Utility of virtual communities for ‘carers of children and disabilities’

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Keywords
Utility, virtual, communities, for, carers, children, disabilities

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CHAPTER 17
Utility of virtual communities for ‘carers of children with disabilities’

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Keywords
Carers of children with disabilities, disabilities, virtual communities, wiki, culturally and linguistically diverse (CALD) groups.

Abstract
A pilot study of services for children with disabilities conducted in the Illawarra (Noble et al. 2005) identified a basic lack of awareness on the part of parents and carers about available services. In particular, there was a lack of awareness of the availability of different support services, application processes to acquire assistance, information about specific disabilities, and the location of various support services. The study indicated that there was no central source of information for parents and carers of children with a disability in the Illawarra. Instead, parents and carers had to learn about these issues by ‘word of mouth’, raising issues of information accuracy and timeliness. The study identified a real and pressing need for the creation of a user-friendly ‘one-stop shop’ for all disability information needs and recommended that a comprehensive online resource be created. Along with information, an online resource would provide the tools to assist in the planning and management of the child’s disability over time.

The purpose of this paper is to describe a prototype portal supporting a virtual community that might serve as a one-stop shop for parents and carers of children with disabilities. The potential organisation and utility of this type of virtual community will be described by referring to a model which was developed from the virtual community literature and the needs identified in Noble et al. 2005. The limitations of portal technology to support a virtual community of parents and carers of children with disabilities will also be discussed.

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Introduction
Many studies have highlighted the fact that carers of children with disabilities are often the most disadvantaged members of our community who suffer greater levels of financial hardship, emotional trauma and relationship breakdown than the rest of the population. To assist these carers in their daily struggles, numerous non-profit and government organisations provide support in various forms, such as: financial assistance, therapy services, physical goods, and specialist equipment. In particular, many non-profit organisations (NPOs) exist for the sole purpose of meeting the specific needs of a particular disability group, such as Vision Australia and Epilepsy Action. These NPOs rely on government funding, donations, and volunteers to help deliver their services. Their services add significantly to the quality of
life of their clients providing much-needed assistance. While these NPOs focus significantly on service delivery, they struggle in assessing and planning for the needs of their client groups. Many NPOs either lack the requisite research skills to survey their client groups or they cannot justify allocating service delivery funding to conduct such research.

Researchers from the Centre for Social Marketing Research (CSMR) at the University of Wollongong have partnered with the Disability Trust (DT) – a community-based organisation that has provided a range of disability services such as respite care, vocational training, and support groups to the community for over 30 years – and together they have conducted a comprehensive investigation into the needs of children with a disability (aged 0-12) within the local community (Noble et al. 2005). The main purpose of this survey was to hear the “voices” of parents and carers of disabled children in the Illawarra, and to provide insights into areas of concern for this group. Specifically, the survey aimed to determine current and anticipated service needs and the level of awareness of disability services available in the Illawarra (see next section). Discussions with CASR at the University of Wollongong indicated that a number of the needs and service gaps identified in the survey could be addressed by using web-based technology. This paper introduces and exemplifies portal technology which could be used to create a ‘one-stop information shop’ for Parents and Carers of Children with Disabilities Virtual Community (see third section). Using an established model of virtual communities developed by Preece (2000), various aspects of the proposed virtual community are described in the fourth section. Preece’s model is modified in the fifth section to accommodate the particular requirements of this proposed virtual community. The final section draws conclusions and describes further research.

A snapshot of disability services in the Illawarra

The pilot study of services for children with disabilities (Noble et al. 2005) revealed two significant findings, evident in both the recorded and transcribed speech of various focus groups undertaken at the time of the survey, as well as in the written feedback sections of the survey instrument. The first significant finding was that the lack of government funding for services was of great concern to many parents and carers of children with disabilities. There was an urgent need for access to respite care, therapy services, early intervention programs and specialised equipment such as wheelchairs, walkers and communication devices. As a result of under-funding and under-resourcing, there was considerable anecdotal evidence suggesting that this group was disenfranchised:

73-Q45 “The services for disability in the Illawarra are fragmented and hidden. Service delivery is done in a bureaucratic and veiled way. Families trying to access services are over taxed and isolated, and often in a position that leaves them with less than average resources – financial, physical and emotional – to discover even what is out there for them. They are made to feel that they are lucky to get what they do. Hence the relationship are [sic] always unbalanced. One of the hardest parts of having a child with disabilities means you loose your independence and your pride as you attempt to keep service providers “on side” for the benefit of your child. This disparate and marginalised group has little opportunity to work together, hence the systems and bureaucracies will always win out.”

The second significant finding from the study involves information and communication. Three related themes were evident in the data: (i) a lack of coordinated information provision and time and emotional costs associated with seeking relevant information; (ii) social
isolation and the need for empathy; and (iii) uncertainty regarding a child’s future. Many parents are overwhelmed by their situation as 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:

52-Q17 “I don’t know what I need to know”

Both the disenfranchisement and the lack of knowledge about support services could be addressed with the provision of timely and appropriate information. Not surprisingly this was suggested by a number of respondents:

62-Q45 “As I had no information given to me when my child was diagnosed with having an ASD. I am hoping an information booklet with information and contacts is available to families when needed. This is very important and I can’t stress enough, that a booklet would have helped me enormously and would have taken a lot of stress out at that time. The booklet or any information for that matter needs to be given out from the first initial diagnosis.”

At the same time, many of these services are discovered in an ad-hoc fashion, and the manner in which this happens (through small social networks) is clearly described by the following response:

179-Q45 “... We access many services in the Illawarra. Some we have been referred to by doctors/health professionals, others by and Non Gov’t agencies, others we found out about ourselves or through other parents of children with disabilities. Having one central person to disseminate info I feel would be beneficial but then I’m not sure one person can know everything. It was for eg, thru another parent I met in hospital (who had a severely disabled child) who informed me that I was probably entitled to a Part Carer’s Pension. Even though I was receiving the Carer’s Allowance at the time (my Community Worker informed me of this), I just assumed that because my husband was working we were not entitled to any sort of a pension. But this was not the case. I made some enquiries and now receive a Part Carer’s Pension and the benefits that go with it, thanks to that parent. I think the Carer’s Allowance is well understood among Disability Services but the Carer’s Pension and its eligibility criteria for parents with children with disabilities I’m not sure is quite so well understood (but I can only speak of my own experience). Maybe others are missing out on an important support.”

Clearly a mechanism needs to be in place whereby the existence of these services can be shared with others so that if a serendipitous discovery is made then others can benefit from it. Timely and appropriate information could be provided and organised in such a way as to be useful for parents and carers of children with disabilities. One of the major findings of CASM’s study (Noble et al 2005, p.10) was the recommendation that a web-based system be funded “… to enhance access by all stakeholders to accurate, reliable and up-to-date information that could assist in the provision of support and care to children with disabilities, [and that this would] follow a model of family and carer empowerment and be set up and maintained in consultation with, and involving, families and carers”. This recommendation describes a website but in fact what is required is a portal to support a virtual community.
Virtual communities and portals

Online communities or virtual communities are similar in several ways to physical communities in that they are groups with common interests, shared goals, activities, and governance, comprising individuals who cooperate to share resources and satisfy each other’s needs. While the concept of a virtual community is not hard to understand, it is difficult to define – but it is certainly not defined or circumscribed by any particular type of technology. According to Preece (2000, p.10) an online community consists of:

- people who interact socially as they strive to satisfy their own needs or perform special roles, such as leading or moderating
- a shared purpose, such as an interest, need, information exchange, or service that provides a reason for the community
- policies in the form of tacit assumptions, rituals, protocols, rules, and laws that guide people’s interactions
- computer systems to support and mediate social interaction and facilitate a sense of togetherness.

The advantages of this definition are that it is sufficiently general to apply to a range of different communities (including physical communities that have been networked), while being general enough to include communities supported by a range of different technologies, such as single bulletin boards, list servers or chat software (including those embedded in websites), and as game-oriented technologies where players can form communities. Preece’s definition also has the advantage of enabling operational decisions to be made in regard to developing technologies for virtual communities. Often the technology of choice for supporting virtual communities is called a portal. Portals were so named because they were the entry point (doorway) to the Internet for those groups they supported. The goal of portals is to aggregate as much media about a domain of interest in one place as is possible – a clearinghouse – so that people will go to this portal first when they are interested in something. In commercial uses dating from the late 1990s, portals started to sell advertising to support their sites and generate revenue. Portals became popular for some major retailers who would attract customers away from other portals by providing cut-price discounts on purchases made through their portals. Portals also have been used to support other kinds of virtual communities, including communities of practice associated with specialist uses, for example portals have been used to support distributed research groups. Regardless of the type of virtual community, portal technologies are readily available, so the crucial questions become: how do you identify the needs of a specific type of virtual community? and which technological and sociological aspects need to be identified and studied? To do this we examine the literature, and in particular a model of virtual community building which was developed by Preece (2000) and which we describe in the next section. We modify this model later in the paper based on the assessed needs of our virtual community.

Unpacking Preece’s (2000) model of a virtual community

You can build a portal, but the virtual community may not come. In both this section and the following one, we critically discuss several issues that must be faced when developing, supporting and fostering virtual communities regardless of which technologies are employed and how they are built. As a point of departure we use an established model of virtual community building developed by Preece (2000), an overview of which is described in this section. A special emphasis is placed on several aspects of particular importance for virtual communities that may be developed to support parents and carers of children with disabilities.
Preece’s (2000) model of the virtual community involves an iterative model of assessing community needs, designing usability, planning sociability, and supporting the evolving community. Preece’s model first demands that an analysis be undertaken to determine the needs of the community to be supported by a portal. This analysis feeds the next two stages, which are called ‘Design Usability’ and ‘Plan Sociability’, and which mutually influence each other and are performed in parallel to support the evolving community. The term ‘usability’ refers to the study and practice of ensuring that interactive technologies are easy to learn, efficient and effective to use, and provide the desired range of relevant functions for their intended users. Within the ‘Design Usability’ stage are categories that include interaction dialogue design, navigation, registration forms, feedback, user representations, message formats, archives and support tools. In portal development environments, many of these choices are already pre-determined. It would require much higher order scripting skills to develop new modules that implement new functionality – such as alternate dialogue designs – than the skills that are required to select existing modules and configure them into the existing portal framework using default settings. In reality people who want to quickly set up a portal for a virtual community using available environments tend to adopt default and relatively risk-free settings and themes (aesthetics of the interface) and then they will tend to live with them once the portal is up and running. The situation is a little different with commercial environments that can be used to develop portals, for example Atlassian Confluence (Clarke 2007). We might expect in this case to have a more robust means of changing the look and feel of the environment, although commercial environments often achieve improved product stability by restricting what may be added to them or not.

The term ‘sociability’ is a neologism that refers to those features that need to be considered when trying to create and sustain a virtual community. Within the ‘Plan Sociability’ stage of Preece’s (2000) virtual community model are categories that include determining who are the anticipated and unanticipated audiences – and therefore who will count as a member of the virtual community and who will not – and also the code of conduct which is expected of members. Planning sociability also raises issues surrounding security, privacy, copyright, and freedom of speech, some of which also touch on legal issues, such as defamation. This stage also considers the question of who will act as a moderator and what kind of moderation strategy will be applied to information posted on the portal. The model connects usability and sociability stages to show that decisions made in one will affect the other. In other words the choices we make about usability will influence sociability and vice versa.

**Modified virtual community model for parents and carers of children with disabilities**

In the previous section we introduced Preece’s model of virtual communities and discussed in depth some aspects of it emphasising its key parallel stages of ‘Design Usability’ and ‘Plan Sociability’. In this section we significantly modify this model by including a stage between the Usability and Sociability stages and prior to the ‘Support Evolving Community’ stage. This new additional stage takes into consideration the previously described findings in our survey (Nobel et al. 2005). This stage consists of issues classified into three categories: Services, Information and Collaboration. The modified virtual community model is shown in Figure 1. The additional stage includes services, information, and collaboration in a dashed box, while all of the other stages are as per Preece’s (2000) original model.

The different types of services include those recognised in the original 2005 survey instrument (Noble et al. 2005) and include support groups, service coordination, respite care, in-home personal care, domestic support, home modifications, equipment/personal care,
transport services, therapy services and recreation/leisure. Different types of information resources include medical and remedial, online resources (aggregation), disability policy, child assessment, pension information, resource locators and school locations. The last category is referred to as resources for collaboration and this involves engaging the mainstream, policy development, lobbying, service coalition, and the provision of external content for the virtual community. We discuss three of these categories more fully: Bringing external content into the virtual community; Seeking a broader coalition of services; and Connecting with the mainstream.

**Figure 1**: Model of a virtual community for parents and carers of children with disabilities, modified after Preece (2000).

**Bringing external content into the virtual community**

While we anticipate that a ‘one-stop’ virtual community could provide real support for parents of children with disabilities (including uses that we have not and cannot foresee), the reality is that the utility of this technology will be judged on its ability to acquire and host information from government agencies and non-government organisations. A range of technical options exist in order to determine if new material has been posted on websites, to acquire this information, and to make it available on the virtual community.

One technical option is using and/or creating programs called *spiders* (or web robots, webbots or simply bots) that visit websites and read pages and other information, in order to index the existence of this information for later use by search engines. Another closely related technical option is collectively referred to as *scraping* (or screen scraping). It involves running scripts that periodically access pages on external websites, comparing these with previous accesses to determine if the contents have changed, and downloading new material for potential use on another site. Scraping is distinct from parsing in that the former deals
with output intended for display to an end user rather than to a program. As a consequence, scraping can be ‘hit and miss’, as scripts have to be insensitive to changes in things like page layout and formatting. Because of this, scraping is often thought of as a technique of ‘last resort’. However, there is a growing body of open source scripts and programs for performing sophisticated webpage parsing, comparison, and extraction of information (see for example Hemenway & Calishain 2003). These techniques are rapidly moving into mainstream management practice as part of non-traditional online marketing approaches (Schrenk 2007). Using these techniques, a virtual community for parents of children with disabilities might scrape content buried deep within government websites, enabling it to be exposed and reused on a virtual community site. There are a range of technical, copyright, and ethical issues that surround this type of information capture, not the least of which is that the content needs to be maintained at two sites.

If we exclude content scraping as an option for acquiring content from other sites then there are other options, all of which involve collaboration between parties – the agencies that create the content and the portal that will use it. One way is for the creating agency to allow external agencies – like the portal community – to access their internal systems using so-called Application Programmers Interfaces (API). This still requires creating scripts at the virtual community end to utilise the fetching of information using the API. The resulting scripts are usually language-dependent and require specific technical skills. Alternatively, database dump from the content creator to the portal can be negotiated on a routine basis but this is also not without its difficulties since databases need to be converted at both ends and this still does not eliminate the problem of multiple data formats.

A much better way of exchanging information between agencies is by using RSS, which stands alternatively for RDF Site Summary, Rich Site Summary, or Really Simple Syndication (Hammersley 2003). RSS standardises a format for the delivery of content and sharing of information between sites. It makes it easy for the content provider to distribute content, and for affiliates to receive and process content from multiple sources. In most cases headlines about the content are distributed rather than the content itself, so that users will go back to the affiliate site if they are interested in the information or resource. This means that there are no revision control problems, and users will acquire the most up-to-date versions of the information or resource. The term for sharing information between sites is called syndication. This term is borrowed from licensing content like TV reruns and newspaper columns. Affiliated networks and partners that host similar content can agree to harvest each other’s RSS feeds and automatically display new stories on each other’s sites. In a community of related websites (an affiliate network) each site specialises in its own specific area of interest. Readership is maximised when sites cross-promote each other. At times one affiliate may carry content that directly relates to another site’s readership. Collocation of content is the web equivalent of having similar types of shops in the same area of the city! RSS feeds are the best way of sharing agreed content between sites, and involve several steps. Once the RSS content is written and before it is syndicated, the RSS file needs to be up-to-date. Individual RSS files may be manually added, or preferably automatically appended as a new post to the RSS file. Once the RSS file exists, any other site can grab it regularly. Displaying an RSS file on a website usually involves converting it to HTML. By using a Server Side Include (SSI), the server can bring the content into a template, and a Cascading Style Sheet is used to style the output to match the formatting of the website. Websites should create an information page about syndicating their headlines which makes existing users aware that the website has an RSS feed so that they can add it to their news reading applications or even include it on their own websites. A convention that is emerging
on many websites is to use either the RSS or XML logos to link to the RSS XML for the current page.

Sites that integrate and collect together thematically related content are called **aggregators**. Aggregators automatically search for and process RSS files from content providers and present news in a variety of ways. Current examples of aggregators include Bloglines, Google Reader and Blogs.com, all of which aggregate currently available technical RSS feeds, and filter news stories by time, topic, keyword and regular expression. Other commercial examples include Motley Fool, Wired News and Slashdot. Some of the proposed portal functionality for parents of children with disabilities will be aggregator functionality.

**Seeking a broader coalition of services**

It is an axiom of modern management that the problems pertaining to a system often lie outside the system, and in order to understand the functioning of any system you need to look at the larger system that contains the one of interest. This kind of synthetic thinking (pioneered by Ackoff 2003) reveals the core issue with a virtual community for supporting parents of children with disabilities that cannot be solved with technical options like spidering and scraping. Conversely, we recognise that all hyper-systems are becoming increasingly interdependent, in that many sites rely upon content that originates elsewhere. This content may include news feeds, events listings, project updates and exchanges of information. Like businesses seeing opportunities to share content, the success of a portal for parents of children with disabilities requires content sources to be on government websites, and thus the best long-term solution will be to enter into agreements to share this information more formally, rather than simply scraping it from government sites. This leads us to the issue of seeking a broader coalition of services – that the portal may be the lightning rod around which these broader coalitions of government and non-government providers may be formed.

**Connecting with the mainstream**

Establishing a virtual community enables the possibility for the mainstream to become more aware of the issues faced by those who care for the disabled in our community. When asked about the needs of the carer and the facility (Noble et al. 2005, p.10), one respondent provided the following succinct response (52-Q11):

1. More Sibling Groups Needed
2. More Counselling Needed

A portal for parents of children with disabilities provides opportunities to educate the broader community. More importantly it provides the opportunity for the mainstream community to engage with parents of children with disabilities. A simple example of this might be **virtual community service** to discover and describe online information sources that might be of interest to particular communities. Volunteers could sign up to do internet searching on particular topics, or on behalf of various communities, and these searches would then be rated by experts, such as representatives from medicine, community support or members of either government or non-government agencies that provide or disseminate information. Once information was published on the portal, parents could rank this information as either useful or not useful. Many users of the Internet are familiar with the idea of rating items on websites, for example those found on Amazon. These rankings form information utility
measures which can be used to direct subsequent volunteer internet search activities. A model for this type of virtual community service is currently being developed within the Faculty of Commerce at the University of Wollongong.

Conclusions and further research
We are certainly mindful of not advocating a technologically determinist position by claiming that a portal-supported virtual community will solve all of the problems facing parents and carers of disabled children. Hopefully a virtual community will provide a mechanism to enable parents to talk together and to acquire and exchange information and experiences. We would certainly hope that it would become a ‘one-stop shop’, since it is not subject to the physical constraints of actual educational facilities, medical, rehabilitation and respite centres. There are two sets of questions that need consideration during the development of a portal for these purposes. The first set of questions relate to access and equity, the second relates to development practices.

Questions of access and equity
The first issue that arises is an issue of equity: how to acquire the necessary technology that will enable parents and carers of children with disabilities to gain access to the proposed virtual community. Noble et al 2005 indicated real financial stresses endured by parents whose available disposable income is generally directed towards providing equipment for more immediate medical and remediation needs. 60% of families of children with a disability earned less than $60,000 annually. In addition, Australians have been paying top dollar for access to the Internet which is by international standards a slow and poor service. Additionally, Australia’s Telecommunication Policy has been in disarray for more than a decade. The recently promised roll-out of broadband to the home – rather than just to the node – by the current Australian Federal Government appears to hold the promise of eventually lowering the barriers to accessing the World Wide Web. While there does not appear to be any programs proposed to assist parents and carers of children with disabilities in acquiring internet access directly, the Digital Education Revolution Initiative (2010) and its support for the “One Laptop Per Child (OLPC) project” (Rudd 2010; OLPC 2010) will significantly assist in lowering the barriers to access. These measures will lower the cost of access to the type of virtual community that we envisage.

The 2005 Illawarra Pilot Study also showed that approximately a third of carers of children with disabilities had only a basic education (technical college qualifications or School Certificate). Also 21% of survey responders were from Culturally and Linguistically Diverse (CALD) Groups, and therefore no single solution will solve these particular access needs. There has been considerable research into the so-called digital divide that includes the social factors that inhibit access to information technology and the web and which exacerbate social inequality and exclusion (Cherry, Goldstein and Cass 2004). Not surprisingly these factors include low income, unemployment, gender (fewer women use the internet and are often in lower-skilled jobs), age (less technically savvy), location (rural and remote communities have less access due to distance from services) and poor English skills. The difficulties in accessing the type of virtual community we envisage will require considerable study, although precedents do exist and these approaches need to be researched and applied.

Questions of development practices
The second issue is an equally important one, going to the heart of the empowerment and inclusion that parents and carers of children with disabilities should have in the development of this type of portal site. We advocate the position that the experience and expertise of
parents of children with disabilities deserves the respect and full attention of researchers and
decision-makers. Beliefs about the transparency of language are built into traditional
approaches to website and computer-mediated communication design (see for example Mok
1996), and even in the growing literature on web internationalisation and localisation. The
reason why IT professionals can consider language this way is because their perspectives and
practices are asemantic.

Before we can support and serve parents and carers of children with disabilities, we need to
understand what they are communicating to us, by understanding the nature of the
communication itself. In other words, knowing the resources used in communication will
help us to understand the communication of those that require services for disabled children.
Developing a useful virtual community using communication techniques is possible if these
techniques enable a detailed semantic analysis of the communication provided by parents and
carers. The type of semantic analysis that we advocate is not found in information systems or
computing science but rather in the fields of socio-linguistics and semiotics. Future research
will involve the development of novel techniques to organise the resulting content in ways
that provide value to parents and carers of children with disabilities, by organising it in ways
that they themselves might use, and by seeking these out. In doing so, we will need new
techniques that empower and engage parents and carers of children with disabilities by using
their communication to structure content on the portal.

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