Participation by adults with lifelong disability: More than a trip to the bowling alley*

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Abstract
Community participation by people with lifelong disability is not a new concept. Yet, within the field of disability there is ongoing debate about the barriers to participation and how these can be solved. At a practical level, participation remains an issue that is often misunderstood by many who seek to promote the integration of adults with lifelong disability into the community. Community presence alone does not denote participation or integration. Furthermore, the role of the speech-language pathologist is rarely, if ever, discussed in the research into participation by people with lifelong disability. In this paper a brief overview is given of the barriers and solutions to participation by people with lifelong disability, including those with complex communication needs who use or require augmentative and alternative communication (AAC). Two innovative solutions, the Change Laboratory and Second Life™, are discussed. These may be useful for the speech-language pathologist to consider when seeking additional ways to support community participation by adults with lifelong disability.

Keywords: Lifelong disability, AAC, participation, communication.

Introduction
Community participation for adults with lifelong disability is not a new issue, yet remains one that service providers may understand at a superficial level only. In the author’s experience, service providers may interpret the concept community participation to mean no more than adults with lifelong disability living in the community with opportunities to be out in the community, completing activities that they enjoy, like bowling.

Historically, in Australia, the devolution of people with lifelong disability from institutions to the community began on a small scale in the early 1970s. Now, in 2010 most people with lifelong disability do not live in institutions, although many adults still live with their parents (Australian Institute of Health and Welfare, 2000). Furthermore, across the world, people with lifelong disability are out and about in the community and their need for communication support and intervention, including augmentative and alternative communication (AAC) interventions from an early age, is well recognized (Beukelman & Mirenda, 2005).

In schools today, it is probably unlikely that a child who learned signing in one class would the following year be expected to use picture symbols, because we don’t sign in this class. This was common in the 1970s.

It may well be one reason why parents of older people with autism, for example, are unwilling to consult with speech-language pathologists and other professionals. These parents perceive that these professionals provided little help when the children were young (Hines, 2009), despite the fact that functional communication is recognized as a key to facilitating community participation by people with lifelong disability. Normalization theory

When considering community participation by people with lifelong disability, it may be helpful to consider the normalization theory initially developed by Nirje (1976). Nirje, in the early 1960s, campaigned for people with intellectual disability to be included in the community as members of the community with the same rights and needs as their peers without disability. Nirje (1985) described the normalization principle as including the normal rhythm of the day, week, year, and life cycle, and how these impact on the normal conditions of life. In addition, the principle included normal economic conditions, normal environmental conditions, normal respect, and normal sexual patterns of culture. Furthermore, although Nirje’s normalization principle focused on people with intellectual disability, he...
suggested that the theory of normalization could apply to people with any type of disability or people from a minority group. Nirje’s theory of normalization was based on rights: “making available to all mentally retarded people patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society” (Nirje, 1976, p. 231) and may resonate as a description of how participation is viewed today. Normalization was further developed by Wolfensberger (1972) as social role valorization which encompassed creating socially valued roles for a person with a lifelong disability in order to improve their value and, hence, treatment or acceptance within a community. In other words, Wolfensberger posited that if people with disability held socially valued roles in their community or society they were more likely to be treated with respect, and dignity. He suggested that social role valorization led to people with disability gaining the same opportunities to participate and be included that are available to others in the same society. Thus, the goal of social role valorization may be achieved by enhancing a person’s role or competencies so that the individual is perceived positively by others in the community.

Nirje (1985) criticized Wolfensburger’s (1972) social role valorization for giving priority to what is deemed within a society as appropriate rather than what an individual might choose. Perrin and Nirje (1985) went on to set the record straight by criticizing the following eight misconceptions of the normalization principle: (i) normalization is about making people normal, (ii) specialist services are inconsistent with the principle of normalization, (iii) normalization supports dumping people in the community with no support, (iv) normalization is an all or nothing concept, (v) normalization is appropriate only for those with mild intellectual disability, (vi) people with intellectual disability are best with others who are similar and must be protected from society, (vii) normalization is only applicable in Scandinavia, and (viii) normalization is an idealistic and impractical concept. Indeed Nirje’s criticism of social role valorization and justification of the principles of normalization fit with the critical view of some British social model theorists such as Oliver (1996).

Oliver (1996) criticized health professionals for oppressing those with disability by trying to make them conform to a mainstream ideal rather than changing society so that all members can fully participate. Indeed, Culham and Nind (2003) noted that normalization has resulted in many practitioners devaluing difference in favour of conformity and adopting an attitude that normal equates with good.

Nevertheless, recently Shakespeare (2006) noted that, despite earlier criticism of Nirje’s normalization theory from social model scholars, academics, and practitioners (Culham & Nind, 2003), there are similarities in values between this theory and the social construct1 model of disability. Furthermore, the aspirations of the International Classification of Functioning, Disability, and Health (ICF) (World Health Organization, 2001), which were clearly articulated by Threats (2010), seem to fit with a better and more egalitarian view of life for all, regardless of level of ability. In other words, it is possible to argue that in the past 50 years, there has been an ongoing focus on the rights of people with disability for equality with the rest of the community, and that this includes participation in all aspects of life. It is also possible to argue that this goal is still some way off being attained.

**Participation and the ICF**

Towards the end of the 1980s, a time when Australian institutions were devolving after the Richmond (1983) report,2 community presence and community participation were further emphasized as key issues for people with disability (O’Brien & Lyle, 1987). O’Brien and Lyle advocated that people with intellectual disability had a right not only to participate in the community but to be supported to take up this right thorough advocacy, self-determination, and personal centred planning. Yet, despite such good intentions, in the early 1990s, Todd, Evans, and Beyer (1990) noted that people with disability were a presence in the community but were not usually part of it. This is a situation that continues for many today (Ballin & Balandin, 2007; Bigby, 2010), even though participation is a term that is well recognized and used commonly by those working in the field of lifelong disability.

Indeed participation is a core concept in ICF (World Health Organization, 2001). The ICF, with a focus on more than the individual, holds promise for helping health professionals, including speech-language pathologists, to move from a medical view of classifying people to a more inclusive and some might say, participatory view, in terms of their function within the communities of their choice.

It is beyond the scope of this paper to discuss the ICF and how it relates to speech-language pathology in detail, particularly as there is an excellent and comprehensive discussion of the ICF and its relevance to speech-language pathologists in issues 1–2 of the *International Journal of Speech-Language Pathology* (2008). Nevertheless, it is worth noting the ICF provides a framework that can assist clinicians to view their clients holistically, and include them actively in both assessment and intervention processes, including functional goal-setting. The ICF also provides a means of facilitating communication about individuals to other stakeholders (e.g., administrators, policy-makers) who also have an interest in health and welfare (Threats, 2008). Yet, the ICF is not routinely used by speech-language pathologists and other service providers, furthermore it is both time-consuming and in some cases confusing to complete (Ma, Threats, & Worrall, 2008). Indeed, as
Threats (2008, p. 60) noted, the ICF is a tool which has broad and important relevance to speech-language pathologists, but it cannot make a “client-centred” clinician.

Furthermore, there is a problem for adults with lifelong disability, including those with complex communication needs (CCN), and the speech-language pathologists that support them. Although the ICF, which is currently the tool of interest in both Australia and much of Europe, presents a framework that emphasizes participation and is applicable to any person in the community, with or without disability, it is not routinely used, particularly in the field of AAC (Iacono, 2004). Researchers such as O’Halloran and Larkins (2008) and Raghavendra, Bornman, Granlund, and Bjorck-Akesson (2007) have noted that the participation component is difficult to measure and the range of professionals who are involved in supporting people who use AAC may conceptualize participation differently according to their roles and experiences. This brings us back to the title of this paper and the concept of the bowling alley as an example of community participation. Are activities performed in a community setting where others are performing the same activity an example of participation? Furthermore, do speech-language pathologists have a role in supporting people with lifelong disability to participate over and above ensuring that they have some sort of functional communication system?

Even if speech-language pathologists working with people with lifelong disability embrace the ICF, adults from this client group rarely access speech-language pathology services. If they do, the service is likely to be specific (e.g., updating technology) or time limited (Balandin, 2002; Raghavendra et al., 2007). Nevertheless, most speech-language pathologists working in the field of lifelong disability, whether they are using an ICF framework or not, would agree with the principles of the social use of the ICF, when applied to people with lifelong disability. In other words, they are likely to agree that there is an ongoing need to (i) enhance choices and control, (ii) enhance and support participation, and (iii) treat people as individuals (Threats, 2010).

Both Imrie (2004) and Shakespeare (2006) noted that the ICF, although theoretically under-developed, may offer a way forward for the inclusion of people with disability. It can be argued that in the case inclusion for adults with a lifelong disability, and in particular for those who require functional communication interventions, the ICF requires further exploration.

Model of participation

Of course professionals working with people who have lifelong disability including those with CCN do not work in a vacuum just because they do not utilize the ICF. Many base their assessment and intervention planning on Beukelman and Mirenda’s (2005) Participation model. This provides a systematic approach to AAC assessment that includes many of the concepts that are integral to the ICF, including the identification of facilitators and barriers to opportunities to participate at all levels. Barriers can include policy, practice, knowledge, attitudes, and the environment. There is a strong focus on looking forward and considering the future, on utilizing the strengths of the individual, and the importance of considering what others who are similar but do not have a disability are able to achieve. This model, then, provides a systematic and common sense way of managing some of the communication needs of people with communication impairment, including those who need AAC. This model cannot provide any blueprint for participation. Indeed, it is reliant on someone, usually a speech-language pathologist or a communication specialist (e.g., members of an AAC technology team, teacher specialized in AAC) having the time and resources to conduct the assessment, plan the intervention, and co-ordinate the ongoing process. Such a service is not readily available for most people with lifelong disability and complex communication needs in Australia.

Participation and leisure

Whatever assessment or classification system is used to support people with lifelong disability, there appears to be general agreement from all stakeholders that going out into the community is important. It is also worth considering whether leisure activities increase participation for those with a lifelong disability. This may depend perhaps on how the different stakeholders define and understand participation. This brings us back to the bowling alley as a form of community participation and adds the concept of leisure which has been described not only as a right but also as a way of building competence, increasing self-esteem, asserting independence, and reducing stereotypical negative attitudes towards people with disability (Dattilo, Estrella, Light, McNaughton, & Seaby, 2008).

Reducing stereotypical views of people with communication disability is a major priority for the speech-language pathology profession (Threats & Worrall, 2004), yet it is not well documented if community presence helps with this. Previous research that explored the impact of children in segregated classes joining mainstream classes for some activities suggested that this is unlikely (Schnorr, 1990). Consequently, outings and leisure activities such a bowling or shopping may be more closely linked to community presence of people with disability than participation. Furthermore, adults with lifelong disability, including those with intellectual disability and those who use AAC, are more likely to spend time at home watching television or listening to music than being involved with others in the community in activities that are mutually
enjoyable (Dattilo et al., 2008; Felce, Lowe, & Emerson, 2001).

It is recognized that when people without disability interact and share time with people with disability, more positive attitudes towards disability including a reduction in perceptions of difference result (Atkin, 2000; Beck, Bock, Thompson, & Kosuwan, 2002; Beck, Fritz, Keller, & Dennis, 2000; Caltaux, 2002; Lennox & Diggens, 1999; Lund & Light, 2007; Murphy, 1997). Nevertheless, there is currently little evidence that presence alone leads to greater community participation by people with lifelong disability, as defined by Nirje (1985).

Understanding participation

Although in 1985, Perrin and Nirje argued that to view the normalization principle as idealistic and impractical was a misconception, it is not unreasonable to ask why the principle has not worked. Why are people with lifelong disability, including those who have complex communication needs, still for the most part not participating fully in society? One possible answer is that there has been a failure to understand participation at all but a superficial level. Maybe speech-language pathologists working in the field of lifelong disability have not been able to fully explore or question their role within the context of participation. This may be due to a variety of reasons, not least the lack of funding to support services and communication systems for adults with lifelong disability. Another reason may be that there has been an overall limited focus on people with lifelong disability, including those with CCN by lobbyists and advocates at a political level. Thus, as a group, people with lifelong disability have been and continue to be somewhat overlooked. In addition, the definition of integration or participation as it applies to people with disability remains poorly defined (van de Ven, Post, de Witte, & van den Heuvel, 2005).

Indeed people with lifelong disability, and in particular those with complex communication needs, are rarely included in discussions about participation; for example in van de Ven et al.’s (2005) study of the concept of integration and the factors that influence this. The respondents in this study included individuals without disability and people with acquired physical disability, arthritis, hearing, and visual impairment, but did not include participants with intellectual disability or those with little or no functional speech.

Five elements of integration

According to the respondents in van de Ven et al.’s (2005, p. 316) study, integration consists of five elements: (1) functioning in an ordinary way without receiving special attention, (2) mixing with others without being ignored, (3) taking part in and contributing to society, (4) utilizing opportunities, and (5) being the director of one’s own life. This view of integration could equally serve as a view of participation.

What follows below is an exploration of some of the issues that are relevant for adults with lifelong disability in terms of their participation, drawing on the author’s own research and that of others both in Australia and overseas. The focus on adults was chosen specifically because for those born in or after 2005 childhood and adolescence lasts for 18 years, whereas adulthood is forecast to last for approximately 63 years in Australia (World Data Bank, http://databank.worldbank.org/ddp/home.do).

Given that many people with disability now have a life expectancy that approximates that of other citizens in their community (Strauss, Brooks, Rosenbloom, & Shavelle, 2008; World Health Organization, 2001), it is possible to argue that 63 years is a long time to live in a community yet not participate fully in that community. Furthermore, the current focus on intervention and support of children is questionable if it does not lead to these children growing up to have a meaningful life, which by definition encompasses participating in their communities of choice. It can be argued that van de Ven et al.’s (2005) five elements of integration are synonymous with participation in a community and therefore provide an excellent model when considering adults with lifelong disability who to date have been more of a presence in the community than active participants (Bigby, 2010).

1. Functioning in an ordinary way without receiving special attention. One of the difficulties that is apparent immediately with this element is the definition of what is special. Many people with lifelong disability and complex communication needs might argue that they do not want special attention, but similar attention accorded to others would be a good start. People who use AAC have highlighted that they may have to wait in shops because nobody wants to serve them (Allan, 1999), that buzzers are removed in hospital because they may overuse them (Balandin, Hemsley, Sigafous, & Green, 2007; Balandin, Hemsley, Sigafous, Wallace, Forbes, & Parmenter, 2001), and that they not only experience problems with accessing the community but also accessing the houses of their friends (Dattilo et al., 2008). Problems with transport are implicated continuously as a major barrier to participation, including in contexts such as work and volunteering (Trembath, Balandin, Togher, & Stancliffe, 2010), leisure, and friendship (Ballin & Balandin, 2007; Cooper, Balandin, & Trembath, 2009; Dattilo et al., 2008; Hines, 2009). Indeed, without special attention, that is often not available due to service limitations, adults may not be able to use their communication devices (McNaughton & Nelson
2. Mixing with others without being ignored. Shakespeare (2006) suggested that this element of mixing with others includes friendships. Adults with a lifelong disability are more lonely than their peers (Balandin, Berg, & Waller, 2006; McVilly, Stancliffe, Parminter, & Burton-Smith, 2006a). In a recent qualitative study of loneliness and friendship some of the seven adult participants with cerebral palsy noted that their current living arrangements did not support friendship development. They had little in common with those with whom they lived and who they had not chosen as house partners (Ballin & Balandin, 2007). People with lifelong disability experience loneliness for the same reasons as people without disability (Emerson & McVilly, 2004; Fees, Martin, & Poon, 1999), but have additional problems with communication, in particular with non-familiar communication partners and on the phone (Ballin & Balandin, 2007; Cooper et al., 2009). Furthermore, problems with acceptance in the community increase their feelings of loneliness.

A study of the friendships and loneliness experiences of six younger adults with cerebral palsy also indicated that communication and problems with accessing appropriate technology impacted on feelings of loneliness. Furthermore, although this group used mobile phones and email, they noted that problems with literacy along with physical impairments resulted in a reliance on others, including staff, who could effectively cut them out of the communicative interaction by speaking for them. This increased the young people’s feelings of loneliness (Cooper et al., 2009). In addition, people with severe intellectual and/or physical disability and those who use AAC often continue to rely heavily on parents and family members to facilitate social interaction by providing transport, personal care, and encouragement (Dattilo et al., 2008; Hines, 2009).

Taken together, research by the author and her colleagues supports that of others (Emerson & McVilly, 2004; McVilly, 1997; McVilly et al., 2006a; McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006b) in that people with lifelong disability are likely to experience problems with friendships and may experience difficulty in mixing with others even if they are keen to do this. These problems may be exacerbated by the limited opportunities they may experience in obtaining paid work.

3. Taking part in and contributing to society. There are many ways to take part and contribute to society. One of the most important ways is through either paid or voluntary work. Employment provides not only an income and meaningful activity but contributes to increased self-esteem and feelings of self-worth as a contributing member of the community (Ashman & Sutnie, 1996; Chadsey -Rusich & Linneweaver, 1997; McNaughton & Nelson Bryen, 2002; McNaughton, Light, & Arnold, 2002; McNaughton, Symons, Light, & Parsons, 2006). Nevertheless, people with lifelong disability experience low rates of employment. Some with cerebral palsy and CCN find that self-employment is a solution, although this may reduce opportunities for social engagement (McNaughton & Nelson Bryen, 2002; McNaughton et al., 2002; 2006). Volunteering is also a way of contributing to society.

A recent study of 24 adults who use AAC and who volunteered indicated that volunteering offers a means of contributing and at the same time educating the community about AAC and disability (Trembath et al., 2010). The results of this study indicated that CCN, and in particular a lack of effective communication systems and appropriate support, impacted negatively on the experience and reduced opportunities to volunteer. Indeed, adults with lifelong disability are at risk of exclusion from the work or volunteering contexts, which are important ways of contributing to society (Balandin, Llewellyn, Dew, Ballin, & Schneider, 2006). Effective communication, reliable AAC technology, accessible workplaces, peers with positive attitudes towards disability, vocational skills, good transportation, and attendant care services are all key factors in gaining and maintaining employment (Bryen, Potts, & Care, 2007; McNaughton, Light, & Gulla, 2003). Speech-language pathologists have a role in ensuring that those seeking paid work or volunteering roles have ready access to effective communication.
systems that they know how to use. Yet it is important to consider whether the role of the speech-language pathologist extends further into job training and education of all stakeholders in the workplace. If this is the case how can it best be achieved?

4. Utilizing opportunities. Shakespeare (2006, p. 59) defined utilizing opportunities as “trying to reach ones potential, maybe with the help of others”. Speech-language pathologists have a role in assisting those with lifelong disability to do this and in supporting those who experience feelings of grief and loss when reflecting that they, over their life course, failed to reach their potential (Dark, 2010).

For example both anecdotally and in published reports (Gill, 1996; Jackson, 1996; Krotoski, Nosek, & Turk, 1996), women with cerebral palsy and those with intellectual disability (Mayes, 2009) have spoken about their desires for children but have in many cases taken the decision, not always willingly, that they would not be able to cope with bearing and raising a child to their own disability. Some have spoken of a trade-off between being supported to have a partner provided they agreed to sterilization. People with CCN may feel confident in talking to speech-language pathologists because, as a group, they are skilled listeners with many strategies to facilitate communication. Additionally they have often had a long relationship over many years with their clients and so have close bonds and a deep understanding of some of the issues that are important to them and which have shaped their lives (Murphy, 1997).

5. Being the director of one’s own life. There are countless examples of how people with CCN with and without intellectual disability are denied the opportunity to direct their own lives, including their own health care (Balandin & Waller, 2010; Buzio, Morgan, & Blount, 2002; Hemsley, Balandin, & Togher, 2007; 2008). Recent research into the perspectives of adults who use AAC on changes in their swallowing and mealtime management indicated that many of the 32 participants with cerebral palsy and CCN were concerned about the risk of being excluded from the short- and long-term decision-making about their mealtimes (Balandin, Hemsley, Sheppard, & Hanley, 2008). One participant said “It’s bloody awful—because I’m on a puree diet, and I hate it. I hate it” (p. 204). She, like others, reported reverting to eating what she liked when she was away from the service that supported her. Another said “Don’t ask me why [my diet has changed] but they seem to advise it, so you just do what you’re told really” (p. 201). Richard said: “The understanding of what I like—that’s a lot, the understanding—you’ve got to be able to enjoy your meal. Not to be told ‘you can’t have that’, ‘you can’t have that’, ‘it’s not for you to eat’” (p. 201). Only two participants openly defied the advice given by the speech-language pathologist, but others talked about their wish to be included in the decisions made about meals. Furthermore, they noted that the advice and subsequent plan was often not followed by staff or not understood by family members. Speech-language pathologists are well aware of the importance of collaboration and including clients in decision-making (Barczi, Sullivan, & Robbins, 2000), but this is no guarantee that staff and others involved in mealtime management will follow through with plans or that clients will feel appropriately consulted in decisions that they would prefer not to make. Therefore, it is important that as a profession, speech-language pathologists avoid situations of blame or feeling defensive, but rather seek alternative or additional ways of sharing knowledge. Better collaboration is needed in order to reach consensus on issues that impact on a range of stakeholders including clients, staff, families, and others in the community.

Innovative solutions to solving problems with participation

There are many potential solutions to improving participation for people with lifelong disability; two of the most recent are The Change Laboratory process (Engeström, 2008) and the use of virtual worlds.

The change laboratory for supporting learning

The Change Laboratory Process is a process in which the working community, for example speech-language pathologists, staff, clients, family members, and maybe others (e.g., dietician, physician), engage in a process of analysing and developing the activity. The aim is to identify the problems that are experienced and develop a new understanding and better way of managing them. The process typically takes 9–10 weekly meetings, each lasting ~ 2 hours. Throughout the process a range of data are collected and analysed which in turn provides an ideal opportunity for collaboration between researchers and clinicians, as suggested by Onslow (2008).

The Change Laboratory Process uses activity-based intervention to support learning (Engeström, 2008). In the case of a person with lifelong disability for example, all stakeholders in a particular context may benefit from analysing the inherent problems within the situation. Subsequently, they collectively design and implement a new activity based on a reconceptualization of its objective and purpose using a range of conceptual tools (Engeström, 2008). Professionals and clients have different issues, views, and interests that need a communicative integration. In other words, the barriers between professionals and clients are tied to separate discourses and practices. This is overcome by the
Engestro"m (2008) suggested that the quality of the analysed according to three different interaction the speech-language pathologist and client) can be encounters between the different stakeholders (e.g., interaction but are dealt with by the group and exclusion either undermined the selected regime or the person with dysphagia felt resentful about the decisions made.

The Change Laboratory Process consists of six phases that occur sequentially but are iterative, in other words they form a hermeneutic circle (Heidegger, 1962).

1) Charting the situation: recognizing the need for change and a commitment to this. Thus, the person’s problem with the mealtime regime is acknowledged and there is agreement from stakeholders to do something about it.
2) Analysing the needs and possibilities of development: examining the current problems and how have they been managed. What contradictions exist? (e.g., a person is on a modified diet but has no history of chest infection; staff are concerned about duty of care vs the individual’s right to choose).
3) Creating a new model for the activity: how do stakeholders want it to be in the future?
4) Concretizing and testing the new model: what new tools are needed for managing this, what new tools and practices will be tried in the next month?
5) Implementing the new model: putting the first new ideas into practice, preparation for what will happen next.
6) Spreading and consolidating the new model: new rules for management, teaching others about the learning process and activity.

Engestro"m (2008) suggested that the quality of the encounters between the different stakeholders (e.g., the speech-language pathologist and client) can be analysed according to three different interaction modes, coordination, cooperation, and communication.

Thus, during the Change Laboratory Process the aim is to move from coordination where each person involved follows their own script, through cooperation where the stakeholders focus on a shared problem to communication where those involved reconceptualize their own ideas and interactions in relation to a shared objective. In the case of a client with dysphagia, the shared objective would be a mealtime plan that is agreed and acceptable to all stakeholders and understood by all. During this process it is expected that there are disturbances and disruptions that may cause deviations in the flow of the interaction but are dealt with by the group and ultimately lead to innovations. Although this process may be blocked by rumbles, which may lead to disturbances at a later time (Engestro"m, 2008), the Change Laboratory Process has been successful in facilitating stakeholders to collaborate, and to identify and overcome problems that have hitherto blocked successful outcomes but hitherto may not have been recognized. It is a time consuming process initially, but the skills learned are transferable to other situations and lead to new learning and respect for the knowledge of different stakeholders.

Currently there are no published reports of the Change Laboratory Process being used by speech-language pathologists working in the field of lifelong disability. Given the problems experienced in supporting community participation and the difficulties that are often experienced when a range of stakeholders collaborate (Balandin & Duchan, 2007) it may be a promising technique that warrants further exploration. In particular, the Change Laboratory Process seems to fit with the elements described by van de Ven et al. (2005): including mixing with others without being ignored, utilizing opportunities, and being the director of one’s own life. On the other hand virtual worlds foster new experiences that can lead to new understanding.

Participating in a virtual world

When I first came into Second Life, I found I had acquired some [new] abilities. I could walk (I can’t walk in real life); I could fly; I could even teleport. I felt more comfortable seated and so got a Segway [scooter] to move around in-world. (Judy Brewer, Charoette Voom in Second Life, Director of the Web Accessibility Initiative (WAI) at the World Wide Web Consortium (W3C)) (Hansen, 2008).

Although virtual environments have been used to promote skills for independence, and improve cognitive performance for people with intellectual disability, few programs have aimed at improving the participation or social skills of people with lifelong disability, apart from the few that have focused on people with autism (Standen & Brown, 2005). These researchers argued that, although virtual environments may not be suitable for all people with disability, the potential of the virtual environment for learning and practice is as yet relatively untapped.

In commentaries on Standen and Brown’s (2005) review, a number of researchers agreed that virtual worlds offer new opportunities for people with disability (Davies, 2005; Harrison, 2005; Lewis-Brookes, 2005; Newland, 2005; Ward, 2005). They noted that rigorous research is required to reveal the opportunities that virtual worlds offer for people with disability. Such research could ascertain the applicability of virtual technology to other disadvantaged groups (e.g., people with acquired brain injury or mental health issues). It is not known how many people with lifelong disability use virtual worlds for
social interaction. Nevertheless, increasingly, academics and educators are using virtual worlds for a range of educative experiences (Molka-Danielsen & Deutschmann, 2009). The author and Norwegian colleagues are currently using Second Life™ to conduct research into (a) whether virtual worlds are useful not only for teaching about lifelong disability but also for changing student attitudes towards disability, and (b) if virtual worlds can be used to develop friendships and increase social interactions for people with lifelong disability. Second Life™ is an open access technology platform where a community of participants creates the content of a virtual world. The environment allows participants, called residents, to interact through motional use of avatars (synthetic characters) that can be personalized in the greatest detail. Besides interactions of avatars in the 3D space, residents can communicate through tools such as text chat or voice chat, using public broadcast or private one-to-one talk options. Consequently the use of Second Life can assist people with lifelong disability to gain experience with all five elements identified by van de Ven et al. (2005) as critical to community integration or participation.

Second Life™ has been used increasingly in the domain of social communication, including with people with Autism Spectrum Disorders. Indeed people with disability have found that virtual environments can be used successfully (Biever, 2007), for example there is a virtual nightclub, Wheelies, where people who in real life use wheelchairs socialize and dance, with or without their chairs. The majority of evidence regarding the benefits of virtual worlds on building friendships or reducing feelings of loneliness for people with lifelong disability is anecdotal. For example, adults with cerebral palsy have noted that in a virtual world they can choose whether to disclose their disability and can participate in a variety of activities that would not be accessible in real life (see Brewer’s quote above). Preliminary results of current research indicates that people with lifelong disability are interested in entering Second Life™ because it is new and they can do this from their home computer (Julnes, Balandin, & Molka-Danielsen, 2010). Both students and people with lifelong disability are positive about the opportunities to interact and learn together in Second Life™ and agree that Second Life™ offers experiences that are not possible in real life (Balandin, Vee, & Molka-Danielsen, 2010). For example if a person uses a wheelchair or uses text to communicate in Second Life™ it is not possible to know if they have a disability in real life so interactions are influenced by what is apparent. In other words, if individuals use a wheelchair in Second Life™ they are likely to be treated by others as if they have a disability, which may be a useful, if somewhat shocking experience for those who do not have a disability in real life.

The authors and colleagues are using Second Life™ for education, meetings, collaborative learning opportunities, and a range of social activities that include people with lifelong disability. It has potential for learning and practice that may not yet have been realized. It is possible to have a virtual beer in a virtual bar or eat a virtual ice cream while strolling through virtual Barcelona. Therefore, to return to the dysphagia example above, people with severe dysphagia could experience eating and drinking with other avatars and perhaps gain new understandings, as could service providers and students who decided to choke on their virtual ice cream.

Future research directions

Research is needed to evaluate the use of both the Change Laboratory and virtual worlds as interventions that may increase participation by people with lifelong disability. In addition research is required to explore how people with disability view these new interventions and the opportunity to collaborate more closely with researchers and service providers. Within the field of services to older people and in the field of education, the Change Laboratory is promising, but as yet it is not known if it is a useful process for speech-language pathologists. Future evaluations might include exploring whether activities learned and practised in a virtual world carry over into the community and if interacting with people with disability in a virtual world changes negative attitudes towards people with disability in the real world.

Conclusions

Participation is much more than a trip to the bowling alley, an evening out with friends, or the chance to choose what outfit to wear on Saturday. It is about being connected and accepted within the community in which a person lives, being able to make decisions about what to do and who to do it with, and includes managing health and finances. In addition, participation includes taking advantage of opportunities and living a life that is satisfying. We do not live in a perfect world, and participation or community inclusion for people with lifelong disability and CCN is far from perfect. Nevertheless it is better than it was even 20 years ago and new ideas and new practices are emerging. People with lifelong disability are part of our community; they deserve the same advantages and opportunities as any member of the community. Speech-language pathologists have the skills and motivation to help ensure that they achieve these.

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Notes

1) This model suggests that it is not impairment that results in people being disabled but rather disableness comes from the environmental, economic, and cultural barriers that exist in society.

2) In NSW, David Richmond conducted a report on the services for those with psychiatric illness or developmental disability. He recommended that people with intellectual disability required alternative accommodation to institutions. These included family style homes within the community staffed by non-medical personnel.

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