People with complex communication needs are limited in their ability to speak and type. This makes it difficult for them to express their specific needs and to gain access to the telecommunications solutions currently available. This paper describes the development of the community-based Newell Network (www.newell.org.au), a Web 2.0 site centred on empowering individuals with complex communication needs, their carers and support organisations. The site enables users to add information on available telecommunication solutions and be directed to known applicable resources. Reflections on the project development, process undertaken and issues identified are discussed.

BACKGROUND

'Complex Communication Needs' (CCN) is a term used to describe the needs of people who have little or no speech. These communication problems are associated with a wide range of physical, sensory and environmental causes which restrict or limit a person's ability to participate independently in society. People with CCN may include those with Cerebral Palsy, Autism, Stroke, Intellectual Disability, sensory impairments and degenerative conditions such as Motor Neurone Disease.

In Australia, just under one in five people (18.5%) have a disability, for which about 6% of the people results in profound to severe restriction of core activities. Of those with a reported disability, 87% had a specific limitation or restriction which also includes communication (ABS 2009). One in seven users of government disability services (over the age of five years) has little or no effective communication. Over 40% of users require assistance for communication (SPA 2012). Communication is one of the most crucial requirements to participation in society. Communication enables us to:

- express feelings and thoughts in order to understand and respond to others
- achieve our goals and advocate for ourselves and others
- build friendships and socialise
- engage services and supports within society
- acquire and share information.

All of these factors may be impacted if a person has CCN.

The UN Convention of the Rights of Persons with Disabilities states that 'communication enables peoples with disabilities to fully enjoy all human rights and fundamental freedoms'. Enabling people with CCN to communicate via the telecommunication system is essential.
Research has shown that with the right processes and support in place, current solutions can assist people with disabilities to effectively communicate with other members of society and access the same range of information systems and services enjoyed by the able-bodied community via the telecommunications system (Nguyen 2007 & 2008, Garrett 2010).

INTRODUCTION

It is well known that there are many significant issues that make it difficult for people with CCN to access the telecommunications network (Goggin & Newell 2003). As a result, it was essential that we identified the important issues through consultation with people with CCN along with their supporters. To this end, a community of end users and their supporters was established.

Initially an email list server was created for discussion of issues, ideas, activities and solutions related to assisting people who have a CCN to gain meaningful and effective access to the Australian telecommunications system either via a phone or the Internet. An email-based system was accessible to people with CCN. Interested individuals were sought from the Australia Rehabilitation & Assistive Technology Association (ARATA), AGOSCI (a group representing people with CCN, as well as those who live, know or work with people with CCN) and other appropriate networks. An important role in the establishment of this community was to identify participants who had experience with CCN and who were prepared to contribute. An invitation to participate in a one-day workshop1 was distributed via the list server.

The objectives of the workshop were to identify and prioritise the problems, issues and needs of the group that were impeding successful access to the telecommunication network. A total of nine people participated in the workshop held on 28 October 2009 at Novita Children's Services; five participants were from South Australia, three from Victoria and one from Western Australia. Three attendees had CCN and six had extensive experience working with individuals with CCN. The workshop participants identified and prioritised the following key areas as important issues (in decreasing order of priority) related to accessing the telecommunications system:

1. access to information
2. funding
3. emergency services
4. training and education
5. access to support
6. innovative solutions
7. equity
8. implementing existing known solutions and services.

When the group considered solutions to the highest priority item 1 ('access to information'), they called for a national phone help-line to support them with telecommunications access. Given a help-line would require ongoing significant commitment of recurrent funding which may be difficult to secure, a website containing details of known solutions was considered a reasonable and possible alternative.

The establishment of a website became the focus2. A funding submission to the Australian Communications Consumer Action Network (ACCAN) Grants Scheme that included in-kind & funding support from Australian Communication Exchange (ACE), Telstra and Novita was successful. The grant requirement was to establish a website to provide a useful and sustainable information and education tool for people with CCN and people supporting them.

Implicit in the creation of the website is an acknowledgement that the existing Disability Equipment Programs are not adequately supporting people with CCN, due to the complex nature of the solutions. Solutions for people with CCN typically involve experienced health
professionals from range of backgrounds who are skilled at identifying and evaluating a person's physical abilities, identification of potential phone control sites on the person's body as well as identification of their particular telecommunications needs. Once this information is known, telecommunication solutions can be identified. Finding workable solutions can be a significant task in its own right.

For an individual who has limited body control and who is able to speak, the solution could require a phone that can be operated via a single switch positioned or mounted so that the user can activate it reliably when needed. Phone solutions are available that enable a single switch press to answer an incoming call in speaker mode or dial a pre-stored phone number. A more complex solution could involve identifying, installing and trialling an assistive technology needed to enable access to a personal computer configured to provide access to text based communication as well as the home and/or mobile phone network. This case might also involve the identification of phone systems that can be connected to the computer, allowing the user access via the assistive technology.

These examples illustrate that the solutions are complex, require a range of skills and knowledge along with good communication between the all of the key players. Some of the key players are individuals with knowledge and experience who are typically scattered across the country. It is important to note that the particular abilities of the end user and the type of solution needed dictate the key players that need to be involved. This project aimed to assist and augment this process.

OVERVIEW

This paper describes the development of a community-based website that empowers individuals with CCN, their supporters and organisations to add information on available solutions and to receive direction to known applicable resources.

Objectives of the project were to:

- share information about solutions for people with CCN
- highlight gaps in telecommunications access and information
- collect information the community needs and collate it in one space
- allow a space where individuals can voice their opinions
- identify actions and funding required to make telecommunications more accessible.

Key features of this website were that it be:

- easy to access
- easy for people to contribute ideas, solutions and comments
- designed for both end users and their supporters
- oriented towards low maintenance beyond the initial funding period.

To ensure the final website did meet the perceived need, end users and their supporters were involved in the development processes as much as possible. A Website Project Reference Group (WPRG) was established to provide support and direction throughout the project. This reference group included three people with CCN and three professionals with extensive experience working with people with CCN. The role of the group was to:

- advise the management team
- respond to proposed web site design
- provide feedback and input
- assess (evaluate and appraise) significance of the website, by commenting on the following areas:
  * accessibility
appropriate for the community
* complexity
* layout and navigation
* use of language

- assist in marketing the website by:
  * making it known in their State and/or community
  * distributing information provided
- contribute to or identify website content contributions needed.

Both before and after the website launch, group members were expected to:

- be contributors
- follow up potential contributors
- suggest other contributors.

Given people with CCN were involved in the website development process, new methods of communication were needed to be explored and tested. In addition, the communication needed to occur between members who were located in New South Wales, Victoria, South Australia and Western Australia.

An initial and essential face-to-face WPRG meeting was held in Adelaide on the 3rd September 2010 to establish a functional group and ensure members understood the communication needs within the group. Subsequent meetings occurred via the free Internet Skype conferencing facility. This solution supported communication via text and voice conferencing simultaneously. The experience was a learning process and issues and challenges ensued including:

- WPRG members using different versions of Skype, hence making it difficult to support remote users when instructions needed to be customised for particular versions of the Skype software. The resolution was to ensure that all users were using version 4.2.0 or above.
- Difficulties in managing meetings because it was unclear as to whether the communications were being received by all members. The reliability of the communication was a major factor for some meetings. Any more than two intermittent connections made the meetings impractical.
- Problems associated with the different mode and rates of communication (i.e. text vs voice) between members. Inevitably some of the responses in the conversation were missed. The keen awareness of all participants to this problem was vital for the teleconference to function effectively.
- The three-hour time differences between different States in summer, made it impractical to have meetings of duration greater than about two hours.

Even with these issues and challenges it was impressive that we were able to function with participants scattered across Australia. Members who were experienced users of Skype were essential to the successful outcome.

The significant outcomes of the WPRG meetings were:

- There was a clear resolution that the project needed to focus on people with CCN.
- The site needed to be straightforward, uncluttered, usable and functional and compliant with W3C guidelines.
- Members contributed to a list of individuals and organisations that needed to be contacted and informed about the new community site.
‘Complex Communication Needs’ was the agreed terminology that will be used throughout the project to describe the community.

The URL 'www.newell.org.au' was chosen in recognition of the contribution of Revd Canon Dr Christopher Newell AM, who made a very significant impact in the field of telecommunications and disability (Goggin & Newell 2003 & 2005).

DEVELOPMENT OF THE WEBSITE

SPECIFICATION

Prior to the development of the website, some of telecommunication products for people with CCN were already listed amongst other products on other websites. However, they were not effectively marketed to people with CCN. The 2009 workshop participants identified that solutions do exist but are scattered across the nation and are not readily known about or available to people with CCN and their supporters. It was important that people with knowledge and experience could easily share their experience on the site. This community-based role of the site called for the careful analysis of likely questions and contributions. Dr Daniel Woo supported the management team with suggested processes. These included the WPRG members identifying questions that are likely to be asked and itemising features they consider essential.

Some of the questions were:

- How can I dial my home phone using just my voice?
- I can't read but need a mobile phone to call for help if I need it when I'm out. Is there a mobile phone with pictures?
- I can't read or speak but can use a switch and drive my power wheelchair. How can I call for help when I'm out?
- I am having difficulty finding a phone that meets my requirements and capability, what help is available?

Analysis of all of the information revealed that issues could be classified into different areas needing moderation and contribution from various individuals with skills, knowledge and experience in the various areas of need. For example, some questions related to the selection of an appropriate phone and others to the implementation of a recommended solution. The support and skills needed for each of these areas of activity is likely to be sourced from different sectors of the community. In addition, some resources are only available within particular regions of Australia. To this end, the specification was written to enable moderators or groups of moderators to be associated with categories or regions selected by the website users.

The 'Must Do's' named by the WPRG members confirmed the original mandate that the site needed to be straightforward, uncluttered, accessible and easy to use. The items named also influenced the priorities of the tasks to be tackled.

The website specification was contracted to Red Neon Designs and the website's logo, look and feel was created by Heidi Rurade Design. Feedback on the specification and appearance was sought from the WPRG members before being passed to the ACE's web developers for implementation.

IMPLEMENTATION

Whereas the specification served as a valuable tool to define the site requirements, it became evident that some parts of the requirements were readily implemented and others did not fit within the available resource and timescale.
The Newell Network site was built using the open source Joomla Content Management System (www.joomla.org) that contains a core framework along with modules to provide additional functionality. Joomla can be modified to create the required user interface through the use of cascading style sheets, but the actual functionality required was determined by the module used. There are numerous modules available across a wide spectrum of functionality. Implementation of the functionality required the selection of the module that most closely matched our requirements. Having identified a potentially suitable module, features could be easily omitted but could not be readily added. The modification of a module's functionality was possible but had the added complication of needing to be repeated or checked to confirm that the changes worked correctly following an upgrade in the version of the module. The resource available and the timescale did not support the writing of software code.

The current website uses the Joomla core framework for management of the 'Home', 'Resources', 'Feedback' and 'Contact Us' features. The 'Ask' section is built on the 'Community Answers' Joomla module. These two modules do not necessarily have common features. For example, the task of adding tag words is readily available in the core module but not in the Community Answers module.

**Website Content**

**The 'Ask' website feature**

![The 'Ask' section of The Newell Network.](image)

Central to the Newell Network website is the 'Ask' section. People with CCN can share information and ideas, ask questions and get answers from their peers or from experts in the field. The 'Ask' section (Figure 1) is based on the 'Community Answers' Joomla module. Users can submit their question and nominate a category from 'Finding the right phone', 'Testing the phone', 'Costs', 'Using the phone' and 'Trouble-shooting'. In each case, the sub-category is consistent with the categories in the Products section i.e. home phones, mobile phones and computer-based solutions. Considerable thought was put into these categories to reflect the real-life situation of a person trying to work through their telecommunications options. These categories are as intuitive as possible and as the content of the website grows, it will assist a user to locate information and share ideas.
A response to a particular question automatically sends an email to the originator. The originator can then check if the answer resolves the question and indicate this on the site. Question listings also indicate if the question was asked hours, days, weeks or months ago and states how many answers have been received. It is also possible to search within the 'Ask' section for particular questions. Currently, the 'Home' section is set up to list up to ten the most recently asked questions and up to six recently resolved questions. The 'Open' tab lists questions that are still to be resolved. The 'Popular' tab lists 33 questions that have been the most 'clicked on'. The 'Answered' tab has 31 questions that have been answered.

The 'Resources' Section

The 'Resources' page (Figure 2) has been categorised as 'Disability service providers', 'Choosing products', 'Phone companies and industry associations', 'Community organisations', 'Your rights' and 'Government information'. An online form has been created for other organisations to submit information about themselves to be included in the Resource section of the website. This single page set format form enables people to provide information in an easy-to-use, structured format and gives the Resource section consistency in the amount and type of information provided and the layout and look.

There are currently a total of 17 resources listed on the website.
The 'Products' Section

The 'Products' page (Figure 3) has been categorised as 'Mobile phones', 'Home phones' and 'Computer-based solutions'. The website description identifies the features of the product that are likely to be relevant to people with CCN and contains a link to the supplier's website for full details. An online form enables the submission of details of relevant products and provides an opportunity to tag the product as 'Single switch', 'Infrared', 'Large button', 'Regular qwerty keyboard', 'Speaker phone', 'Video', 'Text messaging', 'Speech only', 'Touch Screen' and provides an option to suggest additional appropriate tags.

Feedback website submissions

Since the launch of the website in May 2011 at the AGOSCI Conference, a total of 14 people have completed the feedback form online. The overall feedback was positive with the majority respondents indicating that the structure was good (N=4), very good (N=4) or excellent (N=5) (mean = 3.93 out of 5). A high proportion of the respondents said that accessibility of the website was very good (N=4) or excellent (N=7) (mean = 4 out of 5). The feedback about website content was spread with poor (N=1), fair (N=2), good (N=6), very good (N=2) and excellent (N=3) (mean = 3.29 out 5). This could reflect that the content is still being added to the site and be influenced by whether people found the information they were seeking.

Most people offered ideas for making the site even better. The ideas included:

- prompting people to indicate which State they were based in to facilitate better answers to questions asked
- an stronger reminder to the originator of the question to flag that the question has been resolved
- making links to each of the State Independent Living Centres
- increasing the number of images
- adding details about the functionality of a particular product listed in the Products section.
'Contact Us' website submissions

The 'Contact Us' page provides people with an option to communicate information or questions that do not fit into the 'Feedback' and 'Ask' a question sections of the website. It also provides people with a more private forum than the 'Ask' section of the website if they have a question they do not want to be open to the website community.

To date we have received online submissions from five people through the 'Contact Us' page. The reasons people have used this section has been varied, and included enquiries, as well as giving information. Specific examples include:

- One individual informed administrators that she had promoted the Newell Network on her blog, and sought permission to use images.
- Two individuals asked to feature a product or service on the website.
- Two individuals ask questions specific to their needs, similar to those found in the 'Ask' section.

DISCUSSION

COMMUNITY INVOLVEMENT

From the outset of this project, it was clear that no one individual or organisation had the answers needed to resolve all the issues and diversity of needs associated with providing individuals with CCN access to the telecommunications network. The possible solutions were also challenged by the short lifetime of commercially available options and solutions. As a consequence, the establishment of a community of individuals and organisations that are willing to share information and solutions was considered essential for the project to be a success.

Given that the aim was to create a Web 2.0 community-based website, the WPRG was an essential part of the project. Not only did the members define the bounds of the project and raise issues not initially expected, they demonstrated a very high level of commitment to the project, were acutely aware of the unmet needs, provided essential links to other interested parties and fully appreciated the need for the website.

The involvement of the WPRG members from across Australia required new approaches as some participants had CCN. Once a person has access to email, the time taken to create the email has no effect on the communication. However, the time taken to create a text message in a telecommunications based conference can have a significant effect on the flow of ideas and discussion. Our experience using the Skype based conference facility for both voice and text communication demonstrated that the participants needed to be aware of, and experienced with, the alternative communication techniques used by people with CCN and to have guidelines to manage the different rates of communication.

Connection difficulties and drop-outs throughout the Skype conference was unacceptably high making it necessary to have individual contact information for all participants readily available so that it was possible to quickly contact individuals via phone, email or SMS. Our experience showed that a more reliable Internet is needed and increased bandwidth would have been required to enable the addition of video to the conference to function effectively. This will be required to ensure reliable and workable meetings that will enable individuals with various abilities to effectively communicate and contribute.

Video conferencing could well be significant, given the greater effectiveness of face-to-face communication, compared with just voice and text. The use of video was not used for the project meetings because the extra demand on download and upload network bandwidth was likely to decrease the reliability and quality of service. The reliability of the Internet system needs to match the reliability of the current landline phone system before considering the use...
of video. The rollout of the NBN is expected to significantly improve the reliability and support the effective use of video.

**Moderation and Maintenance**

Analysis of the information supplied by the WPRG along with the goal of involving the community in the moderation of the website content to minimise the ongoing operational costs led to the specification including the concept of multiple groups of moderators. Each group of moderators would have skills and experience in a particular area associated with The Newell Network. The aim was to create website categories and tags that would relate to the particular moderator group so that when the users of the site select a category or tag, this information would be used to direct the inquiry to the associated group of moderators automatically. Clearly this approach would depend on the establishment of moderator groups and would be a significant task in its own right.

Early indications from discussions with the WPRG members indicated that there are individuals in this community who would be prepared to participate in this project as a moderator, provided that the frequency of notifications were low and clearly directed to their particular area of expertise. Some of these individuals would contribute, seeing this activity as enhancing or extending their capacity in paid employment, and others as a volunteer with particular skills and experience. Some suppliers of products to this community could well see their contribution as a way of informing the community about their skills and capabilities. Some of the groups could be linked to the categories already in the 'Ask' section, namely 'Finding the right phone', 'Using the phone', 'Testing the phone', 'Costs' and 'Trouble-shooting'. There could also be groups associated with the assessment of products and resources submitted to the site. In this case, the tags specified by the submitter could be used to identify the appropriate group of moderators.

Currently any activity on the site instigates an email to the administrators involved in the development of the site. This situation has meant a website moderator knowledgeable in this field has been employed to respond to site activity by directing activity to appropriate experts in the field. The concept of moderator groups would decrease the paid moderator role but not eliminate it. There would still be a role in the maintenance of the moderator group lists and the creation, development and maintenance of the network of moderators. This group of moderators could well become the knowledgeable and committed group who would direct the development and changes to the site that will be needed over time. It is important to note that the actual site activity needs to be analysed before further development of the moderator groups is undertaken. Ongoing funding to support the moderation of this site is essential.

**Search Capability**

The website is built using the Joomla core Content Management System for all but the 'Ask' section, which is using the Joomla 'Community Answers' module. These components of the site can be considered as two separate websites, both customised to meet the look & feel requirement of The Newell Network site. The consequence of this approach is that the content in one section is not readily available in the other section and the search processes supplied with each section are not the same. For example the questions and answers contained within the Community Answers module added under the category of 'Finding the right mobile phone' have no relationship to the products added under the category 'Mobile phones'. To find similar entries under a particular category requires the activation of two different search processes, one for each component of the site.

In addition to this issue, there is potentially a lack of consistency in the words and tags used in each section of the site. For example, searching for a 'home phone' solution will not find entries that have been submitted using the words 'landline phone' or 'fixed phone'. The introduction of the 'Submit Product' and 'Submit Resource' web based form does promote consistency of the tags as the contributors are asked to select words from a supplied list, alternative techniques are needed in the 'Ask' section.
A careful analysis of the performance of the search facility within the core Joomla system and the search facility within the 'Ask' section needs to be undertaken and, if found inadequate, alternative search processes be considered. This may involve a search system or wizard that requires the user to select items applicable to their needs rather than the user having to try a search word, which may or may not be found.

While the content in the site is relatively small it is feasible and practical to browse the site for solutions to a particular problem or issue. As the content increases, the search facility will become critical and will need to be improved to ensure that users can find content relevant to their issue.

**Future of the site**

In the eight months since the launch of the website, the total number of visitors to the site has been in the order of 150. The questions and solutions shared by the community to date could have a very important impact on the individuals concerned. Further assessment of the value of this website needs to be centred on the impact the results have on the lives of people with CCN.

The approach taken by this site could be significant to other sectors of the disability community. As a result of the difficulties experienced by people with CCN trying to access the telecommunications network, the WPRG felt strongly that the resources available at the time needed to be focused on people with CCN and not diluted by the needs of the other sectors. Having now developed the site, it does seem appropriate to extend the concept to the other sectors in such a way that the site displays only information relevant to the particular community.

The experience so far confirms the significance of this site and now raises the issue of the support for the ongoing future of the site. End user community involvement can support important and cost effective solutions for people with CCN. This new resource needs to be seen as an integral part of the solutions that are currently available that enable people with a disability to access the telecommunication network and funded appropriately.

**Conclusion**

As a result of the broad recognition of the complex issues associated with the identification of workable and satisfactory telecommunication solutions needed for people with CCN, this project has received financial, in-kind and community support from industry, end users, supporters and carers. Creation of The Newell Network community-based website has established a network of Australians wanting to share their experience and to assist others gain access to the telecommunications system. The project has demonstrated that there are important solutions available to assist people with CCN and there are community minded individuals who are prepared to share their experience and knowledge.

Given that the content contribution is driven by end user needs and that the nature of solutions are varied and often customised to meet individual needs, it will take a considerable period of time for a meaningful and comprehensive array of solutions to be included. Once this 'critical mass' of information exists, it will entice others to use the site and to become aware of the site's value and significance.

The experience to date fully supports the concept and now raises the issue of ongoing support for the site. Given that little of the shared community moderation specification could be implemented, ongoing paid moderation and administration support is essential. It is clear there will always be a need for some level of ongoing moderation of content and administration of the website necessary to maintain this valuable resource.

This needs to be recognised and funded along with other services provided to enable people with a disability to access the telecommunication network like the majority of the Australian population are able to do.
ACKNOWLEDGEMENTS

This research project is supported by the ACCAN Grants Scheme, ACE, Telstra's Access for Everyone Marketing Plan & Novita Children's Services.

The authors acknowledge the valued support and contributions from the WPRG members: Jan Ashford, Communication Rights Australia; Matthew Hesketh; Harriet Korner, The Independent Living Centre NSW; Darryl Sellwood; Annabel Vasquez, National Relay Service; and Hank Wyllie.

The authors also acknowledge the following important contributors to the project:

• The ACE Technology Forum members, Darryl Sellwood, Tony Bennetts, Graeme Ridler & Zöe Boyd.
• Robert Morsillo, Group Manager, Consumer Affairs, Telstra.
• The website developers, Shina Yamamoto, Darryn Arndt & Shannon Roos, ACE;
• Gunela Astbrink, GSA Information Consultants.
• Lucy Barnham, speech pathology consultant, Barnham Pty Ltd.

Most importantly, the authors would like to thank all the users of the website that have contributed content to the website either by posting questions, answers, products or resources to make it an effective community based website.

ENDNOTES

1. The Australian Communication Exchange provided the financial support for this activity.

2. A community-based Web 2.0 style that had earlier been suggested by Robert Morsillo from Telstra’s Disability Services in discussion with Rob Garrett as a venture worth trialling.

3. Typically Occupational Therapy, Physiotherapy, Speech Pathology & Rehabilitation Engineering.

4. Assistive Technology can be defined as any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities. ([Assistive Technology Act, 29 U.S.C. Sec 2202(2)]).

5. Such as SMS, email, Twitter, Facebook, MSN, instant messaging, etc.

6. Skype is a proprietary Voice Over Internet Protocol (VOIP) service and software application that allows users to communicate with peers by voice, video, and instant messaging over the Internet.

7. Senior Lecturer, School of Computer Science and Engineering, The University of NSW.
REFERENCES


Nguyen, T; Garrett, R; Downing, A; Walker, L; Hobbs, D. 2008. 'An interfacing system that enables speech generating device users to independently access and use a mobile phone'. Technology and Disability 20 (3): 225-239.


Speech Pathology Australia (SPA), What is a Communication Disability? (Fact Sheet 1.3), Who has a communication disability (Fact Sheet 1.2) and The cost of a communication disability (Fact Sheet 1.5). [Internet] Accessed 12 January 2012. Available from: http://www.speechpathologyaustralia.org.au/information-for-the-public/fact-sheets.