected the importance of having effective help with navigating the journey. Stories also reflected a level of instability a similar to that experienced by many emerging adults, with changes in study direction quite common. Participants’ views on their possibilities around study were variable, and in most cases linked to the quality of service provision in high school and tertiary settings. For some, services were an environmental facilitator which increased possibilities, while for others services were viewed as a barrier which made their participation in study challenging.

5.3.9 A bumpy road: Finding the right job

The journey to securing employment was a bumpy road for most, with many challenges for a number of participants. Deductive analysis identified that their experiences often included a time of instability which is customary to emerging adults seeking a career path. However, unlike their peers without disability, this instability was at times contributed to by a lack of possibilities afforded to them. As has been the case within multiple themes, environmental barriers commonly influenced participants’ experiences in a negative way. These barriers included negative attitudes, discrimination, and a lack of effective support services. Together, they created participation restrictions for a number of participants in terms of their engagement in employment.

Emerging adulthood is a time when young people often explore a range of work options, prior to settling on a long-term career path (Arnett, 2015). For young people with CP, the journey to identifying the right job can be even more complex and many experience bumps and obstacles along their way. Erin spoke about the challenge and stress of trying to decide on a direction. She said, “I still don’t know what I want to be when I grow up”, and later “I’m actually getting quite stressed out over this whole ‘what am I going to do now?’ thing”! These challenges in deciding on a career path are common to many emerging adults, as they pursue a range of options in order to clarify the type of person they are and the future they want (Arnett, 2015). However, Erin’s stress was amplified by factors related to her disability; she was unsure about her capacity to manage full-time...
work\textsuperscript{A/P} and was worried about the possible negative consequences of disclosing\textsuperscript{E} her disability to potential employers. Erin described this few months of instability\textsuperscript{EA} as a “terrible time”, but at the end of the study she had secured work\textsuperscript{A/P} related to her degree, was comfortable in her decision and achieving positive outcomes at work in a flexible environment\textsuperscript{E} that suited her disability-related needs well.

In contrast, other young people spent emerging adulthood exploring different work\textsuperscript{A/P} options, not because they were unsure of what they wanted to do, but because they faced barriers in securing employment\textsuperscript{E} in their chosen career area. Daniel, for example, successfully completed a course to become a librarian but two years later had still not managed to secure a position. He decided to return to university\textsuperscript{A/P} to study a Master’s degree in the hope it would be “easier to find work\textsuperscript{A/P}”, but remained concerned\textsuperscript{P} whether it would be “worthwhile”. Others had not had an opportunity to explore a range of study\textsuperscript{A/P} and work\textsuperscript{A/P} options, and were ok with this. Simon and Paul, who both had intellectual disability\textsuperscript{BS/F}, had both commenced working in a supported workplace\textsuperscript{A/P} immediately after school, and neither had plans to consider trying to move to a different role. Their experience of employment lacked the usual twists and turns of emerging adulthood and instead represented a future that was stable yet lacking in variety of experiences.

Still others held concerns about restricted possibilities\textsuperscript{EA} in the area of work\textsuperscript{A/P} as a result of discrimination\textsuperscript{E} that was outside of their control. Michael’s experience exemplifies this issue when a job interview that was going well did not progress into a job once the employer noticed his limp:

...everything was going fantastic like [I was] really getting a good vibe, and then he said ‘ok, I’ll just show you around’....he said ‘have you hurt yourself’? and I said “no I have slight cerebral palsy’...and he just goes ‘oh’ and I knew instantly that the job was gone.

Michael said, “it makes you think if they’ve got that attitude then maybe so do lots of others and obviously that will affect getting a job”. Jessica too felt she had been discriminated\textsuperscript{E} against” by a past employer, and Jack felt strongly that many
months of unsuccessful job-seeking, despite being selected for numerous interviews, was the result of direct discrimination.

Existing research has also identified discrimination as a major contributor to the high rates of unemployment for people with disability (Lindsay, 2011a, 2011b; Lindstrom et al., 2013). The current study adds to this knowledge base and reinforces the need for significant efforts to be put into raising the awareness of employers in relation to the skills of people with disability and the unlawful nature of discrimination. This is consistent with a recent Australian Inquiry which recommended a sustained community education and information campaign designed to raise awareness, dispel myths, promote available supports, and promotion of inclusive practices (Australian Human Rights Commission, 2016).

Rina had a similar view that negative perceptions and “pre-judgement” by employers around disability would influence her work possibilities in the future. She said, “I feel that even though I have a better transcript deservedly [than a peer without disability], that if we went for a job together...employers would look at me going ‘well she has to prove more’”. Interestingly though, none of those young people who had experienced discrimination from employers or potential employers in the past had chosen to make a complaint against them. Jack simply said, “I don’t have time to go through courts or tribunals or whatever, if you don’t want me then that is your problem”. It seems likely that many Australians with disability have similar views, as only 742 disability discrimination complaints were received nationally in 2014-15, despite almost one in twelve Australians with disability reporting experiencing discrimination in the previous twelve months (Australian Human Rights Commission, 2016).

Unfortunately, some participants’ journeys to secure work were made even more challenging by a lack of positive support. They discussed poor experiences and outcomes with government funded Disability Employment Services. Nathan described his case manager as “hopeless” and he ended up securing a traineeship on his own. Hayley had been engaged with a DES for two years without even
participating in work experience, let alone getting a job. Her service provider tried to direct her to a supported workplace\textsuperscript{A/P} or day program\textsuperscript{A/P}, thereby limiting her possibilities\textsuperscript{EA}. Daniel had worked with a DES\textsuperscript{E} provider for five years, only securing two part-time jobs\textsuperscript{A/P}, neither of which were in line with his tertiary level skills\textsuperscript{A/P} and qualifications. Chris said that his provider was “lovely” but ineffective\textsuperscript{E}. Jack was the only participant who felt the DES “couldn’t have been more helpful” and believed they truly influenced his success in securing work\textsuperscript{A/P} through their support and advocacy.

Overall, though, the stories of participants in the current study clearly point to a need for much more to be done to improve the quality of DES in Australia. A recent Australian National Inquiry supports this view, making a number of recommendations about DES. These include extended access to DES for school leavers, provision of increased choice and control to service users in selecting a preferred provider, a focus on longer term outcomes and improved training for DES providers (Australian Human Rights Commission, 2016). The Australian Government itself has recognised challenges with the current DES system, and is in the process of developing a new Disability Employment Framework in response to continuing poor employment outcomes for people with disability. It is hoped that the new framework will contribute to overcoming the barriers which continue to impede the employment outcomes of people with disability (Australian Government Department of Social Services, 2015). Significant work will be required to implement and evaluate the effectiveness of the new service framework following its development.

In summary, the experience of participants around securing employment was that finding the right job was “a bumpy road”. Securing employment was difficult for a number of participants. Deductive analysis identified that a time of instability\textsuperscript{EA} was common, as emerging adults sought to find a suitable career path. However, unlike their peers without disability, this instability\textsuperscript{EA} was at times contributed to by a lack of possibilities\textsuperscript{EA} afforded to them as a result of environmental barriers\textsuperscript{ICF} including negative attitudes, discrimination, and ineffective support services.
5.3.10 Controlling my journey: Negotiating an adult relationship with parents

Participants’ stories reflected a desire during emerging adulthood to take more control of their journey. For many, this required re-negotiating their relationship with their parents. Participants sought a relationship that was still supportive, but less protective, and that facilitated increased independence where possible. Emerging adulthood typically is a time of separating from parents, of re-establishing a relationship with them as more independent and self-sufficient people who are near-equals. It is also a time of self-focus\textsubscript{EA}, when young people have freedom to choose their activities and may no longer have to justify their whereabouts to parents (Arnett, 2015). Inductive analysis revealed that participants’ capacity for self-focus\textsuperscript{EA} was limited in some cases by overprotective parents, and/or by ongoing activity limitations\textsuperscript{ICF} which meant ongoing dependence on their parents.

Along with establishing an adult relationship with parents, emerging adulthood is generally a time when young people move out of home, although many will return home again at some stage during emerging adulthood (Arnett, 2015). This is an area where the experience of all but one of the participants in this research contrasted to that of emerging adults without disabilities. Only one of the eighteen participants had experienced living out of home\textsuperscript{A/P}; Michael left home at 19 to study at university\textsuperscript{A/P} and live in a student residence. He enjoyed the independence\textsuperscript{P} it brought, and the control he had over his own life, although he had found it “a bit scary” initially. At the time of the study Michael was living with his brother while he looked for work\textsuperscript{A/P} and a place of his own\textsuperscript{A/P}. Rachel, at age 20, was just preparing for her first move away from home, also into a university\textsuperscript{A/P} student residence.

Some participants were not worried about still living at home, and were still able to be fairly independent\textsuperscript{P} while living under their parent’s roof. For example, Nathan was “paying his own way” and had the independence that came from owning his own car\textsuperscript{A/P}. He felt in control of his journey. Erin and Jack were also comfortable still
living at home\textsuperscript{A/P}, especially for financial and practical reasons\textsuperscript{P}. For others though, still living at home\textsuperscript{A/P} created ongoing challenges. They felt their parents were overprotective\textsuperscript{E} as a result of their child having a disability. Megan felt “very limited\textsuperscript{op}” by living with her parents, as they still insisted she “respect their rules and boundaries” and would sometimes control her activities, for example not allowing her to travel home alone on public transport at night. Simon too, felt “restricted\textsuperscript{op}” by his parents, who he described as his “bodyguards”. He felt they treated him “like a child” and they would not entertain the idea of him moving into a group home\textsuperscript{A/P} where he could be with other young people his own age and build his self-sufficiency. Daniel had not been allowed to travel independently\textsuperscript{A/P} by bus until the age of 22 when his parents began to “let” him do this. He greatly enjoyed the increased independence\textsuperscript{P} and control, and not having to “rely” so much on his parents. These experiences are consistent with previous research that has identified a significant proportion of emerging adults with CP desire increased autonomy from their parents (Magill-Evans et al., 2005). In one previous study, a third of participants felt they were overprotected by their parents and treated like children (Blum et al., 1991). Also of concern is existing research identifying that emerging adults with CP and their parents may have different priorities for activities and participation (Maggs et al., 2011), which may influence the conflict experienced in some families.

All of the young people in the current study except for Paul hoped to move out of home\textsuperscript{A/P}, but the timing was uncertain. Daniel for example said it would be “one day”, and like Daniel, for many others it had not yet become a priority at that point in their lives. Most were aware they still needed to develop a range of skills\textsuperscript{P} before they would be independent enough to live out of home, for example Mitchell said he needed to learn to “cook\textsuperscript{A/P} and clean\textsuperscript{A/P} and do my laundry\textsuperscript{A/P}”. Others, like Simon, knew that realistically if they were to leave home it would be to live in a group home\textsuperscript{A/P} with other people with disability, because they would always need significant levels of daily assistance\textsuperscript{E}. Paul, in contrast, had no plans at all to leave home\textsuperscript{A/P}; he was “happy where I am”. Whatever the reasoning, these young people had a common understanding that their disability was a significant contributing
factor to their still living at home. Most had chosen to focus on achieving other goals, for example completing their study\textsuperscript{A/P} and finding full-time work\textsuperscript{A/P}, before they planned to work towards building the independence\textsuperscript{P}, or self-management\textsuperscript{P}, required to live away from home.

For some participants, disability support needs\textsuperscript{A/P} in particular made it difficult to negotiate an adult relationship with their parents. Lauren, Rina, Chris and Justin required significant care and ongoing support\textsuperscript{E}, with personal care\textsuperscript{A/P}, housework\textsuperscript{A/P} and meal preparation\textsuperscript{A/P}, and their parents continued to provide a lot of this support. They were exploring future options that could facilitate their independence\textsuperscript{P}. Justin had plans to eventually move into a more accessible home\textsuperscript{E} that would enable progressive development of independence\textsuperscript{P}. For Lauren and Rina, it was about working toward employing and directing personal care staff\textsuperscript{E} to take over the roles that their parents currently played. They looked forward to having greater control over the timing of their day and how they were assisted. Rina found it “demeaning” that she constantly needed the assistance of her parents for routine daily tasks even as an emerging adult. This restricted her desire and need for privacy, something prerequisite to the self-focus\textsuperscript{EA} customary for emerging adults. She lamented that her sisters were able to have “secret lives”; they were able to come and go as they please and did not have to provide details of where they had been or who they were with. They were in full control of their journeys, while Rina felt her parents still controlled her journey to a degree. Rina’s need for daily care meant her parents were part of every aspect of her life; she felt they knew “an unhealthy amount” about her. She hoped that employing and “managing” personal care attendants would contribute somewhat to increasing her control and independence\textsuperscript{P} and helping her establish an adult relationship with her parents\textsuperscript{A/P}.

Again, this is not the first research to identify that personal care needs can be a barrier to independence and forming an adult relationship with parents. Magill-Evans and colleagues previously identified this issue in their Canadian research with 20-23 year olds with CP, particularly within families who could not afford to pay for private services (Magill-Evans et al., 2005).
In summary, the process of negotiating an adult relationship with their parents, and taking over control of their journey, was an ongoing challenge for most participants. Deductive analysis identified that participants’ capacity for self-focus\textsuperscript{EA} was limited in some cases by overprotective parents, or by ongoing activity limitations\textsuperscript{ICF} which led to ongoing dependence on their parents. Only one participant had moved out of home, reflecting that the vast majority experienced a participation restriction\textsuperscript{ICF} in this area, in contrast to the experiences of most emerging adults without disability. Personal factors\textsuperscript{ICF} like finances, and the prioritisation of other activities\textsuperscript{ICF} like study and work also contributed to delays in participants leaving home.

5.3.11 My crew: Personal care and health services

With their reliance on personal care and health services as a result of CP related functional impairments\textsuperscript{ICF}, some participants were embarking on their journey of emerging adulthood with a crew of professionals and support staff in tow. Thus, they were restricted in their capacity to display the self-focus\textsuperscript{EA} that is common during emerging adulthood and the freedom and spontaneity common at this time of life. This was largely due to inflexible service delivery, particularly in regards to personal-care services. This presented a significant environmental barrier\textsuperscript{ICF} which restricted the opportunities of some participants. This theme also explores the finding that despite their earlier years being inundated with health and therapy services, that this was not a priority for many participants during emerging adulthood. Some participants had chosen to let go of some of their crew during emerging adulthood. For others, health system structures and policies contributed to them no longer accessing their support crew.

After enduring years of therapy and health services as children and adolescents, participants were largely free of them as emerging adults. Many participants did not discuss their experiences of health services much at all. Often when they did it was to explain how little they thought about their health\textsuperscript{BS/F} or accessed health services\textsuperscript{E} in emerging adulthood, other than visiting a general practitioner\textsuperscript{E} when they were ill. For example, Michael said, “I just go to a GP when I’m sick, that’s all”. He was happy to not have to focus so much on health services, having had multiple
surgeries and ongoing physiotherapy as a child and adolescent. He said, “after 22 years of doing it [physiotherapy] you just kind of get over it”. Megan expressed similar views around avoiding health services in emerging adulthood, having “loathed every minute” of visits to doctors, hospitals and therapists as a child. Making independent decisions to no longer access such services was one way some participants demonstrated self-focus during emerging adulthood.

However, for some, the loss of this professional crew of therapists and doctors, as they made the transition from children’s to adult’ services, was significant. Two participants discussed challenges that arose from a poor transition between paediatric and adult health services, and believed that this had contributed to their less frequent engagement in health services during emerging adulthood. Rachel was frustrated that there were no support services for adults with disability in her area and felt that this constituted a “really big failing” in the public health sector. John explained there had been no planned transition for him, instead there just came a time when “the children’s hospital didn’t want to know about me”. This contributed to his disengaging from the health care system.

A marked decline in access to healthcare and community services during emerging adulthood for young people with CP has been identified in a growing body of previous research (Cathels & Reddihough, 1993; Hilberink et al., 2007; Ng et al., 2003; Stevenson et al., 1997). Contributing factors identified in prior literature include an inadequate transition from paediatric to adult health services, adult providers lack of knowledge around the specific needs of emerging adults with CP (Aisen et al., 2011), and young peoples’ frustrations around having to repeat information numerous times (Bagatell et al., 2017). Reduced access to healthcare during emerging adulthood is worrying given ongoing health concerns are often present at this time, including musculoskeletal problems, pain, fatigue, sleep problems, dental problems, incontinence, declines in mobility, and mental health problems (Hilberink et al., 2007; Murphy et al., 1995; Tornbom et al., 2013; Turk, 2009). While a vast amount has been written about improving healthcare transitions, much of the literature is anecdotal and there is actually little high
quality evidence available to guide effective support of emerging adults with CP during the transition to adult healthcare. More research is needed in this area. The issues identified within the current study around the overwhelming experience of frequent involvement in the health care system during childhood and adolescence, and how this contributes to disengagement during emerging adulthood, also deserves further exploration.

In emerging adulthood, a number of participants faced the added job of managing a crew of professional personal care services to support their journey through life. Rina, Lauren and Chris all relied on their parents and/or paid attendant carers to assist with personal care. They all spoke at length about the challenges this presented in terms of limiting their ability to be spontaneous. The lack of flexibility of personal care services was a factor raised by a number of participants as influencing their possibilities as emerging adults. On the one hand they appreciated that their professional crew allowed them a level of independence from their parents, or at least gave their parents a break a couple of times a week. On the other hand, they were frustrated by limitations that fixed service times put on their ability to be spontaneous in their activities.

Lauren wasn’t ready until 10am on the days she had attendant carers, which negatively influenced her options in terms of the business she was trying to run. Rina too was frustrated by how strict her routine would be once she transitioned to using only attendant carers: “I really like sleeping in...my definition is not sleeping late, but not knowing when you’ll get up...and sometimes I resent that when I move out that will just go...the lack of flexibility really scares me”. The simple pleasure of being able to choose when to get up in the morning was a luxury that Rina would no longer have once her schedule relied on the availability of carers. Chris described his life in emerging adulthood as “regimented”. Similar concerns have been raised in previous research with young people with disability (Hendey & Pascall, 2001), reinforcing the need for greater flexibility in service delivery.
To conclude, some participants were reliant in emerging adulthood on a crew of professional support staff, and some had taken the opportunity as an emerging adult to let go of the large crew of health service providers that had dominated their childhood and adolescence. Deductive analysis within this theme identified that for some participants, their capacity to display the self-focus\textsuperscript{EA} customary during emerging adulthood was impacted by inflexible service delivery. A lack of flexible personal-care services in particular was an environmental barrier\textsuperscript{ICF} which restricted opportunities and denied some participants the ability to be spontaneous in their journey. Poor healthcare transitions, negative past experiences and being burnt out by healthcare all contributed to restrictions in access to health services in emerging adulthood.

5.3.12 The open road or a traffic jam: Transport options

This theme represents the large contrast in experiences between participants, depending on whether they had access to the significant environmental facilitator\textsuperscript{ICF} of independent transport. Those with access to independent transport experienced an open road; the freedom to move around their community as they pleased. The experiences of those without independent transport however, is represented by a traffic jam; not being able to get to where they wanted or needed to go, or facing many environmental barriers\textsuperscript{ICF} along the way which delayed their journey. Deductive analysis identified that these barriers had the potential to impact on both self-focus\textsuperscript{EA} and possibilities\textsuperscript{EA} of participants.

Participants’ possibilities\textsuperscript{EA} of involvement in their community\textsuperscript{A/P} and in activities\textsuperscript{A/P} were heavily influenced by the availability of transport services\textsuperscript{E}. In particular, a number of emerging adults discussed the barriers they faced as a result of insufficient, inconvenient and overly expensive taxi services\textsuperscript{E}. Many participants relied on taxis as a means of transport, along with practical support from their families\textsuperscript{E}, as driving was not an option for them. Some were eligible for the NSW Government’s Taxi Transport Subsidy Scheme, which allowed them to travel at half fare, up to a maximum subsidy of $30 per trip. Despite this support, taxis were still too expensive\textsuperscript{E} for regular travel, and presented a number of other problems for
participants. Lauren explained: “they are so expensive, even with the subsidy. And they are not always available”. Quite often you’ve got to wait. You can’t make plans to meet people at a certain time”. In addition to similar concerns, Rina also noted frustration at the low percentage of taxis that were accessible, which led to increased wait times: “will I be waiting for two minutes like my elderly aunt who can catch any taxi, or will I be waiting for two hours”? Participants, including Chris, had also had taxi drivers refuse to take them on short trips, despite this being against taxi industry regulations. These barriers had a significant impact on the possibilities of some participants to be spontaneous and independent in their daily activities. These findings are consistent with previous international research from Europe, Canada and the UK. Such transport barriers have negative impacts on access to education, employment and social and leisure participation (Darrah et al., 2010; McManus et al., 2006; Morris, 1999; Stewart et al., 2012).

In contrast to the experience of participants who relied on taxis or public transport, participants who had their driver’s licence and access to a car were able to come and go with a high level of flexibility and freedom. This enabled them to demonstrate the independence and self-focus customary of this time in life. Nathan was “grateful” for his capacity to drive, and Jessica and Justin recognised it as a big boost to their independence. Michael, who grew up in a rural area said “it was a must...if I couldn’t have had that (driver’s licence) I wouldn’t have been happy...it would have isolated me quite a bit...it takes that freedom away I guess to do what you want when you want...”.

A number of young people including Rachel, Jack and Megan looked forward to getting their driver’s licence. Rachel was excited about the possibility of being able to “go where you want to when you want to”. Megan said “to have a car is to be really independent ...I can’t wait”. However, they were all in the process of undertaking a “drawn out”, expensive and extensive process of assessments, car modifications, and professional instruction to achieve their goal of driving independently. In the meantime, they still relied heavily on their parents or public transport to get around, which restricted their capacity to have full control over the
timing of their day. Environmental barriers to gaining a driver’s licence, including the high cost of specialised driving lessons and vehicle modifications, have also been identified in previous Canadian research (Magill-Evans et al., 2008). It is clear that it is not only personal body structure and function barriers contributing to the challenges faced by young people with disability in securing independent means of transport.

For a majority of the participants in the current research, driving would never be a realistic goal and these young people had less opportunity to demonstrate the self-focus and freedom customary to emerging adulthood. They could not come and go as they pleased, and those who used a wheelchair could not just jump in a friend’s car either. Rina associated being able to “just hop in a car and go” with emerging adulthood, and she found it very frustrating that her two younger sisters both had “a great amount of freedom” that was not possible for her. Many participants were restricted to going out when their parents could take them, to navigating public transport if they physically could, or to booking an accessible taxi, which may well be late or not arrive at all. The findings of the current study add additional evidence to existing research and reinforce the need for a greater range of flexible transport options to be made available if people with disabilities are to see equality in this regard. The flow on impact of a lack of transport in regards to education, employment and social participation outcomes (Darrah et al., 2010; McManus et al., 2006; Morris, 1999; Stewart et al., 2012) make this even more vital.

In summary, inductive data analysis identified that the experiences of participants varied greatly depending on whether they had access to independent means of transport, in particular a driver’s licence. This was described as like being stuck in a traffic jam, versus travelling freely on the open road. Deductive analysis recognised that the availability of transport options could be a clear environmental facilitator or a significant environmental barrier in its absence. Possibilities and the opportunity to demonstrate self-focus were both also influenced by transport options and availability.
5.3.13 Funding my journey: Opportunity costs

It became evident through the current research that a family’s socio-economic status\textsuperscript{P} was an influencing factor on participants’ possibilities\textsuperscript{EA}. Although specific details on familial income were not gathered as part of data collection, it was evident that some families were able to support their young people in ways that would not be financially possible for many families. This impacted significantly on the overall journey through emerging adulthood as the varying financial situations across families shaped opportunities and experiences. Being able to privately finance environmental facilitators\textsuperscript{ICF} like therapies, specialised driving lessons, practical assistance with study, and personal care attendants, contributed significantly to participants’ opportunities.

Many examples of the impact of financial resources on participants’ opportunities and experiences were evident. For example, Rachel sought private therapy\textsuperscript{E} from a psychologist\textsuperscript{E} when she was struggling to come to terms with her transition to a wheelchair. Her family were also assisting her through the very expensive process of trying to gain her driver’s licence\textsuperscript{A/P}, which included a private occupational therapy\textsuperscript{E} assessment and numerous driving lessons with a professional driving instructor\textsuperscript{E}. Justin’s family, too, helped him through this process and purchased him a car\textsuperscript{E} fitted with hand controls\textsuperscript{E}. In contrast, though, his family were not able financially\textsuperscript{P} to undertake the major bathroom renovations that would have been required to facilitate Justin being able to shower independently\textsuperscript{A/P}. While he said he “would like to do it myself”, Justin understood the financial limitations\textsuperscript{P} and was accepting of having to wait until he left home\textsuperscript{A/P} to be able to work on this goal.

Rina and Hayley’s parents were able to offer significant financial support\textsuperscript{P} that facilitated their ability to undertake study\textsuperscript{A/P} at a university\textsuperscript{A/P} level, despite both having severe physical disabilities\textsuperscript{BS/F} and speech impairments\textsuperscript{BS/F}. Both families paid for\textsuperscript{P} a private “scribe” at home to provide what Rina termed “clerical” assistance in the physical preparation of assignments. Without this support they would have been unlikely to be able to succeed at university. Assistive technologies\textsuperscript{E}, such as
speech-to-text software, were not effective alternatives for typing due to the level of their *speech impairments*\(^{85/f}\), and their physical disability made typing painfully slow. Hayley recognised that without her family’s *financial support*\(^{p}\), she would likely spend her days in a government funded *community day program*\(^{a/p}\) or *supported workplace*\(^{a/p}\). Instead she was able to pursue her goals of *university study*\(^{a/p}\) and *open employment*\(^{a/p}\); opportunities available as a result of her family’s capacity to provide financial support.

Rina also felt “*lucky*”\(^{p}\) that her family was able to pay for regular *private physiotherapy*\(^{e}\) that allowed her to stay out of the “*inefficient*” *public health system*\(^{e}\), and were prepared to *pay for*\(^{p}\) *private attendant carers*\(^{e}\) to facilitate her gaining increased *independence*\(^{p}\) with *personal care*\(^{a/p}\). Rina had been on a *public waiting list*\(^{e}\) for attendant care for some time but felt she would never qualify while she was still *living at home*\(^{a/p}\), as funding was very difficult to access unless you were in “crisis”. A number of other young people were still supported in *personal care*\(^{a/p}\) by their parents however, and they *did not have the financial resources*\(^{p}\) to change this situation. Other *possibilities*\(^{e/a}\) were also out of reach of a majority of families. For example, Jack looked forward to a day when he had a *permanent job*\(^{a/p}\) and could afford to commit to the costs involved in paying for *driving*\(^{a/p}\) lessons and purchasing a *modified vehicle*\(^{e}\). While his family provided a lot of *practical assistance and support*\(^{e}\), they were not able to *assist financially*\(^{p}\) with this goal. Scott had had to stop attending the performing arts classes that he was passionate about because his single mother “*couldn’t afford it*”\(^{p}\). His opportunity to be involved in an activity that was very meaningful to him was limited purely by an inability to fund it.

The current study provides some evidence that access to financial resources may increase opportunities and *possibilities*\(^{e/a}\) for emerging adults with CP as they journey through life. This is consistent with evidence of the influence of higher socio-economic status on increased well-being and a successful transition to adulthood for emerging adults in general, with families with greater financial
resources more likely to support the education, housing, and transport of their emerging adult (Galambos et al., 2006).

There is very little previous research in this area in relation to the specific experience of emerging adults with disability, although one international study has found similar trends. Participants aged 21-35 with a range of disabilities who had achieved higher levels of independence were likely to have received financial and other support from their parents, while those from families with limited economic and social resources demonstrated lower levels of independence (Hendey & Pascall, 2001). Overall though, in Australia, the majority of people with disabilities do not have access to the financial resources of a privileged minority. Nearly half of Australians with disability live below the 60% poverty line (Australian Council of Social Service, 2014). When the additional costs of having a disability, and the higher unemployment rate for people with disability (Australian Council of Social Service, 2014) are taken into account, the extent of poverty is actually likely to be even greater.

To conclude, inductive data analysis identified the significant influence of financial resources on the opportunities afforded to participants. Deductive data analysis established a connection between financial resources and the possibilities\textsuperscript{EA} afforded to young people, with those whose journeys were funded by their families having access to possibilities\textsuperscript{EA} that were not available to all. The ICF personal factor\textsuperscript{ICF} of finances enabled some participants to purchase a range of environmental facilitators\textsuperscript{ICF}, including therapies, specialised driving lessons, private personal care attendants, and practical assistance with study, which significantly increased their opportunities and capacity for engagement and participation.

5.3.14 Off the beaten track: The limits of a rural location

The stories of those participants who lived in rural areas highlighted that living off the beaten track could at times limit opportunities afforded to emerging adults with CP. Deductive analysis of experiences around geographical location identified the influence of location on possibilities, particularly around access to services\textsuperscript{E},
education\textsuperscript{A/P}, employment\textsuperscript{A/P} and the community\textsuperscript{A/P}. Predominantly, this theme explores the restricted possibilities\textsuperscript{EA} of emerging adults with CP living in rural areas, as a result of environmental\textsuperscript{CF} barriers.

Participants who lived in rural areas discussed many examples of how their possibilities\textsuperscript{EA} were reduced compared to those available to people living in metropolitan areas. For John, access to healthcare services\textsuperscript{E} had been challenging in the rural coastal town in which he lived. As a child his family regularly travelled interstate for specialist appointments and surgery which was “a drag...but it’s just something that needs to be done”. As an emerging adult John had almost completely disengaged from health services\textsuperscript{E}, and he noted both the lack of access\textsuperscript{E}, and his own competing priorities\textsuperscript{P}, as influencing factors. John also discussed his possibilities\textsuperscript{EA} for employment\textsuperscript{A/P} being significantly reduced as a result of living in a rural area. Even for people without disabilities, finding part-time work\textsuperscript{A/P} was difficult as there was “a lack of jobs at the best of times”. However, as a person with a disability, it was “almost impossible”. John had responded to this challenge proactively\textsuperscript{P}, by establishing his own small business\textsuperscript{A/P} providing computer technical support, which he hoped to build over time while he studied\textsuperscript{A/P}.

Mitchell also lived in a small rural town. He noted poor public transport access\textsuperscript{E}, and poor physical access\textsuperscript{E} around town and commented that these had not improved in over a decade. These limiting factors directly influenced his ability to get out and about\textsuperscript{A/P} and involved in his community\textsuperscript{A/P}. He also discussed challenges that had arisen because healthcare services “don’t exist\textsuperscript{E}” in his area. His family were separated for long periods during his childhood when he and his mother would travel to the capital city for treatments. He loved the rural lifestyle that came with living off the beaten track, but knew that realistically he would have to move to a larger regional centre if he was to participate in tertiary study\textsuperscript{A/P} or secure employment\textsuperscript{A/P}. He thought these would be realistic goals for him in the future but was in no hurry to move out of home\textsuperscript{A/P} or leave his rural area.
Previous Australian research provides further evidence of the additional barriers faced by people with disability in rural and remote areas. In relation to healthcare, people with disabilities in outer regional and remote areas have lower usage rates of general practitioners, medical specialists, dentists and other health professionals than those living in major cities. They also have longer wait times and are more likely to report a lack of communication between professionals (Australian Institute of Health and Welfare, 2015). Access to education, employment, and transport is also more limited in rural and remote areas of Australia, and even those who find work generally have lower incomes (National Rural Health Alliance Inc & Australian Council of Social Service, 2013). There is also a lack of choice of providers, and recent evidence suggests that service availability becomes even more restricted after the age of 18 years (Gallego et al., 2017). It is clear that people with disabilities living outside of major cities currently face an additional layer of disadvantage, and the current study indicates that this is the case in emerging adulthood.

In summary, it was evident through inductive analysis of participants’ stories, that those living “off the beaten track” in rural areas did not have access to the same possibilities as their peers living in metropolitan areas. This impacted on several of areas of participation, including education, work and community access, as well as posing significant environmental barriers, for example access to services, transport and physically accessible communities.

5.3.15 Are we there yet?: Clarifying what it means to be adult

Participants’ stories reflected important considerations around what it meant to be adult. At this point in their emerging adulthood journey they were reflecting on the important question: “are we there yet?” For some, it was a time of reaching an understanding and acceptance that their adulthood may vary in some ways from that of their peers without disability. Deductive paradigmatic analysis established that many personal factors were relevant to participants’ experiences. Most participants still felt adolescence and adulthood, as is common during this life stage.
Emerging adulthood is characterised by a majority of young people as a time of feeling in-between; adult in some ways but not in others (Arnett, 2015). The feeling of becoming an adult is gradual, as the criteria that young people deem as being the key markers of adulthood are developed gradually over time. These key criteria are accepting responsibility for yourself, making independent decisions, and becoming financially independent. Young people are likely to define themselves as adult once they reach a point where they meet each of these criteria. While they are still in the process of developing these qualities, they are likely to have a feeling of sitting somewhere between adolescence and adulthood (Arnett, 2015).

In line with emerging adults in general, the majority of participants in this research discussed this feeling of being in-between. When asked what being an adult meant to them, they commonly raised aspects of the three key criteria identified in the broader emerging adulthood research, in particular taking responsibility and making independent decisions. For example, Rachel spoke about responsibility, independent decision making and “being in control of your own destiny”. Megan thought she had achieved the criteria of taking responsibility, but did not think she would truly classify herself as an adult until she was living independently from her parents. Justin defined adulthood as being mature, autonomous, independent, and “not blaming other people for your stuff ups”. He thought he was getting there “very slowly”. Mitchell and Rina also thought adulthood was about being “mature”, while Simon and Daniel both raised taking responsibility as their key criterion for adulthood and both felt they had not yet fully achieved this.

Lauren knew that moving out of home or financial independence would not be an option for her in the short or even medium term, but she still felt an adult in some ways because she was building her independence through starting to manage her own supports. Rina too, thought adulthood was about “maturity and independence” but because of the level of her physical disability had to redefine in her mind what it meant to be independent: “I can’t do things by myself, but I have to become a manager, a manager of my supports, and that will be a big step...”
towards me being an adult”. Simon, who had an intellectual disability\textsuperscript{BS/F}, wished that he could be more independent but felt he was restricted\textsuperscript{E} by his parents who treated him “like a child”. He had considered options that would allow him to be more independent\textsuperscript{P}, such as moving into a group home\textsuperscript{A/P}, but at this stage his parents were unsupportive\textsuperscript{E}. Interestingly, only two participants in the current study considered financial independence\textsuperscript{P} among their criteria for adulthood, which is in contrast to emerging adults in general. Rina looked forward to starting work\textsuperscript{A/P} and earning her own money\textsuperscript{A/P}, and felt this was an important part of being an adult. Jack had a similar view, and defined himself as an adult because he had left school\textsuperscript{A/P} and was working full-time\textsuperscript{A/P}.

In conclusion, the theme “Are we there yet?: Clarifying what it means to be adult” is representative of the process participants were undertaking to reflect on what adulthood meant to them, and to accept that their adulthood may look different to that of their peers without disability. Deductive paradigmatic analysis established that many personal factors\textsuperscript{ICF} were relevant to participants’ experiences including levels of independence and responsibility. Most participants still felt in-between\textsuperscript{EA} adolescence and adulthood; this was consistent with the experience of their peers without disability (Arnett, 2015). However, they faced an additional challenge on their journey. They had to clarify what it means to be an adult as a person living with disability who may always require support in daily life. In addition, it seemed likely that for some participants at least, the process of taking on adult roles and responsibilities may be prolonged in comparison to peers without disability.

### 5.4 Synopsis

This chapter has presented a paradigmatic analysis of the narratives introduced in Chapter Four. Both inductive and deductive paradigmatic analyses were undertaken. Inductive analysis of narratives provided answers to the following research question: what themes can be developed from the stories of emerging adults aged 18-25 years with CP? Through the process of inductive analysis, fifteen themes were developed and have been explored in depth within this chapter.
Participant experiences in relation to each theme were detailed, compared and contrasted, and highlighted by direct quotes from participants.

Deductive analysis of narratives facilitated the answering of the final research question: are emerging adulthood and ICF theoretical constructs reflected in the themes developed from the stories of emerging adults aged 18-25 with CP? The links between each theme and constructs of the theory of emerging adulthood and the ICF have been highlighted throughout this chapter, and summarised in section 5.2.

Concurrent to the presentation of the results of inductive and deductive analysis of narratives, each theme has been discussed in relation to prior knowledge. The next, and final, chapter summarises the key findings and contributions of this research and discusses these broad contributions in relation to prior research and scholarship. Implications and recommendations are presented, along with strengths and limitations of the research.
Chapter 6. The point of the story:
Discussion and conclusion

6.1 Introduction

This study explored the stories of 18-25 year olds with CP, from their own perspective. The voices of eighteen emerging adults were heard as they provided in-depth insights into: what was important in their lives; key past experiences which had influenced their current situation; current activities and life roles; environmental and personal factors that had influenced their experiences; lessons learned; and goals for the future. A narrative inquiry approach that was informed, but not defined, by the theory of emerging adulthood and the ICF, was utilised to understand participant experiences, at both individual and group levels. In doing so, this study answered the following research questions:

1. What are the stories of emerging adults aged 18-25 years with CP?

2. What themes can be developed from the stories of emerging adults aged 18-25 years with CP?

3. Are emerging adulthood and ICF theoretical constructs reflected in the themes developed from the stories of emerging adults aged 18-25 with CP?

The answers to these research questions were presented in detail in Chapters Four and Five. The findings of this study represent an original contribution to knowledge, addressing previous gaps in understanding the first-hand experiences of 18-25 year old young people with CP, the themes within their collective stories, and the degree to which key constructs from the theory of emerging adulthood and the ICF are reflected within these themes. This final chapter summarises the answers to each of the three research questions, brings together for the first time the findings of the individual questions to highlight the overall finding and contribution of this research, and discusses key contributions in relation to existing research and
6.2 Summary of findings

This section presents a separate summary of the answers to each of the three research questions, presented in detail in Chapters Four and Five. This summary of individual question findings is followed by a presentation and discussion of the inherent connections between the findings in 6.3.

6.2.1 Research question 1

This study explored the stories of 18-25 year olds with CP, from their own perspective. Eighteen individual stories, developed from the verbatim transcripts of interviews using narrative analysis techniques, were presented in Chapter Four. This was in response to the first research question: what are the stories of emerging adults aged 18-25 years with CP? Each of the 18 stories offers valuable insights into the wide range of experiences, challenges, hopes and goals of young people with CP, and emphasises the importance of taking the time to listen and understand each young person as a unique individual on their own life journey. A brief summary of key insights from each story is presented below.

Nathan’s story provided a new level of insight into the importance of being accepted and choosing to associate only with those who make you feel this way. His story also introduced a theme reflected in a number of narratives: a passion and drive to give back to other young people with disabilities. Nathan demonstrated a keen level of determination to never accept people underestimating him; he would go out of his way to prove doubters wrong.

Rachel’s story also emphasised a desire to be seen as a mentor to other young people with disability, to help them reach their goals as she had been able to. She was determined to succeed in life and looked for the positives in every experience. Her transition into using a wheelchair in emerging adulthood was initially a very difficult decision and impacted heavily on her sense of identity. However, she came to realise the positives, including engaging in wheelchair sports, and learnt to accept both the wheelchair, and herself.
Like Nathan and Rachel, Megan too wanted to support other young people experiencing disability or other challenges. For her this was about validating their experience, and hoping they would not have to face the many challenges she had faced, and continued to face.

Similar to Rachel, Jessica’s story reflected an active choice to make the best out of even the most challenging situations. She too had recently transitioned to using a wheelchair for mobility and recognised this as a new beginning, providing new opportunities to represent her country in sports. She was working towards her goal of contributing to the lives of others’ with disabilities through a role as a physical education teacher.

Lauren’s story emphasised a fierce determination to reach her goals, despite having a severe physical disability. She demonstrated a keen awareness that reaching goals may require revisions to her plan and detours along the way, but that did not make them out of reach. She was passionate about addressing the stereotypes and barriers which had influenced her own experiences.

Justin also wanted to use his journey to help others experiencing challenges on theirs. He was studying social work and had goals including opening his own neighbourhood centre, a PhD and contributing to community development. Justin used art as a medium to dispel negative disability stereotypes.

Jack demonstrated a strong sense of determination and recognition that there were “no shortcuts to anywhere worth going”. He was aiming to represent Australia at the Paralympics, and passed on his life lessons to other young people with disabilities through volunteer roles.

Erin’s story offered valuable insights into the experience of a person with mild CP, and the challenge, and importance, of accepting the need to make some adjustments to allow her to reach her maximum potential.

Michael’s story provided detailed awareness of the influence of societal perceptions and attitudes on his past experiences, along with environmental challenges he regularly encountered. His story highlighted the level of drive required to overcome such challenges, again and again.

John’s story also demonstrated that he was extremely driven. He had goals to travel independently overseas, study at university and forge a successful career. He believed his “stubbornness” would be key to reaching his goals.
Rina’s story reflected a belief that hard work would help her reach almost all of her goals. However, her narrative also provided insights into the significant roadblocks she faced along her journey. She wondered whether environmental barriers would be insurmountable in some areas, especially in relation to developing relationships.

Hayley also felt unsure about whether she could overcome barriers to reach her goals; her story reflected a sense that it was becoming tiring to always maintain a sense of positivity about the future. However, her narrative also reflected a necessity to just keep on trying, as the alternative was not worth thinking about.

Daniel’s story highlighted many challenges. Despite being highly qualified, full-time employment in a related area had eluded him for many years. Daniel believed the attitudes of potential employers towards his multiple impairments, including significant speech and communication impairments, had held him back. Even so, Daniel kept on trying.

Mitchell’s story, like Daniel’s, emphasised many past challenges and frustrating barriers trying to access support and the community, to achieve his goals. Regardless, he refused to be caught up worrying about such challenges, highlighting that he would continue to “deal with it as it comes”.

In contrast to other participants, Paul’s story reflected a lack of control over his life journey and goals. As a young man with intellectual disability, his story was dominated with reflections on activities he undertook in supported settings, chosen for him by others. Regardless, he was happy with where he was in life.

Simon’s story was similar to Paul’s in terms of his activities, however starkly different in his perceptions of those activities. He felt that his journey was “restricted” and controlled, and hoped somehow for a future where he could be more independent, despite his intellectual disability.

Scott’s story echoed similar challenges faced by others, particularly in regards to forming relationships. However, in contrast, his story demonstrated a loss of drive to overcome challenges, perhaps connected with his depression. He seemed to have put his journey on hold as he focused on getting through each day.

Chris too, didn’t plan far ahead and concentrated on each day as it came. His story indicated that past challenges had led to a fear of hoping for, or wanting, things too much. He knew that many barriers would have to be overcome if he was to achieve his goals, so had adopted a “whatever will be, will be” approach to his life journey.
6.2.2 Research question 2

After detailing individual stories for their unique and insightful contributions, this research then sought to develop key themes from those stories, utilising inductive narrative of analysis techniques. In doing so, the second research question was answered: what themes can be developed from the stories of emerging adults aged 18-25 years with CP? The fifteen themes, detailed in length and discussed in light of existing research and scholarship in Chapter Five, are briefly summarised below.

Theme 1: The journey to find myself: Identity exploration
For participants, emerging adulthood was a time of reflection, of learning more about themselves and what they wanted in life. The details of disability factored very little in young people’s identity, and many knew little about their CP. As emerging adults, participants were coming to accept themselves and becoming more confident; they were making their “own path”. For some, physical deterioration in emerging adulthood forced a redefining of identity.

Theme 2: Dealing with roadblocks: Resilience
The majority of participants had high hopes for the future and were determined to achieve their goals by overcoming any barriers they faced, demonstrating high levels of resilience. Others were more tentative, wondering if the roadblocks they faced would stop them achieving some of their goals. Still others demonstrated lower levels of resilience, feeling restricted in their possibilities and having lost motivation to pursue the journey they once wished for.

Theme 3: Supporting others’ journeys: Altruism
For many participants, emerging adulthood was a time of passing on life lessons learnt to others living with disability, or of fighting to remove societal barriers and negative attitudes. Participants were passionate about supporting other young people with disability, through work, volunteering or mentoring roles. This was particularly the case for emerging adults who felt their own journey was progressing well.

Theme 4: It’s a hard road: Mental health problems
Mental health problems impacted the lives of a number of participants. Depression and anxiety were both common. For some this was triggered by worsening mobility, while for others low self-esteem. The pressure to achieve at the same rate as people without CP, bullying and/or the lack of relationships could also lead to poorer mental health. A number of participants were ‘turning a corner’ in emerging adulthood and were working through their problems, some with professional help.
Theme 5: Telling others about my journey: Disclosure
Most participants had chosen to disclose their disability in order to access support at school, tertiary education or work. However, some chose not to for fear of, or previous experience of, discrimination. Those with less noticeable disabilities in particular had to make informed decisions regarding disclosure.

Theme 6: Finding my place: Friendships
Almost all participants had experienced significant bullying as children and adolescents, making them cautious emerging adults when it came to choosing friends. Most had a small number of genuine friendships and were not interested in associating with anyone who did not accept them. For some, ignorance and judgement still made forming friendships very hard in emerging adulthood. This seemed particularly the case for young people with severe disabilities.

Theme 7: My journey is limited: Romantic relationships
Only three participants had ever been in a relationship, and for many their lack of participation in this area was a source of much sadness that influenced self-esteem and mental health. They desperately hoped they would find someone who truly accepted them. In the meantime, participants tried to keep busy and not think about it, as it was too painful.

Theme 8: Changing direction and help with navigation: Education pathways
Many stories reflected the instability common in emerging adulthood, as participants tried out a range of study options to find their niche. Experiences were significantly influenced by the quality of service provision and reasonable adjustments provided (or not), with service delivery at both school and tertiary levels being very inconsistent. For some, poor service provision had led to leaving education altogether, or changing schools.

Theme 9: A bumpy road: Finding the right job
The majority of participants had experienced challenges finding suitable work in their area of interest, and attributed this to direct discrimination and negative perceptions of potential employers. Disability-related factors, for example fatigue, created additional considerations for participants in choosing an appropriate job. A number of stories also reflected issues with the providers of DES, with only one participant reporting that such a service had been influential in his securing work.

Theme 10: Controlling my journey: Negotiating an adult relationship with parents
In contrast to most emerging adults, only one participant had moved out of home. Some were able to live fairly independently in the same house.
as their parents and had a good relationship with them. Others felt restricted and that they were not treated in an age-appropriate way. Ongoing personal care needs, and a lack of alternative support options, was a barrier for some people in developing an adult relationship with their parents.

**Theme 11: My crew: Personal care and health services**
A small number of participants discussed experiences of a poor transition from paediatric to adult health care services. For some this contributed to disengagement and was a source of frustration, while others had made a personal decision that accessing health services was no longer a priority in emerging adulthood. Lack of flexibility in personal care services was a significant barrier to spontaneity and participation for those with high support needs.

**Theme 12: The open road or a traffic jam: Transport options**
Barriers were commonly cited in regards to accessing transport. Taxis were deemed to be insufficient, inconvenient and overly expensive. Still, many participants had to rely on them, alongside public transport or their parents for transport. In contrast, those who could drive enjoyed much higher levels of flexibility and freedom, although the process of getting a driver’s licence was expensive and drawn out.

**Theme 13: Funding my journey: Opportunity costs**
Financial resources played a role in the opportunities afforded to participants. Some families were able to access private therapy, professional driving instructors, and private scribes to assist with tertiary education. Opportunities for those who could not were more limited.

**Theme 14: Off the beaten track: The limits of a rural location**
Access to healthcare, employment, transport and the built environment was noticeably more challenging in rural areas. Environmental barriers contributed to reduced possibilities for those young people living in rural areas, highlighting an additional layer of disadvantage.

**Theme 15: Are we there yet?: Clarifying what it means to be adult**
Like their peers without disability, most participants felt they were in-between adolescence and adulthood. Being an adult meant taking responsibility and making independent decisions, consistent with the views of young people without disability. Financial independence was less often mentioned, in contrast to the views of most emerging adults. Many participants’ stories reflected a process to redefine what these markers of adulthood might look like as a young person with disability, and to accept that their adulthood might look different to their peers without disability. For example, some needed to accept that while independence was not achievable, independent decision making and taking control of supports was possible.
Varied experiences within each theme were influenced by a range of developmental, functioning and disability, and contextual personal and environmental factors. These influencing factors will be summarised below in relation to the third research question.

6.2.3 Research question 3

Through deductive analysis of narratives techniques, this study answered the third research question: are emerging adulthood and ICF theoretical constructs reflected in the themes developed from the stories of emerging adults aged 18-25 with CP?

Each of the 15 themes were mapped against the constructs from the theory of emerging adulthood and the ICF to analyse each theme in relation to these theoretical concepts (as summarised in Chapter Five, Table 7, and detailed in Appendix J). This process revealed that constructs from the theory of emerging adulthood (identity exploration, instability, self-focus, a sense of feeling in-between, and possibilities) are evident across the themes, with some concepts being central to some themes, and not others. The most common emerging adulthood construct reflected within the themes was possibilities, reflected within ten themes. Identity exploration, instability and self-focus were each reflected within four themes, while feeling in-between was only reflected in a single theme focused on participants’ deliberations around what it means to be an adult as a person living with disability. Participants experienced these constructs in different ways; at times similar to the broader emerging adult population, and at times in contrast. The constructs of the theory of emerging adulthood can therefore be utilised to highlight ways in which emerging adulthood for people with CP is similar, and different, to their peers without disability.

The deductive analysis of narratives process also revealed that constructs from the two key areas of the ICF, namely functioning and disability (body functions and structures, and activities and participation), and contextual factors (environmental and personal factors) are evident across the 15 themes. Again, experiences of these
constructs varied greatly between participants, representing aspects of both functioning and disability, and highlighting both positive and negative influences on emerging adults’ experiences. The ICF construct of *activities and participation* was reflected across all 15 themes, reinforcing that emerging adults’ stories were dominated by their experiences around participating in valued activities. Contextual *environmental factors* were reflected across 12 themes and helped to highlight important facilitators and barriers contributing to emerging adults’ journeys. Personal factors were reflected in nine themes while body structure and function constructs were less commonly reflected; only present in six of the 15 themes. The ICF can therefore inform a broad understanding of emerging adulthood for young people aged 18-25 years with CP, including an understanding of both functioning and disability, and of the many contextual factors which influence experiences.

### 6.3 Bringing the findings together

The findings of each research question, as summarised above, individually make contributions to knowledge. However, it must be emphasised that the individual stories of emerging adults with CP, their shared experiences and their unique experiences, and the broad contextual and developmental influences on these experiences cannot be viewed in isolation. There are inherent connections between the findings which reveal the overall experience of emerging adults living with CP. It is vital to consider the findings of this research as a whole in order to understand the full story.

This study highlighted that the theory of emerging adulthood and the ICF inform the understanding of emerging adulthood for young people aged 18-25 with CP. At the group level, 15 themes were inductively developed from the 18 individual stories. These themes offer new insight into the collective experience of daily life for emerging adults with CP. Each theme also contains: (i) constructs from the theory of emerging adulthood (*identity exploration, instability, self-focus, a sense of feeling in-between, and possibilities*); and (ii) constructs from the two key areas of the ICF, namely functioning and disability (*body functions and structures, and activities and participation*).
participation), and contextual factors (environmental and personal factors). At the individual level, each story reveals: (i) a unique journey towards adulthood with experiences and aspirations in line with the theory of emerging adulthood; (ii) how CP has impacted the individual’s functioning and disability; and (iii) how contextual factors influence this journey as facilitators and/or barriers for each young person.

The key finding of this research is presented graphically in Figure 3 below. This diagram highlights that the theory of emerging adulthood surrounds the young people in this study and shapes their and others’ expectations of this time of life. The young people in this study belong to the larger group of emerging adults in society. They are emerging adults first and foremost, and their stories reflect many experiences and aspirations in line with this developmental stage. They also belong to the subgroup of emerging adults living with disability, and experience additional roadblocks during this life-stage not experienced by peers without disability. The ICF at the next level helps facilitate an understanding of these roadblocks, providing a lens through which to identity the broad influences, both positive and negative, on participants’ lives. These include functioning and disability-related factors, and personal and environmental contextual factors.

At the next level, the collective stories of participants reveal 15 themes. Key constructs from the theory of emerging adulthood and the ICF are present within these themes, at times representing similar experiences to the broader emerging adult population, and at times representing contrasting experiences. At the core is the individual with their own unique story and journey as an emerging adult with CP. Central to this journey is the desire to take control of life as they transition towards adulthood; to strive for their goals, seek appropriate supports, and overcome roadblocks. This key developmental process of emerging adults living with CP is summed up eloquently by a quote from Hayley: “Making my own path”. Participants identified that this path might look different in some ways to the path experienced by emerging adults without disability. They highlighted additional roadblocks along their journey. However, their focus in emerging adulthood was on taking control of “making” their “own path” in as many ways as possible.
Figure 3: Key research finding: “Making my own path”
6.4 Discussion of key contributions

There are four interrelated key contributions emerging from the findings of the three research questions addressed in this study. In addition, this research contributes new insight into the value of narrative inquiry methods in research with people with disability. These key contributions are now discussed in relation to literature and research. They are:

(i) stories of emerging adults with CP represent a unique journey towards adulthood that can be described as “making my own path” (research question 1);
(ii) the fifteen themes generated from the collective stories of emerging adults with CP offer new insights into diverse experiences (research question 2);
(iii) thematic insights extend the theory of emerging adulthood in relation to people with CP (research question 3);
(iv) the ICF helps facilitate a detailed understanding of the influence of functioning and disability, and contextual factors, on the journeys of emerging adults with CP (research question 3);
(v) narrative inquiry methods can be successfully used to understand the experiences of vulnerable people, at both the individual and group levels (methodological contribution).

6.4.1 A unique journey towards adulthood: “Making my own path”

This is the first study to reveal detailed individual stories of emerging adults with cerebral palsy. Each story clearly shows that these young people were engaged in a journey towards adulthood and benchmarked their experiences against those of others their own age – both with and without disabilities. They were no longer adolescents, and aspired towards adulthood, evaluating whether they had achieved adult status, worrying that they might never achieve their aspirations of being fully in control of their own destinies due to their CP. They were finding their place in the world, trying out different options, looking to establish meaningful friendships and romantic relationships with varying degrees of success, and renegotiating
relationships with parents for greater control and freedom. As such, they exhibited all the hallmarks of Arnett’s (2000a; 2015) theory of emerging adulthood, with experiences related to identity exploration, instability, self-focus, feeling in-between, and exploring the possibilities of this stage of life.

However, the stories of 18-25 year olds with CP also described a range of additional challenges along their journey in comparison to those experienced by peers without disability. These challenges made identity exploration confronting and difficult at times, and for some participants reduced their capacity to demonstrate instability or self-focus. Possibilities were influenced by a range of external factors outside the control of emerging adults, which for some was the cause of much frustration. In response to these challenges, participants had recognised the need to make their “own path”, knowing that this path would be unique to them, and may look different to the paths of emerging adults without disability. Some were accepting of this unique journey and focused on the positives of their experiences, while others found the ongoing challenges overwhelming and distressing. All were working on taking control of their “own path” in whatever way worked best for them, or in the ways available to them. For some this looked very similar to the lives of emerging adults without disability, particularly for those with milder physical impairments. For others with more severe disabilities, making their “own path” in emerging adulthood was related more to taking on greater responsibility for decision making or directing their own supports.

Concepts similar to “making my own path” were found in another qualitative exploration with ten emerging adults with a range of disabilities (Mannino, 2015). This study highlighted the importance for young people with disabilities of creating their “own meaning” in life and being able to “stand on their own” (Mannino, 2015, p. e137), for example through making independent decisions. The current study lends support to this research and adds to knowledge from the perspective of emerging adults with CP specifically.
It is also important to highlight that it was never Arnett’s intention when he coined the term emerging adulthood to suggest that it is a life phase experienced in the same way by all young people. Arnett states that emerging adulthood is “one stage with many possible paths within it...most young people in developed countries experience emerging adulthood...but they experience it in a wide variety of ways” (Arnett, 2015, p. 26). He emphasises that a wide range of factors may influence young people’s experience of emerging adulthood, including culture, social class, gender, personality, and individual life events (Arnett, 2015). Hence the concept of a unique journey of emerging adulthood appears relevant to all emerging adults. The current study provides detailed insights into what that unique journey looks like for a group of emerging adults with CP.

6.4.2 Collective stories of emerging adults with CP reveal 15 themes, offering new insights into diverse experiences

This is the first time stories of emerging adults with CP have been inductively analysed to generate key themes within their collective experiences. Certain concepts within each developed theme have been identified within prior research with young people with CP. The discussion of how each theme individually relates to prior knowledge was presented in Chapter Five. The literature cited in Chapter Five typically represented research exploring distinct aspects of young people’s experience in isolation. For example other research, discussed earlier in this thesis, has considered such concepts as:

- self-esteem (Magill-Evans & Restall, 1991);
- the impact of functional decline (Bottos et al., 2001);
- resilience (Mannino, 2015);
- citizenship and engagement (Yeung et al., 2008);
- mental health (Galambos et al., 2008);
- social outcomes (Morris, 2001; Reddihough et al., 2013);
- education experiences (Ganguly et al., 2015);
- employment (Lindsay, 2011a, 2011b; Lindstrom et al., 2013); and
- access to healthcare (Hilberink et al., 2007; Ng et al., 2003).
Whilst such research makes valued contributions to knowledge, the current study adds a new level of understanding of the overall experience of being an emerging adult with CP. This study provided a broader, unrestrained opportunity for young people to tell their story, about all aspects of their life they considered a priority. In addition, existing published literature and research discussed in Chapter Five included research conducted with younger and older groups as well as emerging adults, and research with groups of people with a range of disabilities, including CP. The current study adds a detailed understanding of the specific experiences of emerging adults aged 18-25 with CP.

The themes developed in this study present for the first time the shared experience of emerging adults with CP. Each theme reflects an important consideration or priority in participants’ collective journeys. The themes highlight both commonalities and differences that exist across participants’ individual stories. Not all individual stories contained reference to all themes, and the themes were not experienced by all participants in the same way. These distinctions were highlighted in Chapter Five, summarised in section 6.3.2 above, and provide new insights into the diverse experiences of emerging adults with CP.

6.4.3 Extending the theory of emerging adulthood in relation to people with CP

While Arnett has reinforced that the theory of emerging adulthood provides a useful guide for thinking and research on this important developmental period, he has also emphasised that the heterogeneity of experiences needs to also be explored and understood (Arnett, 2006b). The specific gap in knowledge around how people living with disability experience emerging adulthood has also previously been highlighted (Cote, 2006; Hinton & Meyer, 2014). The current study contributes to addressing this gap, through developing an understanding of how the experiences of emerging adults with CP reflect: i) the key developmental processes
of emerging adulthood, and ii) the specific constructs of the theory of emerging adulthood. This contribution will now be explored.

6.4.3.1 Developmental processes of emerging adulthood

Three key sequential developmental processes have been identified by Tanner (2006) as occurring during the life stage of emerging adulthood and necessary for a successful transition to adulthood. The first is renegotiating a relationship with parents and others on whom there has been some level of dependence (Tanner, 2006). This process has also been described as launching (Arnett & Fishel, 2013). As discussed in Chapter Five in the theme Controlling my journey: Negotiating an adult relationship with parents, all participants in the current research except for one were still living at home with their parents, and a number experienced restrictions in this environment and felt overprotected. This indicates that some young people with CP experience significant challenges in renegotiating their relationship with parents.

The second key developmental process of emerging adulthood relates to trying out a range of opportunities and potential pathways (Tanner, 2006), also termed exploring (Arnett & Fishel, 2013). This exploration was discussed in Chapter Five in relation to the current study, particularly in the themes surrounding identity, study and work. The current research provides evidence that the majority of participants were indeed in a process of significant exploration, consistent with their peers without disability. There was also evidence however, that participants faced considerable environmental barriers that their peers without disability did not, which influenced the opportunities and pathways available to them during this time of exploration.

The third and final developmental process is committing to adult roles and responsibilities (Tanner, 2006), a process which has been described as landing in adulthood (Arnett & Fishel, 2013). As previously discussed in Chapter Five under the theme, Are we there yet?: Clarifying what it means to be adult, the process of taking on adult roles and responsibilities was ongoing for all participants within the current
study. It seemed likely that for some this would be a lengthy journey, lasting well beyond the traditional end of emerging adulthood. In some cases, the adult roles and responsibilities of participants were likely to always look different to those of their peers without disability. For example, independence may be represented by independent management of support services for those who would always rely on physical assistance with daily activities.

Prior scholarship highlights that some vulnerable young people do manage to make a successful transition to adulthood regardless of the barriers they face. Those who succeed demonstrate such personality traits as persistence, confidence and resilience (Osgood et al., 2010). The stories of a number of participants in the current study provided further evidence of this. Persistence to overcome challenges and work towards achieving goals, increasing self-esteem and confidence in emerging adulthood, and high levels of resilience were all highlighted within individual stories in Chapter Four, and within the themes presented in Chapter Five.

6.4.3.2 Constructs of the theory of emerging adulthood

The five key constructs of the theory of emerging adulthood are identity exploration, instability, self-focus, feeling in-between, and possibilities (Arnett, 2000a). The current study contributes an understanding of how these constructs are reflected within the experiences of emerging adults with CP.

Consistent with their peers without disability, emerging adulthood was a time of great identity exploration for participants. However, they faced additional challenges in their explorations, as they tried to establish their identity as a young person with disability. It was clear that participants desired positive instability, self-focus, and possibilities in line with their peers without disability. However, they faced many challenges which at times reduced the presence of these constructs in their lives, often creating angst and frustration. For example, instability in regards to relationships was notable in its absence, with few participants ever having experienced a romantic relationship. The ability to demonstrate self-focus was for some limited by overprotective parents, inflexible services, and insufficient
transport options. *Possibilities* were influenced by the presence of a range of environmental facilitators, or more commonly, barriers. Participants were *feeling in-between* adolescence and adulthood, just like their peers without disability. However, they faced the additional challenge of accepting that their adulthood may look different to that of their peers, for example that instead of increased independence, they may achieve increased independence in managing their lifetime supports.

In short, the constructs of the theory of emerging adulthood proposed by Arnett (2015), *identity exploration, instability, self-focus, feeling in-between, and possibilities*, form a useful framework for exploring the experiences of emerging adults with CP, and can be used to highlight ways in which their experiences are similar to, and different from, their peers without disability. This study has shown that young people with CP aspire to the same things as their peers without disability during emerging adulthood. It has also shown however, that they often have an acute awareness of how their lives are different to their peers and of the numerous roadblocks they will need to overcome if they are to achieve their aspirations. For some the recognition that they may never achieve some of their goals is extremely challenging in emerging adulthood, and linked to the development of mental health problems.

To the author’s knowledge, this is the first study to specifically explore whether the constructs of the theory of emerging adulthood are reflected within the first-hand experiences of young people with disability. Existing research exploring the relevance of emerging adulthood to heterogenous groups has focused predominantly on young people from various cultural groups (eg. Buhl & Lanz, 2007; Facio & Micocci, 2003; Mayseless & Scharf, 2003; Vleioras & Mantziou, 2017), emerging adults from different socio-economic groups (Arnett, 2006a), and young people aging out of foster care (Arnett, 2007a). Results of the current study thus extend the application of the theory of emerging adulthood to young people with disability. This thesis for the first time brings young people with CP into the discussion of developmental trajectories in emerging adulthood.
6.4.4 The ICF helps facilitate a detailed understanding of factors influencing the journeys of emerging adults with CP

The ICF was developed to provide a universal language and framework for understanding health and health-related states, including disability (World Health Organisation, 2001). It has been praised for reflecting the social construction of health and disability by recognising the influence of environmental and personal contexts on people’s lives (Bertoti & Moyers, 2004). It has been used across the world as both a detailed classification system, and a broad conceptual framework. It was utilised as a conceptual framework in the current study. This use has been recommended in Australia, due to the capacity of the ICF to facilitate a broad understanding of phenomena and ensure that important considerations are not missed (Australian Institute of Health and Welfare, 2003). The use of the ICF as a guiding framework for research with people with CP has also specifically been recommended (Rosenbaum & Stewart, 2004). A recent systematic review highlighted the capacity of the ICF to facilitate both an understanding of the full range of factors which influence people’s experiences, and the identification of unmet needs (Alford et al., 2015).

The current study makes an original contribution to knowledge by revealing how the ICF can be used to consider and frame the shared experiences of people with CP. The ICF facilitated a detailed understanding of the full range of factors influencing the experiences of emerging adults with CP. These included functioning and disability related factors, and personal and environmental contextual factors. The ICF also encouraged consideration of the direction of influence of these factors. It allowed a broad understanding to be gained of factors which facilitated increased functioning, as well as factors which increased disability. It also stimulated an understanding of whether a range of contextual factors were facilitating experience in a positive way, or creating barriers to participation.

As detailed in Chapter Five, the ICF constructs of activities and participation, and contextual environmental factors, were reflected across the vast majority of themes
and helped to emphasise important factors contributing as facilitators or barriers to emerging adults’ journeys. Activities and participation constructs were reflected across all 15 themes, emphasising their importance to emerging adults with CP. Environmental factors were reflected across 12 themes, and personal factors across nine themes, again highlighting that emerging adults with CP consider these contextual factors to have a major influence on their experience. Interestingly, body structure and function constructs were only present in four of the 15 themes, highlighting that the emerging adults viewed the specifics of their physical impairments as of much less importance to their stories than the other ICF domains.

The influence of ICF domains on experiences of young people with CP has been identified in other published research. However, such research has tended to view domains separately. For example, previous CP research, discussed in detail in Chapter Five, has explored:

- Body structure and function issues, including declines in gross motor function (Bottos et al., 2001) and prevalent mental illness (Galambos et al., 2008);
- Participation in relationships and social and civic life (Morris, 2001; Reddihough et al., 2013);
- Participation in major life areas including education (Ganguly et al., 2015) and employment (Lindsay, 2011a, 2011b; Lindstrom et al., 2013);
- The influence of personal factors, such as self-concept (Gannotti et al., 2011) and self-esteem (Magill-Evans & Restall, 1991);
- Environmental influences including bullying (Kramer et al., 2012), insufficient provision of reasonable adjustments and support (Freeborn & Mandleco, 2010), discrimination (Lindsay, 2011b; Lindstrom et al., 2013), and access to services (Hilberink et al., 2007; Ng et al., 2003) and the community (Darrah et al., 2010; Stewart et al., 2012).

The current study adds a new level of understanding of the influence of ICF constructs on the experience of emerging adults with CP, through considering all aspects of the ICF from the participant perspective and within the one research
study. It therefore offers a more detailed understanding of the interplay between body function and structures, activities and participation, and environmental and personal factors in shaping the life experiences of emerging adults with CP. Results revealed that experiences of emerging adults in relation to these constructs were varied and unique to each individual, thus highlighting the importance of listening to individual stories and understanding the broad influences on experiences. This study offers valuable insights into the usefulness of the ICF framework for research with emerging adults with CP. In particular it offers a broad perspective that facilitates a detailed understanding of experience that has often been lacking in prior research. The study offers empirical data previously lacking that could help inform the proposed development of an ICF Core Set for adults with CP.

6.4.5 Understanding the lives of vulnerable people through narrative inquiry methods

In addition to the key contributions of this study in relation to the specific research questions answered, as discussed above, this study makes an additional methodological contribution, namely confirming the appropriateness of narrative inquiry methods to facilitate a broad understanding of the experiences of people with disability, at both individual and group levels. In doing so it offers a valuable example of qualitative research design and methods that may be useful for future research with vulnerable groups of people.

Narrative inquiry is based on the premise that stories provide humans with opportunities to understand themselves, their lives, and the world around them (Gergen, 1994). Thus stories can also be utilised to understand lives through qualitative research inquiry. Narrative inquiry can take various forms and there are many examples of different approaches to narrative inquiry within the literature across numerous disciplines including sociology, psychology, anthropology and human sciences (Reissman, 2008). Within the health and social sciences, narrative inquiry has been identified as particularly useful in understanding the lives of those whose experiences depart from “normative” expectations, such as those with
disability or whose lives have taken an unexpected turn (Bruner, 1990; Mishler, 1991; Reissman, 1993). It is an approach relevant to understanding the experiences, actions, motivations, and life journeys of people who are challenged by health, disability, trauma, change, adaptation, loss, or other significant life circumstances. Narrative inquiry is thus recognised for its capacity to give voice to people whose voices have so often been discounted (Clandinin & Raymond, 2006; Holloway, 2007). In doing so, narrative inquiries are recognised as having potential to inform positive changes to practice, policy, education and theory (Chase, 2011).

The current study provides a unique example of the ways in which narrative inquiries can facilitate broad research with people with disability, to answer a range of different types of research questions. This study utilised complementary narrative and paradigmatic approaches to narrative inquiry, as described by Polkinghorne (1995). It also utilised both inductive and deductive approaches to the paradigmatic analysis. Each approach facilitated the answering of a particular research question. Narrative analysis allowed individual stories to be told, while inductive analysis of narratives facilitated the development of themes within and across stories, and paradigmatic analysis of narratives allowed an understanding to be gained of how theoretical constructs were reflected across these themes. Thus, researchers can be guided to choose an appropriate approach to narrative analysis depending on their research question/s.

In addition, this study may influence more researchers to consider the complementary use of two or more types of narrative analysis. Other studies have previously utilised dual approaches successfully (eg. Cussen et al., 2012; McCance et al., 2001; McCormack, 2004), however to the authors’ knowledge, this study represents one of the first attempts to utilise all three forms of narrative analysis within the one research study. It therefore provides an exemplar of a comprehensive approach to narrative inquiry that could be successfully be employed in future research that seeks to gain an understanding of experience in the broadest possible sense. Such an approach may be useful in many areas of disability research, as well as research with a broad range of vulnerable groups.
across the health and social sciences. More detailed guidance is provided on this approach for future researchers in a book chapter recently published by the author and colleagues (Sharp et al., 2018).

### 6.5 Implications and recommendations

The key findings and contributions of this research have broad implications for the theory of emerging adulthood and for research with people with disability. Additionally, the detailed findings based on participant experiences in relation to each of the 15 themes, already discussed in detail in Chapter Five, have additional implications for policy, and disability service provision across a range of sectors. This study has also highlighted a number of areas requiring further research. The key implications and recommendations resulting from this study are now detailed. Recommendations for research are embedded where relevant to provide greater context for the need for future research arising from the findings of this study.

#### 6.5.1 Implications for the theory of emerging adulthood

This was the first study to explore in-depth whether the key developmental processes and constructs of the theory of emerging adulthood were reflected within the collective experiences of 18-25 year olds living with disability. As noted previously, results indicated that the theoretical constructs of emerging adulthood could usefully be explored within the stories of participants. Emerging adults with CP had aspirations in line with their peers without disability in relation to the developmental processes of launching, exploring and landing in adulthood. Emerging adulthood was a time of great identity exploration for participants. However, they were facing additional challenges in their explorations, as they worked to establish their identity as a young person with disability. Participants desired positive instability, self-focus, and possibilities in line with their peers without disability. However, they faced many challenges which at times reduced the presence of these constructs in their lives. Participants were feeling in-between adolescence and adulthood, just like their peers without disability. However, they
faced the additional challenge of accepting that their adulthood may always look different to that of their peers.

This study therefore extends the applicability of the theory of emerging adulthood through detailing how this developmental stage is experienced by 18-25 year olds with CP. Future research across a range of disability types, and with other diverse groups of people, is warranted.

Recommendation 1: That future research continues to explore how emerging adulthood is experienced for people from diverse backgrounds, including those with different types of disabilities.

6.5.2 Implications for research with people with disability

The ICF provided a useful framework in the current study to explore the experiences of emerging adults with CP. It facilitated a broad and comprehensive understanding of their experiences across functioning and disability, along with a detailed understanding of the influence of environmental and personal contextual factors. This research has highlighted the appropriateness of the ICF as a conceptual framework to inform qualitative research with people with disabilities, and to frame detailed understanding of the complexities of their health related experience.

Recommendation 2: That the ICF be considered by investigators as a possible conceptual framework to inform future qualitative research with people with disability

6.5.3 Methodological implications for research with people with disability

This research has important implications for research design and methods. It is one of the first attempts (to the author’s and supervisor’s knowledge) to have combined the use of narrative analysis and both inductive and deductive paradigmatic
analysis of narratives within the one study. This contributed to the comprehensiveness and utility of the research findings, through enabling both the telling of in-depth, individual stories, the identification of common themes, similarities and contrasts between stories, and the relevance of developmental and disability frameworks to participants’ experiences. The uniqueness and potential utility of this approach was verified when the author was invited to submit a book chapter on this novel methodological approach to the interdisciplinary reference work *Handbook of Research Methods in Health Social Sciences*, released by the reputable publishing house, Springer in 2018 (Sharp et al., 2018).

**Recommendation 3:** That future investigators, who adopt narrative research methodologies, consider using, and critiquing the use of, combined narrative analysis and analysis of narratives approaches to data analysis.

This study also effectively utilised a range of interview formats to gather detailed qualitative data, including face-to-face, telephone and email interviews. This improved access to the study for people with verbal communication impairments, and for those in rural locations. Flexible approaches to data collection can facilitate the hearing of voices that may not otherwise occur through research.

**Recommendation 4:** That qualitative researchers consider using, and critique the use of, a range of data collection strategies, including those facilitated by communication technology, assistive devices, and broader technological advances. This may allow a broader range of voices to be heard through research, and offer guidance to other researchers on the utility of varied data collection methods.

**6.5.4 Implications for disability policy and related research**

It is clear from participants' stories that more flexible and person-centred support and funding options could have greatly assisted these young people to reach their goals of full and active participation. For example, a lack of available funding at the time of data collection for flexible personal care services, or to cover the expensive
process of learning to drive, led to serious participation restrictions for a number of young people. Areas of participation impacted included education, employment, social and community engagement, access and transportation, and living arrangements. Since the time of data collection, the NDIS has been trialled in parts of Australia and full rollout is well underway. The scheme claims to give people with disability ‘choice and control’ over the supports they need to achieve their participation goals, and commits to providing funding for all ‘reasonable and necessary’ supports for those Australians with ‘significant and permanent’ disabilities (Australian Government, 2013). Ongoing description of NDIS participant experience, the experience of their families and significant others, monitoring of impact and evaluation of the effectiveness of the NDIS in relation to the life experience and goals of people with disability will be important.

In relation to the broader International and Australian disability policy framework, in principle clear guidelines exist around how the rights of people with disability should be promoted, and how people with disability can be supported to achieve full participation and inclusion. The aims and vision of the UN Convention on the Rights of Persons with Disabilities (United Nations, 2006) and government initiatives such as the Australia’s National Disability Strategy (Australian Government Department of Social Services, 2011) provide frameworks for consideration and action. Identifying and removing physical, social, cultural and political environmental barriers to activity and participation currently faced by people with conditions may help to reduce the impact of disability. However, it is clear from the stories of participants in the current research, and reinforced in existing research and outcomes statistics discussed earlier in this thesis, that Australia is on a long journey to full inclusion and participation.

**Recommendation 5:** That research continues to explore the lived experience of people with disability and that disability policy is driven by a person-centred approach that takes into account these unique life stories, life situations and environmental contexts.
6.5.5 Implications for service provision

This study has provided insight into the experiences and priorities of emerging adults with CP. Participants themselves have explicitly recommended many changes to service delivery practices, and others can be extrapolated from their stories. There are implications for service delivery across multiple areas: health; mental health; education; employment; and social participation and community access. Furthermore, results have highlighted areas of service provision requiring additional research and evaluation, and areas where additional education is needed.

The wide variation within participants’ stories of emerging adulthood emphasises that service practices, across all sectors, need to be flexible, person-centred and contextualised to the unique life situation of the person. Emerging adults have different needs and priorities, and varying levels of engagement with services. Individual service providers, organisations and organisational policies, all need to be responsive to the person’s experiences, goals and life situation if they are to effectively support young people with CP.

Recommendation 6: That a flexible, person-centred approach cognisant of unique life situations be taken by service providers who work with emerging adults with CP, in all sectors and settings, in order to identify and address individual goals, barriers and support needs.

Despite disability sometimes having significant implications on their everyday lives, this study has highlighted that disability is not a defining feature of emerging adults’ identities. Emerging adults with CP do not often see themselves as being any “different to anyone else”. John clearly articulated a view that was common among participants when he said “there’s the disability, and then there’s me”. Therefore, the theory of emerging adulthood can provide a useful lens through which a person’s experience can be appreciated and through which services can be appropriately targeted.
Recommendation 7: That the developmental stage of emerging adulthood and the likely priorities of people aged 18-25 can help inform young people, their families and carers, and providers regarding developmentally appropriate service provision to individuals and groups of emerging adults with CP.

6.6 Strengths and limitations

This study aimed to articulate the stories of 18-25 year olds with CP, from their own perspective, to identify key themes existing across stories, and to identify the relevance of the theory of emerging adulthood, and the ICF, to their stories. It employed narrative inquiry methods under the assumption that through listening to the stories of young people with cerebral palsy, understanding could be gained about the way they make meaning of their everyday lives within historical, social and cultural contexts (Bruner, 1990; Gergen, 1994). In-depth, unstructured interviewing was utilised to allow participants to drive the narrative process and to tell their story in their own words. This facilitated the researcher’s capacity to develop a deep understanding of the participants’ perspectives (Fontana & Frey, 1998; Minichiello et al., 1990). Participants told their stories in a familiar environment of their choice, mostly over multiple occasions, and they controlled when the interviews would end. Opportunities were provided during interviews for member-checking of emerging ideas and themes, to facilitate increased trustworthiness of the findings (Curtin & Fossey, 2007). Data was analysed using rigorous narrative analysis and paradigmatic analysis of narratives methods in order to answer the three research questions.

This study has contributed significantly to our understanding of the lives of emerging adults with CP from their own perspective, and of the diverse factors which influence their lives in both positive and challenging ways. It has contributed new perspectives around the theory of emerging adulthood and its relevance to the lives of emerging adults with disability. It has also highlighted the usefulness of the ICF framework in capturing a comprehensive understanding of disability and the many factors which influence the lives of emerging adults with CP. In doing so, this
study has enabled a large number of evidence-based recommendations to be made across theory, policy, research, practice and education which have the potential to guide future developments to enhance the lives of young people with CP, and others living with disability.

This study also has methodological strengths. It makes significant contributions in particular around the use of multiple flexible data collection techniques to give voice to people who have often been excluded from research, and around the combined use of multiple narrative analysis procedures within a single research project. The successful use and detailed description of such methods may assist researchers in the future who are seeking to use inclusive data collection techniques and data analysis methods that will facilitate answers to a wide variety of research questions.

While contributing new knowledge to both lifespan development and disability research, and making significant contributions to research methodology, this study is not without limitations.

### 6.6.1 Limitations of the sample

The findings describe the experiences of a group of eighteen young people with CP, all from NSW, Australia. Young people with varying types and severity of cerebral palsy were represented, although it is important to note that there were no participants at GMFCS level IV. Participants lived in metropolitan, regional and rural areas, although there was an overrepresentation of metropolitan participants, and only two participants from rural areas. Participants had varying family backgrounds, although middle class, white, dual parent families were overrepresented. Participants were all representatives of Generation Y – aged between 18 and 25 during the discrete period of data collection between 2005 and 2007. Their experiences were inevitably influenced by this context and timeframe, and cannot be said to represent the experiences of all 18-25 year olds with CP. Significant time has passed between data collection and the completion of this study, and the experiences of emerging adults with CP today may be different.
However, the stories of these 18 individuals revealed an expansive range of experiences across all areas of life, and similarities and differences within experiences were identifiable and explored within Chapter Five. In line with the narrative inquiry approach, this research did not sample for representativeness, instead emphasising the inherent value in listening to individual stories. Notwithstanding this, further research with larger samples, in different geographical locations or countries, or at a different point in time, may reveal new and different experiences again. Similarly, longitudinal research following young people with CP across the whole span of emerging adulthood would offer a depth of insight into how stories evolve and develop across this life stage that was not possible in the current study.

6.6.2 Limitations in data collection

A key aim of this research was to explore the stories of emerging adults with CP from their own perspective. For this reason a decision was made not to utilise the voices of proxies for young people who could not communicate independently. Flexible data collection methods, including face-to-face, telephone, and email interviews, were used, which enabled some people to participate who would not otherwise have been able. However, by design there were still some people with CP who were excluded because they could not actively share their experiences and ideas, either because of limitations in cognition or communication. The stories of some young people with mild intellectual disability were included, along with stories of people with significant dysarthria, including one young woman who communicated via email. However it is not known whether, or how, the experiences of young people with CP and severe intellectual, cognitive or communication impairments may differ from those of the participants in this study, and further research with these groups is warranted.
6.6.3 **Limitations in design**

This research involved the active participation of young people in the data collection phase; they were active participants in deciding what stories to tell, how much detail they wanted to share and when they were finished telling their story. The participants were accepted as the experts in their own lives. However, the overall research design and data collection and analysis methods were imposed by the researcher. There is significant scope within future research to further enhance the participation of emerging adults with CP in all stages of the research process. If young people are included as active participants in all stages of research there is potential to further improve the relevance of research, the authenticity of its findings, and the contribution of those findings to truly person-centred service delivery (Curtin & Murtagh, 2007). Further research using participatory approaches at all stages of the research is recommended.

6.7 **The story ends for now: Conclusion**

This thesis ends during the time of emerging adulthood for the 18 young participants with CP. Some had not long commenced this life stage, while others were at the end of it, beginning their journey of adulthood. Their stories however, have not ended with the completion of this thesis. Future research is needed to explore what happens next for these and other emerging adults, and adults, with CP; how their journeys develop and change over time and the implications for policy and service delivery.

Each participant’s story was unique, similar to all emerging adults. Each story offered insight into varied experiences, goals, challenges and ways in which emerging adults with CP are making their “own path” to adulthood. Fifteen themes could be developed from participants’ collective stories, each reflecting an important consideration or priority in the journeys of emerging adults with CP, and highlighting the diversity of experience. This research has provided evidence to extend our understanding of the theory of emerging adulthood in relation to people
living with CP and highlighted how their experiences of the developmental processes and constructs of this theory are similar and different to their peers without disability. It has detailed the usefulness of the ICF as a framework to facilitate a detailed understanding of the influence of functioning and disability, and contextual factors, on the experiences of people with disability. Lastly, it has made methodological contributions that may guide future researchers in the implementation of narrative inquiries to understand the lived experiences of a diverse range of groups. In particular it has highlighted the value of narrative inquiry in hearing the stories of people experiencing vulnerabilities.

This research has identified many roadblocks on the journeys of emerging adults with CP. There is much scope to address these roadblocks and facilitate opportunities for young people with CP to experience a journey of emerging adulthood more consistent with their peers. Recommendations have been made for theory, research, policy, and service provision. It is hoped this research will prompt further efforts across all of these areas, and that emerging adults with CP in the future will have increased opportunities to ‘make their own path’ a path which truly reflects their aspirations and priorities. Emerging adults with CP recognise the importance of taking responsibility for their own path. Eliminating the many roadblocks they face on their journeys to adulthood however, is the responsibility of many. This research demonstrates the huge value in listening to the stories of the people we seek to support, and encourages us all to take on that responsibility.

“I have to make my own path through my life because nobody will do that for me”

Hayley
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Appendix A: Recruitment advertisement

YOUNG PEOPLE
HAVE YOUR SAY!

Want to tell it like it is? Want to say what it is like and what you need as you move from being an adolescent to being an adult? Want to tell us what the gaps and good things are? Then here’s your chance!

If you:
☑ Have cerebral palsy
☑ Are aged 18-25
☑ Are able to participate in interviews

then you can have your say about what life is like for you.

If you are interested in participating in this research study, or would like more information, please call
Nicole Sharp on (02) 4620 3591
or email n.sharp@uws.edu.au.
Appendix B: Participant information statement

Information Statement

Emerging adults with cerebral palsy: The transition from adolescence to young adulthood

Introduction
You have been invited to participate in this project because you are a young person, aged between 18-25 years, who has cerebral palsy. The researchers are conducting this project to gain an understanding of the experiences and goals of young people such as yourself. The researchers are Nicole Sharp, who is completing this project for a PhD at the University of Western Sydney (UWS), and her research supervisors Dr Anne Cusick, Rosalind Bye and Iona Novak. All of the researchers are occupational therapists.

What is involved?
This project will involve your participation in interviews with Nicole. The interviews will be conducted at a time and place convenient to you, and travel costs will be reimbursed if you can provide receipts. It is anticipated that the interviews will take between 1 and 3 hours each. You will be asked to be involved in at least 2 interviews, more if you feel that there are further issues you would like to discuss. With your permission, the interviews will be audio-taped and then later typed. This is so Nicole can concentrate on what you are saying during the interview and not have to take notes. Depending on what would be most suitable for you, there is also the option for some interviews to take place using email.

During the interviews Nicole will ask you some questions and explore issues that you raise. You can choose what to talk about; you do not have to talk about anything you do not feel comfortable with. There are no right or wrong answers; the aim is to find out about the different experiences that people with cerebral palsy have in the transition from adolescence to adulthood.

Nicole will also ask you to fill out 8 forms during the first interview. She will work through the forms with you and help you to fill them out if necessary. These forms
are questionnaires which aim to find out a bit more about you and your views. One will ask for general information, such as your age, gender, type of cerebral palsy, living situation and education. Another looks at your general health, and another two at your level of participation in certain areas. The fifth will ask you about future expectations, the sixth about quality of life, the seventh about what it means to be an adult, and the last about your views of this time in your life.

**Confidentiality**

Any information you provide in this research project will be considered confidential. Your name will not be recorded on the interviews when they are typed out, fake names will be used instead. The name of anyone else you mention during the interviews will also be replaced with a fake name. All records and audiotapes will be kept in a locked filing cabinet at the University of Western Sydney. All information you provide will be destroyed 5 years after publication of the research project. The results from this project will be presented in a thesis, at conferences and in journals or books, however you will not be able to be identified in any way. Your anonymous contribution to helping us understand the experiences of young people with cerebral palsy will be acknowledged.

**Benefits and Risks**

This project will lead to a better understanding of what life is like for young people with cerebral palsy. It will lead to knowledge about the experiences and goals for the future of young people such as yourself. It is hoped that this knowledge will help services and supports, developed in the future, to be relevant and meaningful to you and other young people who have cerebral palsy.

It is highly unlikely that there will be any risks to you by participating in this study. It is hoped that you will enjoy the experience of telling your story. Should you however become upset or uncomfortable during the course of this project Nicole or her supervisors, who are all qualified occupational therapists, will be happy to discuss any concerns with you or help you to find another person to talk to if you wish. Alternatively, you may phone the CP Helpline on 1300 13 29 20 (TTY: 1300 30 29 25; Translating and Interpreting Service: 131 450) to talk to a qualified person confidentiality. This person will talk with you about your concerns and, if you like, will refer you to a qualified social worker for counselling.

**Your rights**

Participation in this research project is voluntary. You have the right to withdraw from the project at any time, even in the middle of an interview, and you should do so if you feel uncomfortable or threatened in any way. Please be aware that if you do withdraw from the project, it will not affect your treatment at the Spastic Centre, or any other institution, in any way. If you choose to withdraw, the information collected from you will not be used in the study unless you give permission for this to occur. The information will be returned to you or destroyed at your discretion.

We appreciate your participation in this research project. If you have any questions, please do not hesitate to contact any of us (details below):

**Nicole Sharp**, BAAppSc(Hons)OT  
PhD Candidate, UWS  
**Telephone** (02) 4620 3591  
**Fax** (02) 4620 3792

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Manager, Research and Education
The Spastic Centre of NSW
Telephone (02) 9972 8148
E-mail ionovak@tscnsw.org.au

NOTE: This study has been approved by the University of Western Sydney Human
Research Ethics Committee. If you have any complaints or reservations about the ethical
conduct of this research you may contact the Ethics Committee through the Research
Ethics Officers (tel: (02) 4736 0883). Any issue you raise will be treated in confidence and
investigated fully, and you will be informed of the outcome.
Appendix C: Participant consent form

College of Science and Health

Informed Consent

Emerging adults with cerebral palsy: The transition from adolescence to young adulthood

Researchers’ Names: Nicole Sharp, Anne Cusick, Rosalind Bye, Iona Novak

Participant’s Name: …………………………………………………………………………

Methods and demands: This project will involve your participation in interviews with Nicole Sharp, a PhD student from the University of Western Sydney. The interviews will focus on your experience of transition from being an adolescent to being an adult. The interviews will be conducted at a time and place convenient to you, and any travel costs will be reimbursed. It is anticipated that the interviews will take between 1 and 3 hours each and you will be involved in at least 2 interviews. With your permission, the interviews will be audio-taped and then later typed out by the researcher. If suitable, some interviews may also take place using email. The researcher will also ask you to fill out 8 forms during the first interview, with her help if required. These forms are questionnaires which aim to find out a bit more about you and your views. Any information you provide in this research project will be considered confidential. You will not be able to be identified from the results of this research.

Benefits and risks: It is highly unlikely that there will be any risks to you by participating in this study. It is hoped that you will enjoy the experience of telling your story about transition from adolescence to adulthood and that this will be a beneficial experience. If you become upset or uncomfortable during an interview, you can either continue the interview or terminate it. Nicole is a qualified occupational therapist and is able to discuss concerns with you or help you to find another person to talk to if you wish. You can also ring one of the supervising
researchers who are occupational therapists, or the CP Helpline on 1300 30 29 20 (TTY: 1300 30 29 25; Translating and Interpreting service: 131 450).

**Your rights:** Participation in this research project is voluntary. You have the right to withdraw from the project at any time. If you do withdraw from the project, it will not affect your treatment at the Spastic Centre, or any other institution, in any way. If you withdraw, you can choose whether or not information collected prior to your withdrawal can be used for the research.

Having read the above information and the separate information statement, and having asked any questions you may have about this research, please read the following statements and tick the appropriate box.

I have had the purpose of the study explained to me. □

I have had the potential benefits and risks of the study explained to me. □

I have read and understand the information statement. □

I understand what I will be required to do during the study. □

I know that I do not have to take part in the study. □

I know that I am free to leave the study at any time, and that if I do, it will not affect my future treatment in any way. □

I know who the researchers are and I know how to contact them. □

I have been given a copy of the information statement to keep. □

I have had the opportunity to ask questions about the study and have had my questions answered appropriately. □

*If you agree with the above, please sign below*

Signed (Participant): ___________________________ Date:

Signed (Researcher): __________________________ Date:

Signed (Witness): _____________________________ Date:

Relationship: __________________________________

**NOTE:** This study has been approved by the University of Western Sydney Human Research Ethics Committee. If you have any complaints or reservations about the ethical conduct of this research you may contact the Ethics Committee through the Research Ethics Officers (tel: (02) 4736 0883). Any issue you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.
Appendix D: Interview guide

Interview guide: Narrative terrain of interviews

The interviews will commence with a broad opening question: "Can you tell me about your experience of life in the last few years"? Responses to this opening statement will be explored in depth with subsequent questions. Based on theoretical and research literature, it is possible to identify focus areas, or issues, which are likely to be identified as relevant and explored in-depth during the interviews. These focus areas include:

- Emerging adulthood
  - What being an ‘adult’ means and whether they feel they have reached adulthood
  - Identity
  - Instability
  - Possibilities
  - Focus of activities

- Body structure and function – impact of CP

- Activity and participation
  - Getting around, looking after themselves, home life
  - Relationships with parents, family, friends, peers and potential partners
  - Community involvement
  - Education, training and work experiences

- Environmental issues
  - Support and attitudes of others
  - Service provision
  - Issues in the physical environment

- Personal issues
  - Character traits – what makes you who you are?
  - Social background and impact on experiences
  - Goals, plans and hopes for the future

Not all focus areas will necessarily be discussed with every participant. The depth of discussion about each issue will vary depending on the relevance of that issue to the individual participant. The issues will not be discussed in the above order; the ordering of issues and specific questions to be asked will emerge in response to the progression of each interview. Due to the emerging nature of qualitative research, focus areas and questions will also be adapted as the interviews and concurrent analysis progress.
Appendix E: Published manuscript

This is the authors accepted manuscript of an article published as the version of record in International Journal of Social Research Methodology 3 March 2009
http://www.tandfonline.com/
http://www.tandfonline.com/doi/full/10.1080/13645570902752365
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Having their say: Email interviews for research data collection with people who have verbal communication impairment

Nicole L. Ison

Abstract
In-depth interviewing research methods traditionally rely upon face-to-face or telephone conversation between investigator and participant. Participation of people with verbal communication impairments has often been restricted in research studies using these methods; their stories have all too frequently been left unheard or told by proxies. This paper describes the use of email interviewing to rectify this gap and facilitate research participation by people with impaired verbal communication. Issues related to this method are detailed using literature, previous scholarship and the author’s research that explored the experience of people aged 18 to 25 who have cerebral palsy. Recruitment, informed consent, rapport development, data collection, storage and analysis techniques are described. Benefits and potential limitations of email interviews for both participant and researcher are identified. Offering an alternative to traditional verbal interviews can increase opportunities for participant involvement and enhance the quality and inclusiveness of research data.

Introduction
Qualitative research methods provide ways of understanding the experience of people living with chronic illnesses and disabilities and have the capacity to capture individual meanings, perspectives and differences. Understanding the views and experiences of people with disabilities is important in its own right, but is essential for people who design services and environments, and develop policies in this area. Qualitative research can inform service providers, promote services that are responsive, flexible and appropriate to the needs of individuals, and underpin policy that addresses priorities for people with disabilities. Listening to the stories of people with disabilities has also been recognised as a positive first step towards empowerment (Lloyd, Gatherer, & Kalsy, 2006). The challenge for qualitative research is not only in addressing issues and questions that are important to people with disability, it is in using the right techniques to reveal data that can only come from them. In studies that seek to understand the stories of people with disabilities, researchers all too frequently restrict the way in which these stories can be told. There is an assumption that experience will be shared through verbal means; through the traditional face-to-face interview, or telephone research. This prevents people who cannot physically converse from participating in research that may be of direct relevance to them and reserves participation for people who are verbally articulate. This barrier has been identified previously in literature in the following populations: people who have verbal communication impairments (Carlsson, Paterson, Scott-Findlay, Ehnfors, & Ehrenberg, 2007; Lloyd et al., 2006) learning disabilities (Kelly, 2007) or acquired brain injuries (Egan, Chenoweth, & McAuliffe, 2006; Paterson & Scott-Findlay, 2002).

Where qualitative research in these areas has taken place, researchers have often conducted proxy interviews with caregivers or healthcare service providers instead of exploring the experience of people with disabilities themselves. From an epistemological point of view this has clear limitations, as the knowledge gained will not be from the perspective of the person living the experience. Proxies often have a different perspective from that of the person with a disability; indeed they are likely to provide more information about their own experiences than those of the person with a disability (Carlsson et al., 2007; Lloyd et al., 2006). Given that people with these types of disabilities are likely to experience difficulties making their voices heard in everyday life, it seems particularly imperative that
attempts are made to elicit their experiences and perspectives in qualitative research (Lloyd et al., 2006). This paper presents an approach to data collection, which has been put forward in literature and applied in the author’s own research, for people with verbal communication impairment.

The author’s research explored the experience of young people with cerebral palsy aged 18 to 25 years (Ison, Cusick, Novak, & Bye, in progress). It utilised narrative inquiry to understand stories of ‘emerging adulthood’, providing an opportunity for young people to have their say about significant life experiences, hopes and goals as they transitioned into adulthood. In the course of recruitment, young people with cerebral palsy who had verbal communication impairment indicated their willingness and indeed enthusiasm to participate and share their experience. From a researcher point of view, the practical ‘hurdle’ of face-to-face in-depth interviews for data collection had to be overcome in order for these young people to share their perspectives. Following a careful search of scholarly literature relating to cerebral palsy, the experience of people with disability and qualitative methods, the technique of email interviewing was adopted to meet the communication needs of participants and their commitment to participating in a research project they valued.

**Alternatives to verbal communication**

Increased access to and use of the internet has resulted in alternatives to speech becoming mainstream with widespread uptake of computer-mediated communication (CMC) technologies. CMC technology is for everyone, but can be particularly useful for people who have verbal communication impairments. CMC refers to the use of computers in text-based communication. This includes synchronous, real-time communication through ‘chat rooms’ and instant messaging systems. CMC also includes asynchronous communication which commonly occurs through electronic email and discussion boards. Asynchronous electronic messages can be sent to recipients who can ‘read, reply, print, forward or file them at their leisure’ (Mann & Stewart, 2000, p. 2). Asynchronous communication is a convenient tool that can enhance communication. This may be particularly the case for people with disabilities, who may be precluded from participating in many environments where people socialise. Poorly designed public spaces, inflexible timetables and inhospitable environments all make it difficult for people with disabilities to participate. Those who have impairments in verbal communication, who have difficulty articulating words, are easily, or are not easily understood by others, experience additional challenges (Lloyd et al., 2006; Seymour & Lupton, 2004).

Many people with disabilities find the internet an appealing medium for social interaction. An online study of people with disabilities found participants used the internet as ‘an invaluable way to develop and maintain friendships’ (Seymour & Lupton, 2004, p. 294). CMC has been found to offer opportunities for mutual support and problem solving, information sharing, expression of feelings, catharsis, general social interchange unrelated to disability issues and the development of friendships and social relationships (Finn, 1999). Successful use of computer technology by people with disabilities is also proposed to be linked with independence, quality of life, a sense of control, and empowerment (Seymour, 2001). It is therefore not surprising that there has been increased recognition of the potential of CMC for research data collection in recent times, including use of email interviews. Email interviews have previously been utilised to explore, among others: stories of women who had experienced trauma during childbirth (Beck, 2005); lived experience of acquired brain injury (Egan et al., 2006; Padilla, 2003); narratives of children with long term health problems (Fleitas, 1998); psychological reactions to alopecia (Hunt & McHale, 2007); and use of information technology as a medium for social participation by people with disabilities.
(Seymour, 2001). To the author’s knowledge, the Ison et al (in progress) study is the first to use email interview methods with young people with cerebral palsy.

**Exploring the experiences of emerging adults with cerebral palsy**
Cerebral palsy is: ‘a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication and behaviour, by epilepsy, and by secondary musculoskeletal problems’ (Rosenbaum, Paneth, Levinton, Goldstein, & Bax, 2007). There are many types of cerebral palsy, varying levels of severity, and individuals can have a unique array of impairments that affect not only their daily life but their ability to participate in research data collection through interviews. Verbal communication impairments in particular can have a large impact on a person’s capacity to participate in research interviews. It is the author’s experience that people with cerebral palsy may: be physically unable to formulate words to communicate their ideas; restrict their verbal repertoire to reduce the physical exertion involved; get distracted by the physical effort of speaking; or fatigue before the scope of their intended communication has been completed. Many people with verbal communication impairments choose to use alternative and augmentative communication (AAC), including speech generating devices. However, those who prefer not to use AAC, or find it difficult because of disability related factors, may look to other forms of communication.

Research studies which aim to explore the experience of people with disability therefore need to consider how the presentation of the condition may influence communication, and thus data collection. In the case of the Ison et al (in progress) study, the likelihood of communication impairments was anticipated, but at study commencement it was thought face-to-face verbal or augmentative communication would be adequate given the researcher’s clinical background and willingness to participate in multiple interviews at locations and times convenient to participants. As recruitment went on, however, participants themselves expressed an interest in using other forms of communication for interviews more in keeping with their daily communication routines. They commonly used email conversations in social interaction, and therefore this method suited their needs and preferences and enabled them to participate in a research project that they valued. Face-to-face interviews using verbal or alternative and augmentative communication were therefore offered, along with email interviews. This paper explores considerations and adaptations related to the use of email interviews in qualitative research. Recruitment, informed consent, rapport development, data collection, storage and analysis techniques are described. Benefits and potential limitations of email interviews for both participant and researcher identified in this study are detailed in the light of previous research.

**Recruitment**
A number of purposive sampling strategies were used in the Ison et al (in progress) study to identify, notify and invite potential participants with cerebral palsy. Purposive sampling seeks ‘information-rich cases’ capable of providing the researcher with an in-depth understanding of issues relevant to the purpose of the study (Patton, 2002, p. 230). Recruitment strategies employed included online methods in addition to more conventional strategies. The study was advertised through a peak disability service provider for people with cerebral palsy; advertisements were displayed on noticeboards, in a variety of newsletters and publications, and the researcher met with professionals working with the target population. Advertisements were posted on relevant websites and included in an e-newsletter with a wide distribution. Snowballing techniques were also employed, whereby initial participants were asked to pass
on information about the study to other people with cerebral palsy in their networks. This multi-faceted approach to recruitment was successful, with eighteen young people being recruited for the study.

Other researchers who have used email interviews have recruited all their participants through means external to the internet, such as advertisements in newsletters (McAuliffe, 2003) or through organisations relevant to their research topic (Beck, 2005). Recruitment solely through online methods has been identified as a challenge (Mann & Stewart, 2000), but some researchers have employed this technique successfully (Seymour, 2001). Announcements or notices sent through internet sites or list-serves have been recommended as strategies that may elicit better recruitment if a short description of the study is provided and interested people are asked to request further information through an email address (Mann & Stewart, 2000). This technique was used in the Ison et al (in progress) study and was found to be successful; however the use of both online and other recruitment techniques in combination had the biggest influence on recruitment success.

Participants were provided with more detailed information about the research when they made contact with the researcher, and advised of the options available to them in terms of data collection formats. Four of the eighteen participants took up the option of email interviews. For three, this was a matter of convenience, timing or geography. Email was perceived to provide them with flexibility to be involved at their own pace and to fit participation in with other commitments, and also enabled participation of people from locations geographically distant to the researcher. These three young people chose to participate in a combination of email and face-to-face interviews during the course of data collection. The fourth participant chose to be involved solely in email interviews, as her verbal communication impairment precluded participation in verbal interviews. `Jody’ [pseudonym] has dyskinetic, athetoid cerebral palsy which involves both an abnormal pattern of posture and movement, and the presence of involuntary, uncontrolled movements (Rosenbaum, 2003). The difficulty Jody experiences in controlling movements extends to the muscles used when speaking; she has severe dysarthria. Speaking for Jody takes a high degree of effort and her speech is very slow and difficult to understand. Jody identified that email is a more suitable form of communication for her; she said 'it is better to interview me by email rather than coming to me because it is hard for you to communicate with my speech'. The remainder of this paper will explore issues related to informed consent, rapport development, and benefits and limitations of email interviewing. The experience of Jody’s participation in email interviews will form a focus of the discussion, and offer useful insights to researchers considering adopting this data collection method.

Informed consent and rapport development

The requirement for informed consent necessitates that the decision to participate in a research study is a voluntary choice based on ‘sufficient information and adequate understanding of both the proposed research and the implications of participation in it’ (National Health and Medical Research Council, 2007, p. 19). Ensuring informed consent is at least as important when using email interview methods as in face-to-face interviewing (Hunt & McHale, 2007). Researchers who have used email interviewing have dealt with the challenge of gaining informed consent in varying ways. Consent can be obtained in the usual fashion, with information statements and consent forms being sent and returned by postal mail. Information statements and consent forms can be made available for downloading online, allowing participants to print, sign, scan and email, or fax or mail back to the researcher. Human Research Ethics Committees may accept a yes or no typed response on the consent form which can then be emailed back to the researcher (Mann & Stewart, 2000), or a statement typed at the beginning of the participant’s first email response stating that they
understand what participation involves and that their responses confirm ongoing consent (McCoyd & Kerson, 2006). In the current study it was decided that maintaining traditional consent practices may have additional benefits. An initial face-to-face meeting was arranged to allow opportunities to provide written and verbal information about the study, for Jody to ask questions, and for written informed consent to be gained. This technique has previously been recommended for studies with limited numbers of participants (Hamilton & Bowers, 2006) and in this study was found to have the additional benefit of assisting rapport development between Jody and the researcher.

Through arranging a face-to-face meeting prior to commencement of the email interviews, Jody and the researcher were able to develop an initial level of rapport. Jody was able to see who she would be ‘speaking’ to through email and vice versa. The researcher was able to describe the study in detail, explain the rationale and methods, and answer any questions Jody had. Through meeting Jody at her home, the researcher was able to gain an understanding of Jody’s life context, and gather relevant background information that facilitated further rapport development during the email interviews. For example she saw where Jody lived, met her family, her dog and saw her DVD collection, all of which provided further opportunities for discussion during emails. Including these friendly and informal conversation points in emails supported the further development of rapport and trust, as did providing a level of personal disclosure at relevant points in the discussion (Mann & Stewart, 2000). The researcher used friendly opening statements, and closing statements which expressed gratitude toward Jody’s participation, and acknowledged previous comments and feelings expressed by Jody, as recommended by McAuliffe (2003). A swift response to emails was also identified as important; efforts were made to respond within 24 hours to establish a sense of “conversation”. Even if the next set of emailed questions could not be included at this time, effort was taken to acknowledge receipt of the email, and thank Jody for her ongoing participation. These strategies were appreciated by Jody and made the exchanges satisfying and rewarding in terms of rapport building and data received for the researcher.

Data collection, storage and analysis
Retention of participants through the email interview process may be a challenge. Mann and Stewart (2000) indicate that, like in other studies, it is the individuals’ experience of the process that influences whether or not they continue as participants. They suggest it is the role of the researcher to make the email experience as interesting and fulfilling as possible to retain participant interest. Various techniques were utilised in email interviews with Jody to promote a positive experience. A key factor in the ongoing success of the interviews was ensuring that Jody felt she was being listened to and that her responses were valued. The researcher provided regular feedback to Jody reassuring her that her responses were relevant and appreciated, for example ‘it was great to learn about your time at university and your experiences, these are exactly the sorts of things I am interested in learning about’. She also made an effort to respond promptly to emails, to express particular interest in points made, and ask follow-up questions to gain more detailed information or examples (Mann & Stewart, 2000).

Similar questioning techniques to those used in face-to-face interviews were found to be useful. The techniques of ‘funnelling’, whereby initially broad and general questions are followed up by later use of more specific and personal questions (Minichillo, Aroni, Timewell, & Alexander, 1995), and ‘recursive questioning’, where the answers to one question lead to the next series of questions (Schwartz & Jacobs, 1979), were both used widely. The researcher found it possible to use these techniques to good effect between subsequent emails as long as steps were taken to maintain a conversational style. It was helpful to reiterate what was said in a previous email prior to asking a new series of questions.
For example ‘thank you for sharing in your last email a bit about how people judge you based on your disability. Would you mind giving me a few examples of times when this has happened? Where does it usually happen? How does it make you feel?’

While similar questioning techniques were used in the email interviews as in face-to-face interviews, it was necessary to take additional steps to ensure the security of the data collected by email. As recommended by McAuliffe (2003), the researcher confirmed with Jody prior to commencement of data collection that her email system was password protected and not able to be accessed by others. Likewise the researcher ensured that her own system was similarly protected. Data was managed by ensuring that email interviews were printed and hard copies kept in a locked filing cabinet. The email messages were also copied into a single Word document in chronological order with the dates included. All identifying information was removed from this document and it was stored on a password protected computer system under Jody’s participant number. Following these measures and after replying, the original emails were deleted. This data storage method was found to be successful and secure, and similar techniques have been reported in other research using email interviews with good effect (McAuliffe, 2003).

Email interviews with Jody were conducted over an 18 month period. The researcher emphasised to Jody numerous times over the course of data collection that she could cease the interviews at any point. The following was indicative of her response: ‘I don’t mind answering your questions, when I have shared all that I want to share I will let you know but I am finding it quite interesting to do’. A total of 42 email interviews took place; each consisting of the researcher’s emailed interview questions and Jody’s response. The email interviews produced over 13000 words of data for analysis. The depth and richness of data was comparable to that gathered from face-to-face interviews, and indeed much more detailed than the limited responses Jody would have been able to share verbally. The same paradigmatic data analysis techniques, whereby phrases are coded and categorised under common themes (Polkinghorne, 1995), were successfully used to analyse both email and face-to-face interview data.

Benefits of email interviewing for participants
The key benefit of participating in email interviews for Jody was that she was able to have her say in a study from which she would otherwise have been excluded. Her severe verbal communication impairment means that her spoken communication is extremely limited. Attempting to participate in face-to-face interviews would have been exhausting and frustrating for Jody as she struggled to make herself understood. Jody found email to be a much more successful form of communication as she was able to type messages at her own pace and ensure the meaning was clear. Email also gave her the opportunity to provide a lot more detail than would have been possible verbally. Email interviews may have similar benefits for other people who may find face-to-face interviews inconvenient or difficult. Email interviews can provide opportunities for people with various circumstances access to research participation, including people with personal care needs, fatigue or concentration difficulties, parents with small children at home, shift workers (Mann & Stewart, 2000), populations who are often socially marginalised (Mann & Stewart, 2000; Nicholson, White, & Duncan, 1998), and people who are geographically isolated from the researcher (Lakeman, 1997).

Email interviews are also convenient for participants. They can write as often as they like, when they like, and where they like; most often from the comfort of their own home (Mann & Stewart, 2000). They can extend on particular topics, qualify points and clarify their responses over time. It has been said that email interviews help make the contribution of participants more equal, as they, as much as the researcher, can revisit data, control where the
direction of discussion goes, and influence the nature of research processes (Seymour, 2001). In comparison to a single face to face interview, email interviews offer participants a ‘much more generous opportunity to express their views and to influence the research outcomes’ (Seymour, 2001, p. 152). Because the thread of email is continually available, it means that discussion can draw on any material, rather than relying on recall of information from past interviews (Seymour, 2001). Research has shown that participating in email interviews can also be cathartic for participants. Beck (2005), in her study with women who had experienced trauma during childbirth, found that through email interviews participants felt they were being ‘listened to’ and acknowledged; had a sense of belonging; had an opportunity to ‘make sense of’ and ‘let go’ of their experience by writing it down; felt empowered by telling their story in their own words; were given a purpose of helping others through their writing; and were given a ‘voice’ where previously they had none (Beck, 2005, p. 411).

Benefits of email interviewing for researchers
Extending the range of participants who can potentially be involved in research is the key benefit of email interviews for researchers. As detailed above, offering alternatives to face-to-face interviews enables research to be more ‘incorporative’ (Seymour, 2001, p. 147). If only face-to-face interviews were offered in the Ison et al. (in progress) study Jody would have been excluded from participating. A gap in data would have resulted whereby rich and extensive descriptions of her experience, not given ‘voice’ through other methods, would have remained silent. Her story would not have been told; in part because no one had previously asked her, and in part because traditional methods would not have allowed it.

There are many additional practical benefits for the research investigator when email interviewing is utilised. Data collection and transcription is simultaneous as the participants’ written text forms the transcript. This can save a significant amount of money as no transcription costs are associated with data collection, and also time, as transcripts are immediately available for analysis. In addition, data collection can take place at any time convenient to the participant and researcher, even across time zones or vast distances (Roberts & Woods, 2000). There is no need to travel to face to face interviews, which further reduces costs associated with data collection (Mann & Stewart, 2000). Email interview data is also immediately complete, which is rarely the case in transcribed interviews. Participants have the chance to ‘clean up’ their responses before they send them. They can take the time to reflect on their answers, often leading to responses which are detailed, thoughtful and richer than those possible in the immediate environment of a face-to-face interview (Mann & Stewart, 2000; McCoyd & Kerson, 2006, p. 397). Additionally, email interviews allow a longitudinal aspect to emerge from the data, which is not possible from single face-to-face interviews (McCoyd & Kerson, 2006). Similarly, it allows researchers a ‘second chance’; to ask follow-up questions, clarify information and gather more detail. This was certainly evident in interviews with Jody; follow up emails gave the opportunity to ask for examples, explore feelings and experiences in depth and clarify comments to ensure an accurate understanding was developed. It has also been identified that the email interview method may lead to greater participation rates in research dealing with sensitive topics; participants may feel more comfortable answering sensitive questions through the medium of email than in a face-to-face situation (Mann & Stewart, 2000; McCoyd & Kerson, 2006). While there are multiple benefits to the researcher of conducting interviews via email, “it must be remembered that the point of email interviewing is to provide another means for research participants to take part in studies important to their lives and not to create a research design that is the most convenient one for the researcher” (Hamilton & Bowers, 2006, p. 830-1). As was the case in the Ison et al. (in progress) study, the aim of using email interviews is to provide participants
‘a means of engaging in research where it would not otherwise be possible’ (Chen & Hinton, 1999, p. 9).

Potential limitations of email interviewing
Despite the many benefits of email interviews for both participants and investigators, there are limitations that should be considered in research design and conduct. These are both practical and theoretical. Practically, barriers to potential participant involvement can arise if they do not have sufficient education to be able to read and communicate in written form, don’t have capacity or skill to use a computer, don’t have access to a computer or an email account, or don’t have an interest in using a computer to participate in research (Fleitas, 1998). Email based interviews restrict participation to people who have access to the internet. Economics, culture, age, gender and language may all influence whether this access is available, or even desired, by a potential participant (Mann & Stewart, 2000), which may have implications for recruitment. In the Ison et al (in progress) study, some participants reported that typing was very limited by their physical disability, which would have made participating in this research by email challenging, impractical, or even impossible. For this reason it is recommended that email interviews are offered as an alternative, rather than as the only option for data collection, particularly in research with people with disabilities. While email interviews may be ideal for some potential participants, offering this method in isolation is likely to create as much exclusion as what it solves.

On a theoretical note, if email interviewing is utilised in isolation, the data is ‘faceless’ and ‘body-less’. This creates key challenges to traditional notions of qualitative data. Qualitative research has historically been characterised by face-to-face encounters and the social interaction between researcher and participant has been seen as critical to the construction of data (Seymour, 2001). The human body has been identified as central to the development and maintenance of social encounters (Goffman, 1959), with voice qualities, body language and facial expressions seen to add ‘layers of meaning to human communication’ (Seymour, 2001, p. 156). The absence of the body in research communication by email changes the nature of assumptions about the research process. It also creates possible concerns about the truth and veracity of the data collected. There is a risk that email interviews may not be authored by the intended participants. Researchers must assume in good faith both that the responses are authored by the person they believe they are, and that the responses are accurate rather than façade responses (Fleitas, 1998; Seymour, 2001). In response to these challenges, Seymour (2001) argues that we should feel no more or less confident with this data than with data collected in face-to-face situations as participants in face-to-face interviews are also able to create their own ‘invisibilities’ (Seymour, 2001, p. 163).

Additional steps were taken in the Ison et al (in progress) study to reduce the impact of ‘body-less’ communication and increase the likelihood that data collected was authentic. As discussed, the researcher met with Jody face-to-face prior to commencings the email interviews. This enabled the researcher and participant the opportunity to develop both rapport and a level of background knowledge which could be later used to verify the accuracy of email interview data. The researcher actively sought a level of detail about the type and intensity of emotions Jody was feeling as she communicated her experiences, and encouraged her to use ‘emotions’, including smiling, frowning and angry faces, as a symbol-based representation of these emotions. Special care was taken when formulating responses and questions to ensure that accurate messages were portrayed, and to reduce the risk of inadvertent misunderstandings which may lead to confusion or offence. In this research, detailed data rich with emotions was gathered without the use of speech or body language. It is suggested that as long as care is taken to develop and maintain rapport, and facilitate clear
and detailed communication, email interviews have the potential to collect ‘rich data that has comparable credibility to traditional interviewing formats’ (McCoyd & Kerson, 2006, p. 404).

Conclusion
This paper has provided a detailed discussion of issues surrounding the use of email interviews for qualitative research data collection. It has explored the author’s use of this method in a study with young people with cerebral palsy who had verbal communication impairments, and provided practical examples along with reflections on previous research. Techniques utilised to recruit participants, gain informed consent, develop rapport and collect and analyse data in face-to-face interviews were found to be just as effective when adapted for use in an email environment. Additional steps employed to counter potential limitations of the method were described, including techniques utilised to ensure maintenance of rapport, veracity of data, and collection of detailed and rich accounts. Benefits of email interviews for both participant and researcher were outlined, including the convenience, time and cost savings, and opportunity to gain a longitudinal perspective and clarify points over time. However, the overwhelming benefit of this method remains its capacity to facilitate participation in research by individuals who are unable to participate in face-to-face interviews. This paper has described in depth this benefit for people with verbal communication impairments; people whose views have typically been restricted in research studies using interview methods and whose stories have often been left unheard. Similar benefits of email interviews may also extend to other groups who are excluded from participating in face-to-face interviews, including people with personal care requirements, fatigue or concentration difficulties, people from socially marginalised groups and people who are geographically isolated. Email interviews offer one alternative to face-to-face verbal interviews that can increase inclusiveness of research data and provide an opportunity for people, who would otherwise be excluded, to have their say.

Acknowledgements
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Appendix F: Example of analysis of narratives

Kelly, a young woman in her early 20s, is an example of how personal narratives can provide insights into complex social issues. Kelly’s journey is marked by resilience and determination, reflecting the power of individual stories in shaping our understanding of the world.

Kelly was raised in a family of four, with two older siblings and a younger brother. From a young age, she was aware of the financial struggles her family faced, and this influenced her academic pursuits. Despite her family’s limitations, Kelly excelled in her studies, earning good grades and gaining admission to a university.

In college, Kelly encountered challenges that tested her resolve. She faced pressure to conform to societal expectations, especially regarding her appearance and behavior. These pressures were compounded by a lack of support from her family, who could not afford the extra expenses associated with higher education.

Despite these obstacles, Kelly remained committed to her goals. She sought mentorship and guidance from teachers and peers who recognized her potential and encouraged her to pursue her dreams. Through her determination and hard work, Kelly not only completed her degree but also made valuable connections that would benefit her career.

Kelly’s story is a testament to the enduring power of personal narratives. It highlights the role of resilience and support in overcoming adversity and achieving success. By sharing her story, Kelly contributes to a broader understanding of the experiences of young adults from disadvantaged backgrounds.

Kelly’s journey is an example of how individual narratives can shed light on larger social issues. It underscores the importance of resources and support systems in enabling individuals to realize their potential. Through such narratives, we can gain insights into the complexities of personal experience and the broader social contexts within which these experiences are situated. Kelly’s story is a call to action for fostering environments that support and empower young adults like her, recognizing the value of their contributions to society.
Appendix G: Ethics approval: Western Sydney University

Dear Nicole,

Re: HREC 05/117 Emerging adults with cerebral palsy: The transition from adolescence to young adulthood

The Committee has reviewed your responses to the issues raised and the project mentioned above has now been fully approved.

You are advised that the Committee should be notified of any further changes to the research methodology should there be any in the future. You will be required to provide a report on the ethical aspects of your project at the completion of this project. The form is located on the Research Services Ethics Web Page.

The Protocol Number HREC 05/117 should be quoted in all future correspondence about this project. Your approval will expire 31 March 2007. Please contact the Human Ethics Officer, Kay Buckley on tel: 02 47360885 if you require any further information.

The Committee wishes you well with your research.

Yours sincerely

[Signature]
Professor Elizabeth Deane
Chairperson
UWS Human Research Ethics Committee
Cc Professor Anne Cusick

University of Western Sydney
Appendix H: Ethics approval: Cerebral Palsy Alliance

04/07/2004

Nicole Sharp
C/O University of Western Sydney

Dear Nicole Sharp and Professor Anne Cusick,

RE: Emerging adults with cerebral palsy: The transition from adolescence to young adulthood

Your application for research and ethics approval from The Spastic Centre has been approved. Please attach a footer to Appendices A, C, D and E and call these Version 1. If you wish to change these in the future please send a copy to the Ethics Committee for review.

This project is now approved for a period of three years. If you need further time to complete the project you will be required to request an extension.

Please supply a one-page summary of your progress on a yearly basis to the Ethics Committee commencing July 2006. A final report on completion and notification of any publications from this project is also requested.

The Ethics Committee wishes you well with this important project.

Yours sincerely

Sarah McIntyre
Research Fellow
On behalf of Research and Ethics Committee

The Spastic Centre
159 Alexander Road
Mounts Bay, NSW 2011
PO Box 146 Bardia 2130

T 02 9451 1000
F 02 9451 1277
t spastic@spastic.org.au
w www.spastic.org.au

384
Appendix I: Ethics approval: University of Wollongong

University of Wollongong

INITIAL APPLICATION APPROVAL
In reply please quote: HE11/425
Further Enquiries Phone: 4221 4457
GH:CJ

20 October 2011

Ms Nicole Sharp

Dear Ms Sharp,

I am pleased to advise that the Human Research Ethics application referred to below has been approved.

Ethics Number: HE11/425
Project Title: Emerging adults with cerebral palsy: The transition from adolescence to young adulthood
Researchers: Ms Nicole Sharp, Professor Anne Cusick, Ms Rosalind Bye, Mr Jeffrey Amett
Approval Date: 20 October 2011 (Transferred from UWS)
Expiry Date: 19 October 2012

The University of Wollongong/llawarra Shoalhaven Local Health District Social Sciences HREC is constituted and functions in accordance with the NHMRC National Statement on Ethical Conduct in Human Research. The HREC has reviewed the research proposal for compliance with the National Statement and approval of this project is conditional upon your continuing compliance with this document.

A condition of approval by the HREC is the submission of a progress report annually and a final report on completion of your project. The progress report template is available at http://www.uow.edu.au/research/so/ethics/UOW009385.html. This report must be completed, signed by the appropriate Head of School, and returned to the Research Services Office prior to the expiry date.

As evidence of continuing compliance, the Human Research Ethics Committee also requires that researchers immediately report:

- proposed changes to the protocol including changes to investigators involved
- serious or unexpected adverse effects on participants
- unforeseen events that might affect continued ethical acceptability of the project.
Please note that approvals are granted for a twelve month period. Further extension will be considered on receipt of a progress report prior to expiry date.

If you have any queries regarding the HREC review process, please contact the Ethics Unit on phone 4221 3386 or email rse-ethics@uow.edu.au.

Yours sincerely

A/Professor Garry Hoban
Chair, Social Sciences
Human Research Ethics Committee

Cc Professor Anne Cusick, Faculty of Health and Behavioural Sciences, Bldg 41.207
## Appendix J: Mapping of themes against theoretical constructs

### Mapping of themes against constructs from the theory of emerging adulthood

<table>
<thead>
<tr>
<th>Theme</th>
<th>Emerging adulthood (EA) construct</th>
<th>Identity exploration</th>
<th>Instability</th>
<th>Possibilities</th>
<th>Feeling in-between</th>
<th>Self-focus</th>
</tr>
</thead>
<tbody>
<tr>
<td>The journey to find myself: Identity exploration</td>
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<tr>
<td></td>
<td>Identity exploration was inherent to EA stories and thus recognised as a key theme.</td>
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<tr>
<td></td>
<td>Worsening mobility for some EAs created instability and a need to redefine identity.</td>
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</tr>
<tr>
<td>Dealing with roadblocks: Resilience</td>
<td>×</td>
<td>×</td>
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<td></td>
<td>EAs had varying views of their possibilities. Higher levels of resilience seemed to contribute to a positive belief of possibilities.</td>
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<td>Supporting others’ journeys: Altruism</td>
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<tr>
<td></td>
<td>EAs positive about their future possibilities showed high levels of altruism towards others with disability.</td>
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<td></td>
<td>In contrast to self-focus, many EAs revealed a strong other-focus, especially those who felt positive about their own journey.</td>
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</tr>
<tr>
<td>It’s a hard road: Mental health problems</td>
<td>×</td>
<td>×</td>
<td></td>
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<tr>
<td></td>
<td>Identity exploration for half of EAs was challenging and contributed to mental health problems.</td>
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<tr>
<td>Theme</td>
<td>Emerging adulthood (EA) construct</td>
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<tr>
<td>Telling others about my journey: Disclosure</td>
<td>Identity exploration for EAs with milder CP included challenging decisions about disclosure.</td>
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<td></td>
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<td>✗</td>
<td>✗</td>
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</tr>
<tr>
<td>Finding my place: Friendships</td>
<td>EAs identity exploration included decisions around the qualities of true friends. Most were comfortable with having a few close friends.</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
<td></td>
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</tr>
<tr>
<td>My journey is limited: Romantic relationships</td>
<td>Experiences were in contrast to other EAs – there was a lack of instability, and few EAs had experienced relationships.</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
<td></td>
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</tr>
<tr>
<td>Changing direction and help with navigation: Education pathways</td>
<td>Instability and changes of education direction were quite common, consistent with EAs without disability.</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
<td></td>
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</tr>
<tr>
<td>A bumpy road: Finding the right job</td>
<td>Some EAs experienced instability trying to find suitable work.</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
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</tr>
</tbody>
</table>

**Legend:**
- ✗: Present
- ✗: Absent
- ✗: Partially Present

388
<table>
<thead>
<tr>
<th>Theme</th>
<th>Emerging adulthood (EA) construct</th>
<th>Identity exploration</th>
<th>Instability</th>
<th>Possibilities</th>
<th>Feeling in-between</th>
<th>Self-focus</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Controlling my journey:</strong> Negotiating an adult relationship with parents</td>
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<td>❌</td>
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<td>Self-focus, including control over one’s life was important to EAs, but limited for some by over-protective parents.</td>
</tr>
<tr>
<td><strong>My crew:</strong> Personal care and health services</td>
<td></td>
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<td>❌</td>
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<td>❌</td>
<td>Some EAs showed self-focus through decisions to no longer access health services. In contrast, inflexible personal care services restricted the ability of those EAs who relied on them to demonstrate self-focus.</td>
</tr>
<tr>
<td><strong>The open road or a traffic jam:</strong> Transport options</td>
<td></td>
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<td>❌</td>
<td>❌</td>
<td>Self-focus was easier for those who could drive and had a car, and limited for those without independent transport.</td>
</tr>
<tr>
<td><strong>Funding my journey:</strong> Opportunity costs</td>
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<td>❌</td>
<td>❌</td>
<td></td>
</tr>
<tr>
<td>Theme</td>
<td>Identity exploration</td>
<td>Instability</td>
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<td>Feeling in-between</td>
<td>Self-focus</td>
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</tr>
<tr>
<td>Off the beaten track: The limits of a rural location</td>
<td>✗</td>
<td>✗</td>
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<td>✗</td>
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</tr>
<tr>
<td>Possibilities to access services, education, employment and the community were more limited for those living in rural locations.</td>
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<tr>
<td>Are we there yet? Clarifying what it means to be adult</td>
<td>✗</td>
<td>✗</td>
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<tr>
<td>The majority of EAs felt in-between, in accordance with peers without disability. Accepting that their adulthood may look different was hard for some.</td>
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</tr>
</tbody>
</table>
### Mapping of themes against constructs from the ICF

<table>
<thead>
<tr>
<th>Theme</th>
<th>ICF construct</th>
<th>Functioning and disability</th>
<th>Contextual factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>The journey to find myself: Identity exploration</td>
<td>Impairments to body structures and functions were rarely mentioned. Many emerging adults (EAs) knew little about their CP; it was not important to their identity.</td>
<td>Activity limitations caused by worsening mobility in EA caused identity challenges for some participants.</td>
<td>Identity exploration was influenced by such personal factors as confidence and self-concept.</td>
</tr>
<tr>
<td>Dealing with roadblocks: Resilience</td>
<td>EAs had clear goals for participation in education, work, domestic life, relationships and social life. They also faced many barriers to participation.</td>
<td>Resilience helped some EAs overcome barriers they faced. Others were less resilient and felt their possibilities were out of their control.</td>
<td>Environmental barriers including physical and attitudinal barriers greatly influenced EAs’ possibilities, creating numerous roadblocks for some.</td>
</tr>
<tr>
<td>Supporting others’ journeys: Altruism</td>
<td>Altruistic activities formed an important part of some participants’ community, social and civic life.</td>
<td>Altruistic character traits were demonstrated, particularly by EAs who were comfortable with their own journey.</td>
<td></td>
</tr>
<tr>
<td>It’s a hard road: Mental health problems</td>
<td>Body functions of some participants were influenced by diagnosed depression and/or anxiety.</td>
<td>The significant pressure and workload of participating in education contributed to poor mental health for some EAs.</td>
<td>Coping styles and self-esteem influenced mental health.</td>
</tr>
<tr>
<td>Theme</td>
<td>ICF construct</td>
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<td>Functioning and disability</td>
<td>Contextual factors</td>
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<tr>
<td></td>
<td>Body structure and function</td>
<td>Activities and participation</td>
<td>Personal factors</td>
</tr>
<tr>
<td>Telling others about my journey: Disclosure</td>
<td>EAs with milder impairments had to make decisions about disclosure.</td>
<td>Disclosure had to be considered in relation to participation in school, tertiary and work settings.</td>
<td></td>
</tr>
<tr>
<td>Finding my place: Friendships</td>
<td>Participation in friendships was a challenge for some EAs, although most had a small number of good friends.</td>
<td>Poor experiences in the past had impacted some EAs self-esteem.</td>
<td>Environmental barriers including exclusion and bullying made it difficult for some EAs to develop reciprocal friendships.</td>
</tr>
<tr>
<td>My journey is limited: Romantic relationships</td>
<td>Participation in romantic relationships was restricted for almost all EAs, although they desired it.</td>
<td>Negative past experiences in this area influenced self-esteem of many.</td>
<td>Attitudes of, and non-acceptance by, others were environmental barriers that restricted relationships for most EAs.</td>
</tr>
<tr>
<td>Changing direction and help with navigation: Education pathways</td>
<td>Participation in school and tertiary education was important to EAs, and featured heavily in stories.</td>
<td></td>
<td>Service provision in education settings could either facilitate or create barriers to participation.</td>
</tr>
<tr>
<td>A bumpy road: Finding the right job</td>
<td>Experiences of employment and unemployment were important to EA stories.</td>
<td></td>
<td>Discrimination was a barrier to employment for many. Ineffective employment services were also noted as a barrier, while flexible working conditions facilitated participation.</td>
</tr>
<tr>
<td>Theme</td>
<td>ICF construct</td>
<td>Functioning and disability</td>
<td>Contextual factors</td>
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<tr>
<td>Controlling my journey: Negotiating an adult relationship with parents</td>
<td>EAs participation was restricted in terms of domestic life with all except one EA still living at home. Activity restrictions impacted independence, with many participants still requiring a lot of assistance from parents.</td>
<td>Limited financial resources impacted the ability of most EAs to increase independence from parents.</td>
<td>Overprotective parents were an environmental barrier for some EAs.</td>
</tr>
<tr>
<td>My crew: Personal care and health services</td>
<td>Reliance on personal care and health services was impacted by the level of functional impairment. Some EAs relied on assistance to participate in self-care activities. Spontaneity of participation in the community was restricted by inflexible personal care services.</td>
<td>Poor transitions and a lack of flexible services were environmental barriers to participation for EAs with more complex needs.</td>
<td></td>
</tr>
<tr>
<td>The open road or a traffic jam: Transport options</td>
<td>Severe functional impairments restricted capacity to drive</td>
<td>Access to transport facilitated or restricted participation in activities of choice. Capacity to drive was a major facilitator.</td>
<td>Participation was restricted by poor transport services, and facilitated by parental assistance or access to a car.</td>
</tr>
<tr>
<td>Funding my journey: Opportunity costs</td>
<td>Access to financial resources could either facilitate or restrict opportunities for participation.</td>
<td>Socio-economic background influenced the opportunities afforded to EAs.</td>
<td>Access to finances to purchase environmental facilitators including private therapists or assistants, equipment and modifications significantly facilitated participation.</td>
</tr>
<tr>
<td>Theme</td>
<td>ICF construct</td>
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<td>Personal factors</td>
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<tr>
<td></td>
<td>Environmental factors</td>
<td></td>
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</tr>
<tr>
<td>Off the beaten track: The limits of a rural location</td>
<td>×</td>
<td>Opportunities to access education, employment, transport and the community were restricted in rural areas, impacting participation.</td>
<td>×</td>
</tr>
<tr>
<td>Are we there yet? Clarifying what it means to be adult</td>
<td>EAs believed that independent physical functioning was not required to be considered an adult.</td>
<td>Some EAs believed that to be an adult they would need to work full time, move out of home and/or manage their own supports.</td>
<td>EAs believed personal traits were most important to being an adult, including taking responsibility, making independent decisions, and maturity.</td>
</tr>
</tbody>
</table>
Appendix K: List of publications and conference presentations related to PhD Candidature

Publications


Book Chapters


Conference presentations


**Sharp, N., Cusick, A., Novak, I., & Bye, R. (2006).** Having their say: Email-based interviews as a means of increasing access to qualitative research for young people with dysarthria. *ACSPRI Social Science Methodology Conference*, University of Sydney, Sydney, 10-13 December, 2006.