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Meeting the information needs of carers of children with disabilities: a case for the use of virtual communities

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Abstract

From the initial diagnosis parents of children with a disability need timely and accurate information to effectively manage their child's condition. Focussing on the findings of a collaborative research project examining the needs of parents of children with a disability (0-12 years) the study identifies several information related factors adding to parental stress levels. These include a lack of awareness of support services, application processes, and disability specific information. To overcome the limitations of existing information delivery approaches we propose creating a wiki-based virtual community to serve as a user friendly "one-stop shop" for carers . Such a community would give them greater access to the lived experience and empathy of other parents who have successfully managed their childs condition.

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Introduction

Many nonprofit organizations (NPOs) exist for the sole purpose of meeting the specific needs of a particular disability group such as Vision Australia, Epilepsy Action. These NPOs rely on government funding, donations and volunteers to help deliver their much needed services. These services add significantly to the quality of life of their clients providing much needed assistance. While these NPOs focus significantly on service delivery one area in which they often struggle is in assessing and planning for the needs of their client groups. Gaining the necessary insights from their client groups can be problematic for two reasons, they often lack the requisite research skills to survey their client groups, or, simply cannot justify the allocation of service delivery funding to conduct such research.

Such research skills do however exist within the tertiary sector and this paper presents the findings of a community engagement project between the Centre for Social Marketing Research, University of Wollongong partnered with the Disability Trust (DT), a community-based organisation that has provided a range of disability services (for example respite care, vocational training, support groups) to the community for over 30 years, to conduct a comprehensive investigation into the current and anticipated needs of children with a disability (aged 0–12) within the local community.

Two significant findings emerged from the study, first, the lack of government funding for areas of urgent need such as access to respite care, therapy services, early intervention programs and specialized equipment such as wheelchairs, walkers and communication devices.

The second finding relates to communication and information issues for parents and carers. We found that the current information transfer approaches adopted by NPOs and government agencies are not as effective in meeting needs as parents require. Repeatedly during the project, it emerged that being aware of the availability of different support services, eligibility criteria for different services, application processes, information on a child's specific disability, where to go for family help were major issues for parents and carers. Not being able to access information solutions quickly added significantly to the normally high levels of stress, anxiety and family tension associated with caring for a child with a disability.

In this paper we provide qualitative evidence which identifies the difficulties parents and carers face in relation to communication and information transfer. We then use these findings to frame our proposed solution to the problem, a wiki-based virtual community and justify it based on evidence from other studies. The following sections of this paper describe the research methodology used and present some qualitative findings.

Methodology

We used a mixed method research approach. Three focus groups were conducted to determine key issues and a questionnaire developed using a combination of existing measurement scales and new questions. The questionnaire included structured questions and an opportunity for respondents to give written comments at the end of each section. The draft questionnaire was sent to other local nonprofits in the disability sector for their input and to garner support for its distribution to their clients. After a pretest the survey was distributed to the nonprofits that had agreed to participate resulting in 180 returned questionnaires, a 39.6% response rate.

Study Findings

Specifically, five themes emerge regarding the information needs of parents and carers:

1. Frustration from a lack of awareness of services:

"more formal information services to parents so we can find out what services there are. I find we often "stumble" to find services we are not informed of."

"My main concern is not being aware of all the services, agencies, or departments that may be able to assist our family. Just knowing who to contact can ease a lot of the stress felt by parents when trying to decide important things like schooling, therapies, equipment needs"

2. Frustration from the effort required to obtain information due to no centralization:

"It is very frustrating – no one body has all the information needed. Lots of running around, pushing and shoving, jumping through paperwork hoops."

"It is a matter of hard work searching and finding out for oneself what services/assistance are available"

"We need a place to contact after we find out a child's problem and then ALL the info is sent out to us."

3. Access to the experience, knowledge and empathy of other parents in similar situations:

*"I would like a support group to just talk to other parents about **REAL** issues that happen 24/7 to help learn skills."*

"We are just entering into the system – I am finding the process very slow and unless you ask you won't be told. I have found out more by talking to other mums"

4. Distress due to no information at diagnosis:

"When my child was diagnosed by a paediatrician, no information was given to me at all. I had to research autism myself. I used local libraries"

> *"As I had NO information given to me when my son was diagnosed ... a booklet would have helped me enormously and would have taken a lot of the stress out at that time"*

5. High levels of stress due to uncertainty about their child's future:

> *"Despite there being a multitude of providers/services I don't even know what our future holds, with school, post school, respite care. I spend all my energy helping us survive the present."*

> *"If parents had more information on what to expect for the future care of their child, when they are older.... I believe we could cope better now and do a better job if some of the worry and anxiety were relieved."*

Implications of findings

Seeking answers to questions plays a significant role in the management of a child with a disability. To successfully manage their child's condition parents require information on crucial matters such as health care provision, social service provision and education at a time when they need it and in a form that they can use it (Blackburn and Read, (2005a). Unfortunately, Mitchell (2001) found parents and carers of disabled children frequently found information seeking a confusing, stressful and erratic experience and many people felt that they received the most information from other parents. Our findings are similar, a large number of respondents (41% of 156 responses) felt that information about accessing services, funding and other aspects of caring for a child with a disability was rarely or never available.

The need for a *single* point of contact for all information needs is critical. In all, 89% of parents and carers indicated that their child's level of care would improve if such a system was in place and could provide them with the information from a centralized point. On the face of these parent comments developing a centralized on-line information source would be a way to help reduce the stress and frustration of parents and carers.

A greater use of the internet for centralizing information seems like the obvious solution. In their UK study of internet usage amongst parents with disabled children, Blackburn and Read (2005a) identify several reasons for the increased use of the internet: (1) it is becoming a mainstream method of delivery of public and private information and services, (2) it can offer specialized information for parents and patients, (3) it is already a well developed source of social and health related information, (4) it can deliver vast amounts of information quickly and in a flexible manner, (5) it has the ***potential*** for computer-mediated social support, self-help, chat rooms, exchange of lay knowledge and so forth (c.f Please et al, 2001).

However, and importantly, they found that while the internet did provide access to large amounts of information many parents and carers had time-related difficulties which prevented them from successfully using the internet to solve their problems. Firstly, the actual process of accessing services and information was seen as time consuming as they only had limited opportunities due to caring commitments. Secondly, the search process took too long as many carers reported a lack of computing skill as a barrier to using the internet. Their findings raise

concerns for the use of the internet as the primary source of information for parents and carers.

In Australia, the use of the internet as an information source has been examined from the perspective of parents of deaf children by Porter and Edirippulige (2007). They found that while the use of the internet was frequent a large percentage of parents where unable to find the information that they were looking for on a regular basis (30%), while (56%) found it sometimes, only a small percentage (5%) always found the information they needed. To overcome many of the problems of internet use identified by Blackburn and Read (2005) and Porter and Edirippulige (2007) and also meet the information needs identified by our research we propose the development of online or *virtual community.*

A wiki-based virtual community

Such communities provide social support, information, shared experiences and behavioural models, empowering participants and fulfilling the functions of a community (Cline and Hayes, 2001; Yoo, Suh and Lee, 2002). According to Preece (2001) an online community consist of people: (1) who interact socially as they strive to satisfy their own needs or perform special roles, such as leading or moderating, (2) have a shared purpose, such as interest, need, information exchange, or service that provides a reason for the community, (3) develop policies in the form of tacit assumptions, rituals, protocols, rules, and laws that guide people's interactions, and (4) use computer systems to support and mediate social interaction and facilitate a sense of togetherness.

A virtual community would meet the information needs of parents and carers by dealing with the specific issues identified by our study. Firstly, the frustration from a lack of awareness of services would be overcome by using chat rooms, forums and social networks (Please et al, 2001) to receive answers to questions from those already in the system, as well as servi e provider web-links.

Secondly, frustration from the effort required to obtain information would be overcome as *portal*s (doorways) are an integral component of virtual communities which aggregate as much media about a domain of interest in one place as is possible - a clearinghouse - creating a starting point for those interested about an area. We propose the development of such a "one stop portal" using wiki-based virtual community technology to overcome many of the shortcomings of existing communication and information transfer methods. Wiki-based systems have been proven to offer distinct advantages over previous offerings in terms of being user friendly, easily navigated. Mitchell and Sloper (1999) suggest a "single door" source of information for families to tap into but importantly recommend "a 'sign poster' ideally an individual, informing and helping families to access relevant services". In virtual communities the 'sign poster' could be any member of the community.

Thirdly, access to the experience, knowledge and empathy of other parents in similar situations was very much sought after. This human factor was highly valued as parents could talk to someone who they felt cared and whom they could trust. In Australian research, Porter and Edirippulige (2007) found that parents where interested in the stories of other families, their successes, their ups and downs and also being able to contact them via support groups was very important to them. International experience also supports this carer need. In the US, Baum (2004) found that internet parent support groups not only improved the relationship with the healthcare providers it also had social benefits in finding people they could trust.

The fourth need identified relates to parental distress due to no information at diagnosis. Not only is this a failing of the medical system, this finding seems counter intuitive in a cyberspace age when access to information is at a premium. Research evidence indicates that when parents

are able to access health related information they feel empowered (Pain, 1999; D'Alessandro, and Dosa, 2001). In the UK, Capel et al, (2007) found that older citizens where active in self-help online and used their social networks to disseminate relevant information to each other. Creating a virtual self-helping community which draws together those in similar circumstances by utilizing their combined experiences and expertise holds great potential for rapid information dissemination.

The final identified need relates to the high levels of stress due to uncertainty about their child's future. The realization that your child has a disability was an overwhelming experience for many of the parents involved in the focus groups. Many questions flooded their minds and not knowing the answers was very distressing. Many commented that if they had access to parents who had have successfully managed their child's disability from childhood, school and through to adulthood would have greatly reduced the initial trauma and shock of the diagnosis.

Conclusions and Implications for NPOs

Many parents are overwhelmed by their situation, they do not have the opportunity to research into the disabilities they find themselves dealing with on a day-to-day basis, and they cannot easily find support services and information, for example:

"I don't <u>know</u> what I need to <u>know</u>"

The creation of a virtual community has distinct advantages over the accepted approach taken by NPOs and government agencies of using the internet as a primary delivery mechanism for information by introducing the concept of "community". It is this human factor which we argue should be brought into the lives of parents by utilizing the greatest asset available, the lived experience and empathy of other parents and carers who have navigated the disability sector successfully. For many parents confronted with the unknown, the benefits from drawing upon a community of experienced parents in terms of advice, emotional support, reassurance, is invaluable and cannot be obtained on their own.

While virtual communities are theoretically appealing developing such a virtual community is beyond the reach of time poor and often financially constrained parents and carers. What is required is a coalition of NPO service providers, government, the tertiary partner, parents and carers, to bring together the elements necessary for the an initial online community portal. When participant parents receive value from their involvement in the virtual community it will grow into a self supporting community (Rheingold, 1993; Yoo et al, 2002; Porter, 2006). However, NPO service providers and their tertiary partner must provide the initial support to the virtual disability community until it can be self moderated and controlled.

In conclusion, we suggest that developing a virtual community that works effectively within the network of government, NPOs and client groups in fast tracking access to timely, relevant information is the natural progression from predominantly web based information delivery approaches. It allows parents and carers to become considerably more self-reliant and empowered thus allowing service providers to shift their emphasis from "fighting fires" to better service delivery.

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