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Disability citizenship and independence through mobile technology: a study exploring adoption and use of a mobile technology platform

Abstract

This paper explores the use of mobile technology as experienced by people with disability. The intention of the mobile technology is to increase community independence and participation by increasing the user's autonomy through a range of apps and a 24/7 Help Centre. It examines their experiences of the device, the perceptions of its effectiveness through the eyes of carers and service providers, and the impact of the technology on the lives of the individuals. An interpretive qualitative study design was adopted involving observations and interviews with 15 participants, their significant others and their service providers. The data is analysed using the 'PHAATE' model which represents the factors for consideration in service design which are policy, human/person, activity, assistance, technology and environment. The findings indicate that the mobile technology extensively increased the participants' communication and sharing of events and information particularly with family members. Carers and service providers talked about the benefits of the technology in terms of security, safety and independence. Nonetheless, all involved in the research identified technical, behavioural and roll out problems associated with the mobile technology. Overall incorporating mobile technology into the lives of people with disabilities provides opportunities for the development of greater independence and disability citizenship.

Keywords

Community independence, PHAATE Model, mobile technology, disability citizenship, mobile phone

Points of Interest

- the study empirically tested the adoption of a mobile technology platform by people with a variety of impairments and support needs
- the findings provided a typology of users being "evangelists", "embarkers" or "discontinuers" that were affected by a multitude of factors that enabled or constrained social participation
- for those adopting the technology, there were increases in skill development, social participation and disability citizenship
- the mobile technology empowered individuals to be creators of their own narratives that were communicated to family and friends, and newly established social networks
- The perceptions of the significant other/s and the service providers acted as a constraint on the adoption of the technology for some study participants
- social model and PHAATE analysis identified the importance of individual customisation of hardware and software, ongoing training and support, together with the 24/7 Help Centre to maximize uptake

Introduction

Mobile phones are ubiquitous to social participation and citizenship (Goggin, 2012). They are the communication tool of choice (Australian Communication and Media Authority, 2015) with 1.3 active mobile services for every man, woman and child in Australia (Australian Bureau of Statistics, 2015). Yet it is a technology that has been difficult for people with significant disability to access (Goggin & Newell, 2003; Macdonald & Clayton, 2012). Hence, in many ways people with significant disability have had their rights of citizenship constrained by not having access to mobile technology. The notion of “disability citizenship” has been widely canvassed in the literature with an overriding understanding that people with disability should not only have a right to all areas of citizenship but that these rights need to be supported through legislation, policy and provisions to challenge barriers that prevent social participation (Barton, 1993; Darcy & Taylor, 2009; Meekosha & Dowse, 1997; Meekosha & Soldatic, 2011; Power, Lord, & DeFranco, 2013; Singleton & Darcy, 2013; Smith, 2013). Disability citizenship has been reinforced through the UN *Convention on the Rights of Persons with Disabilities* (CRPD) (United Nations, 2006). The CRPD creates an expectation that people with disability have a right to all areas of social participation that are required for citizenship.

There has been a growing recognition of the value and benefits that can accrue from mobile technology and in particular smart phones and tablets for people with disability (Alper, Ellcessor, Ellis, & Goggin, 2015; Goggin, 2012). This paper researched the outcomes of a pilot project that brings together a smart phone and tablet platform together with customisation and 24/7 Help Call Centre (24/7HCC). The mobile technology platform (referred to VilTech™ in the paper as a pseudonym) was developed by a not-for-profit disability service organisation, Village Networks [pseudonym] that is a provider of accommodation and community support for people with significant disability. The organisation in conjunction with a government grant developed VilTech™ that is affordable, accessible and relevant by design to increase users autonomy, community independence and participation with the added assistance of hardware and software customisation together with a 24/7HCC.

The research was positioned within social approaches to disability (Barnes, Mercer, & Shakespeare, 2010) adopted under the United Nations CRPD (United Nations, 2006) and the systemic policy change driven by the introduction of the National Disability Insurance Scheme (NDIS) in Australia (Commonwealth Government, 2013; Green & Mears, 2014). The effect of the technology on the social participation and, hence, disability citizenship of those involved was central to the research. To assist in contextualising assistive and information communication technology (ICT) a framework for analysis was developed combining social approaches to disability, and the PHAATE model (policy, human/person, activity, assistance, technology and environment) (Cooper, 2007). This paper briefly examines our understanding of disability, before examining the literature on the use of mobile technology and discussing the research design for the project.

Understanding disability

Two main models dominate the theoretical debate on understanding disability. The first is the medical model premised on an individualised understanding of a person as a biologically normative human being where variations from "normal" are viewed as abnormal or deficits based on a person's impairment(s). In this model, individuals must make adjustments to their imperfections through medical interventions, rehabilitation, therapy and the use of assistive technology to "normalise" their bodies (Swain, French, & Cameron, 2003). The second model of disability is the social model. It breaks 'the linear causal link between impairment and the state of being disabled' (Reindal, 2010, p. 126); which is the basic tenet of the medical model. It takes a socio-political perspective that separates impairment, the physical condition or restriction, from the personal experience of being disabled, which is the state that occurs within a specific environment or context (Vehmas & Mäkelä, 2009). Its focus is the lived experience of people with disability and the disabling environmental and attitudinal barriers that they encounter that transform a person's impairment to a disability (Oliver, 1996, p. 38). It firmly places disability on the economic, political and social agendas where people with disability have a right to social participation. The social model seeks to identify the barriers to social participation whether that be environmental or attitudinal. However, like other social constructionist or critical theory, the social model of disability seeks transformational outcomes rather than merely identifying those barriers to social participation (Swain et al., 2003).

Moreover, following the advent of the UN CRPD (United Nations, 2006), which was framed on a social model of disability and human rights discourse (Gill & Schlund-Vials, 2014; Kayess & French, 2008), Article 9 states the right to the accessibility of facilities and services including assistive and ICT. These are identified together with need to incorporate appropriate training including access at a minimum cost. The CRPD through its definitions and other articles goes on to outline those areas of social participation and disability citizenship that people with disability should expect. Mobile phone technology as a form of assistive technology and ICT facilitates much of the other areas of disability citizenship including work, recreation and creative expression.

Assistive and Information Communication Technology

Significant achievements in addressing barriers that create disability can be seen in the built environment and technological developments with examples ranging from wheelchairs and motor vehicle control adaptations to speakerphones, voice recognition and text to voice software. The range of developments in assistive technology is constantly increasing. More recently the needs of people with mobility, sensory and cognitive impairments have begun to be addressed through developments in information and communication technology (ICT) (Alper et al., 2015; Goggin, 2012). This has included computers, digital cameras, handheld personal digital assistants (PDA), mobile and smart phones.

Yet, these technological advancements have largely been unused by people with disability because of cost factors (Goggin & Newell, 2003; Macdonald & Clayton, 2012), and community and allied health views that people with disability with significant support needs could not use such devices. Literature reviews of studies of ICT use with people with disability with significant support needs conducted over the past 25 years generally agree that there is real potential for the use of these technologies (McKnight, 2014; Watling, 2011) and that the area of ICT warrants greater attention as a tool for teaching, training and support (Pennington, 2010; Wehmeyer et al., 2006). Nonetheless, they also agree that there are significant limitations due in part to the commercial software available, the usability of the hardware and as Kennedy and colleagues (2011) found, the attitudes of the web development companies. Yet, the speed of development in ICT is unprecedented (Mitchell, 2005) and the possibilities of new products for people with disability with significant support needs continues to be explored (McKnight, 2014; McNaughton & Light, 2013).

The advent of smart phone technology provides a platform for people with disability which is already prevalent in the general community (Cumming, Strnadova, Knox, & Parmenter, 2014; Philipson, 2010). The accessibility and assistive potential of smart phones for people with disability has been a focus for developers, regulators and providers (Australian Communication and Media Authority, 2013). Features such as instant messaging, GPS-enabled navigation with speech directions and landmark identification and apps that scan currency and read barcodes are just some of examples of the technology's assistive potential (Alper et al., 2015; Australian Communication and Media Authority, 2013). The literacy and numeracy requirements of previous mobile phones that limited their use by some people with intellectual or developmental disability with significant support needs have been significantly reduced (Stock, Davies, Wehmeyer, & Palmer, 2008).

The application of ICT in training and support is only useful if it is likely to be used independently by people with disability with significant support needs. If this is the case then the technology provides opportunity to create their own narrative of their lives, explore their identities and improve their self-confidence (Bunning, Heath, & Minnion, 2009; Cumming et al., 2014). Some technological innovations such as the use of ICT may require service support for users with disability and to be used to maximum effect these need to be integrated into their service support systems. This effective training and support requires a positive attitude and technological competence on the part of those working with the users. Similarly, the commitment of service providers to the benefits of ICT is critical in the successful adoption of ICT by people with disability (Parsons, Daniels, Porter and Robertson, 2008). Notwithstanding the above research, Ellis and Goggin (2015, p. 1) make the point that within all the claims of ICT potential for people with disability, 'there is little informed discussion, public debate or critical analysis and research on their actual characteristics, potential and implication'.

The Australian Policy Context

The policy context in Australia is undergoing radical change. For the past thirty years, Federal and State governments have granted block funding in advance to organisations to provide services to people with disability. Whilst some choice has been exercised on the part of people with disability, the main locus of control and decision-making has resided with service providers. This is about to change with the rollout of the NDIS, which is a no-fault

insurance cover for Australians with significant disability (Baker, 2012, p. 1). It changes the funding process with the funds given to the person with disability not the provider organization. The intended result is user-controlled budgets and direct service purchasing (Dowling et al., 2006). Individualised budgets are designed to give choice, flexibility, control and real purchasing power to the person with disability. Theoretically they can decide what they need and want, and buy it from the provider they choose (Lord & Hutchison, 2003).

Nonetheless, critics of individualised funding and marketisation of support also point out issues associated with people with different types of disability, significant support needs, and the lack of an evidence base as to how well the policies are working (Brennan, Cass, Himmelweit, & Szebehely, 2012; Harkes, Brown, & Horsburgh, 2014). The UK has been implementing similar policies with their experiences suggesting that there can be a reduction in training and quality in some services (Cunningham & Nickson, 2010). Moreover, for people with disability who have little or no agency, their choices will be made and managed by others. Inherent in this is the influence of the views of the ‘others’ (Green & Mears, 2014). With these caveats, the potential of individualised funding policy nearby, the reduction in cost of smart phone technology places an opportunity within reach of some people with disability in a way it has not been in the past.

Research Context

Research to date suggests that the most effective ICT device for training and support for people with disability with significant support needs would be a regular mobile phone that has been adapted for specific functions. The software would be specifically developed and tailored for the individual user. Finally, the implementation of the ICT device in training and support would include a full induction on the use and potential of the device for carers and support workers. This study researched the pilot of an introduction of a mobile technology to people with disability with significant support needs, and assessed its use through the perceptions of the users, significant others and support workers.

VilTech™ was developed by Village Networks in conjunction with government funding and a commercial telco company contract. The combination of the mobile technology, customisation for individual users, software configurations and 24/7HCC was designed with the aim to increase the independence, dignity and equality of people with disability. The

service delivery was based on affordable technology that has the potential to change the way disability training and support is provided and managed. The philosophy of the project was guided by NDIS and National disability strategy principles (Commonwealth Department of Social Services, 2010).

To match VilTech™ to people's needs and to understand how these could best be met, a 13-week introduction was undertaken which included people with a range of different disability and support needs. The individuals came through a number of service providers and families from the Sydney area, regional NSW and Tasmania. The introduction was facilitated by the Village Networks staff at no cost to the individual. Each person received a mobile phone, case, charger and lanyard, and the phone was connected to a mobile phone plan (covered by Village Networks). Each person received two familiarisation sessions in which the technology was introduced and personalised to maximise its effectiveness for the individual. Every week throughout the introduction, the 24/7HCC contacted each person at random intervals in order to familiarise them with the process of answering calls on the phone. Each individual was also asked to contact the 24/7HCC on a daily basis.

Summary and Research Aim

With this background, the aim of the research was to assess the usefulness of the ICT in the development of community integration, training and support of the participants with disability whose supports needs ranged from low to very high. The objectives of the project were to:

1. Determine the level of adoption and use of mobile technology by the participants over the timeframe of the pilot project;
2. Assess the effect on the participants' social integration and participation;
3. Examine the perceptions of the participants, their significant others, attendants, carers or guardians (referred to as significant other) and service providers on the effectiveness of the mobile technology in terms of empowerment, social participation and citizenship.

The Theoretical Framework

The theoretical framework adopted to understand how VilTech™ was delivered and how it contributed to the lives of the participants with disability was based on the social model of disability, NDIS and National disability strategy policy implications and the afore mentioned ‘PHAATE’ model (Cooper, 2007). Within the research framework, we needed to acknowledge the important contribution that assistive technology can have on accessing the community from mobility, sensory and cognitive perspectives. To recognise the importance of the assistive technology dimension of this research, the research framework incorporated the PHAATE model (Cooper, 2007) as a framework for investigating this phenomenon. PHAATE originates from the assistive technology service delivery literature (Cook & Polgar, 2008; DiGiovine, Schein, & Schmeler, 2012), has been used previously in therapeutic rehabilitation settings in the choice of assistive technology (Cooper, Ohnabe, & Hobson, 2006; Friesen, Russell, & Theodoros, 2015; E. Friesen, D. Theodoros, & T. Russell, 2013; Friesen, Theodoros, & Russell, 2015b; E. L. Friesen, D. Theodoros, & T. G. Russell, 2013; Souza et al., 2010). As shown in Figure 1, Cooper’s explanation of the model is that people with disability are affected by both public and private *policy*; they use *technology and assistance* to accomplish tasks or perform activities. People with disability live in the ‘real world’ and therefore the *environment* influences their functioning being either enabling or disabling. Finally and most importantly, the person (*human*) is the centre of the model. A key component of the model and the assistive technology service delivery is the ability to match the appropriate technology to the individual requirements of the person with disability.

Friesen, Theodoros, and Russell (2015a) have gone on to suggest that any assistive technology use for people with disability is really about “usability-for-one”. This approach melds well with Thomas’ (2004) concerns that within social model approaches there should be room for an individual’s “impairment effects” and creating enabling environments based on an individual’s needs. However, to date PHAATE has only been applied in therapeutic settings where the interaction was between the individual with disability and a clinician more akin to the medical model of disability. In this study, the PHAATE model is applied to community settings where the interaction is between the study participants and their social networks and environments.

Research Design

Village Networks based the project on an experiential learning conceptual approach (Gentry, 1990). This took the project into real time. Village Networks provided educational and training support as an adjunct to, the personal support provided by families/carers and service providers. The research design adopted the principles of participatory action research which is suitable for working with the not-for-profit sector and people with disability (Denzin & Lincoln, 2003). Within this approach, the research design implemented an inductive interpretive approach where the voices of the stakeholders (participants with disability, their significant others¹ and their support workers) guided the findings of the research. The project was designed for a staged implementation over 12 months across the individual and organisational context. The research used three distinct populations: participants with disability; their significant others; and the support managers of the participants with disability (where applicable). This research design created a triangulation of data sources to examine the phenomena.

Population and Sample

The research team working in conjunction with Village Networks, worked with a 152 participants involved in the pilot project. From this population a sample was drawn with the researchers developing an information sheet that was distributed to prospective users by Village Networks. Those who were interested contacted the researchers and a time was organised to meet with a member of the research team. Fifteen recruited participants consisted of seven women and eight men and were comprised of ten participants with intellectual disability (of these ten, two also had physical disability and three also had speech disability), four participants with physical disability including two with speech disability and one participant with a cognitive disability as a consequence of a brain injury. The participants were recruited between March and December 2013.

In-depth interviews were used to gain a meaningful understanding of each participant's current community participation and integration from the participant's point of view and the points of view their significant other and that of their support manager if they had one. The research design planned for three sets of interviews with participants, their significant others and their support managers (if appropriate) between March 2013 and January 2014. The first

¹ "significant other" in this study may refer to a person with a disability's partner, family member, carer, attendant or guardian whom they identify. The language used in the findings is reflective of the language that the person with disability used.

sets of interviews were held where possible before the pilot project commenced. The participants subsequently took part in the 13-week introduction. The second interviews where possible was conducted after six week and then the third interviews was conducted at the end of the 13-week introduction. The interviews involved a semi-structured guide as this format offered the flexibility to vary question order, the time spent on each category and, where appropriate, investigating other avenues identified during the interview but not covered by the guide.

The research team sought to develop conversations with those being interviewed through the use of a semi structured interview guide. Rather than having a structured set of questions, a semi-structured guide provides an opportunity to be cognisant of the individuals involved, their particular circumstances and to interview in a way to accommodate an individual's communication needs. Similarly, this was an important consideration for the significant other, and the various industry settings of the participant's support service. The interview guide included questions about the participants' current community access particularly in relation to employment, medical, leisure, shopping, banking, family and friends. Additional questions sought to establish current levels of support in terms of support hours (parents, friends, direct care workers), associated support activities (classes, 1:1 training) and support devices (prompt cards, reminder devices, signs). Current use of ICT was also ascertained (e.g. the use of computers, phones and tablet). The purpose of the ICT use (e.g. personal management, leisure and/or contacting friends and family) was investigated and questions were included about usage constraints (i.e. environmental, physical, literacy, numeracy, sequencing, memory, social knowledge, skills, and reading cues).

Ethics

The independence of the research was paramount so that there could be no apprehension of bias attached to the findings. The researchers were independent and separate to Village Networks, which developed VilTech™ and provided the 24/7HCC. As previously mentioned Village Networks had received funding from a government agency, engaged in a commercial contract with a telco company and then developed the IP/processes for the VilTech™. The research report was completed without feedback from Village Networks and under the contract academic freedom was ensured. Ethics clearance from the University human research ethics committee ensured that people with disability with low to very high support needs were exposed to minimal risk (i.e. negligence, inconvenience, discomfort, harm or

pain) and procedures were put in place to support the person with disability and their significant other.

Data analysis

All interviews were tape-recorded, transcribed and spot-checked for accuracy. Transcripts where appropriate, were forwarded to interviewees for checking. Following the transcription of the interviews, the data was analysed using NVivo version 9 software. The software assisted in typological analysis that divides information into nodes and sub nodes ‘... on the basis of some canon for disaggregating a whole phenomenon’ (Howe & Brainerd, 1988, p. 314). Data is then placed in the corresponding category or typology. It is a process used to analyse textual items (Henderson, 1991). Importantly, this analysis used then combined lens of social model and PHAATE (Barnes et al., 2010; Cooper, 2007; Oliver, 1996). After the initial filtering and categorisation the analysis involved constant comparison of pre-and post-interviews (Glaser & Strauss, 1967).

Findings

This section presents the findings of the research in respect to the level and typology of adoption, social participation activities and disability citizenship. In reporting findings within qualitative research, there is always a tension between developing the individual narrative and constructing a collective understanding of emerging groups within the data. With respect to the adoption of ViTech™, the focus is on examining the broad emergent patterns of behaviour amongst the sample as a collective rather than the individual narratives of the use of the technology. Whereas the sections on social participation and disability citizenship are outlined in terms of individuals’ narratives. To provide a more nuanced understanding of individual experience within the adoption, typology and use, Table 1 shows the characteristics of the participants. Wherever direct quotes are used to illustrate the typology, social participation and disability citizenship of the participants, the participant number from Table 1 is identified in brackets at the end of the quote to allow cross-referencing to the table to provide a better context for the quote. Each of the findings sections will now be presented.

Number	M/F	Age	Disability Type	Description of participant	Support	Access in the community	Support needs	Usage constraints	Phone use prior	Tech use prior	Adoption after 3 months	Typology
1	F	18–30	Cognitive	moderate intellectual disability	Service provider	Training centre/service provider	Medium	None	Yes	Frequent	High	Evangelist
2	F	18–30	Cognitive	very mild intellectual disability	Service provider	Work experience/training centre	Medium	None	Yes	Frequent	High	Evangelist
3	M	18–30	Cognitive/Mobility	intellectual disability and a physical disability which limits his ability to walk	Service provider	Part-time work	Independent	None	Yes	Frequent	High	Evangelist
4	M	18–30	Cognitive/Mobility	cerebral palsy with limited mobility and an intellectual disability.	Service provider	Accompanied outings	Very high	Compulsive behaviour	Yes	Frequent	High	Evangelist
5	F	18–30	Cognitive/Sensory	Joubert Syndrome developmental , poor vision and epilepsy	Service provider	School	Independent	Vision	Yes	Frequent	High	Evangelist
6	F	18–30	Mobility/Sensory	cerebral palsy with mobility and speech	Independent	Work from home/ independent community access	Independent	Speech	Yes	Frequent	High	Evangelist
7	M	31–64	Cognitive/Mobility	cerebral palsy with an intellectual disability and walking limitations	Service provider	Living in the community	Independent	Physical	Yes	Frequent	Medium	Embarker
8	M	18–30	Cognitive/Sensory	intellectual disability, little speech and on the autistic spectrum	Service provider	Training centre/service provider	High	Speech	No	Frequent	Medium	Embarker
9	M	65+	Mobility	cerebral palsy that affects walking	Independent	Retired but did work in the community	High	Physical	No	Frequent	Medium	Embarker
10	M	18–30	Mobility/Sensory	cerebral palsy and is non verbal	Supported Living Fund	Buys in services/ limited community access	Very high	Speech	No	Frequent	Medium	Embarker
11	M	18–30	Cognitive	intellectual disability	Supported Living Fund	Part-time work	Medium	None	Yes	Infrequent	Low	Discontinuer
12	F	18–30	Cognitive	mild intellectual disability	Service provider	Training centre/service provider	Medium	None	Yes	Frequent	Low	Discontinuer
13	F	18–30	Cognitive/Sensory	an intellectual disability and is non verbal	Service provider	Part-time work	Medium	Vision	Yes	Frequent	Low	Discontinuer
14	F	18–30	Cognitive/Sensory	intellectual disability and has speech difficulties	Service provider	Training centre/service provider	Independent	Speech	Yes	Infrequent	Low	Discontinuer
15	M	65+	Cognitive/Sensory	brain injury	Service provider	Retired but goes out with a carer	Very high	None	Yes	Infrequent	Low	Discontinuer

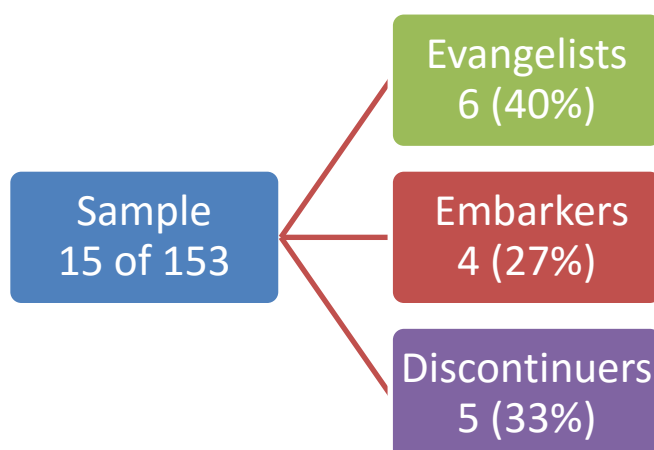
Table 1: Respondent Characteristics

Adoption of mobile technology

As Figure 2 shows, from the interview transcripts three user typologies were identified and named as: Evangelists, Embarkers and Discontinuers. The Evangelists were extremely enthusiastic VilTech™ users who continued with their use after the pilot had completed. The Embarkers were happy to try something new and interested in continuing use of VilTech™ after the pilot but needed more time, training and support to maximise the potential benefits that they could see emerging from their experience. The Discontinuers began to use the technology but withdrew and ceased altogether during the time of the pilot.

It is important to understand that the typology was not based on impairment groupings but the overall technology uptake, which was the result of numerous influences. These included each individual participant's personal circumstances; the relative level of support they received from their network; degree of customisation/training required; and their previous technology use and experience. Hence, with a sample of 15 users it was far more difficult to establish experiences grouped by impairment or broader disability type. The value of the typology is that it shows that the level of adoption could not be isolated to any uniform influences or circumstances across the sample and is supportive of the concepts of Thomas (2004) "impairment effects" and Friesen et al. (2014) "design for one".

Figure 2: Sample and Subgroups



As Table 1 documents, there is little to distinguish between the typology other than the Discontinuers all had cognitive disability and all had prior mobile phone use. A description of each of the user types will be provided before examining the lived experience of the participants through their areas of adoption of the technology, resulting social participation and disability citizenship outcomes.

Evangelists

Six participants or 40% of the sample could be defined as Evangelists. These participants displayed a strong belief in the value of VilTech™ in their lives. They were high adopters of VilTech™ and used it on a regular basis for a range of activities. The Evangelists felt confident contacting the 24/7HCC for advice and assistance and used it often. These participants integrated VilTech™ into their everyday lives with few problems. As one user stated “I told the person that I spoke to how good it was to have the phone with me so if I needed help I would be able to use the phone” (Participant # 2). Furthermore, VilTech™ was seen as an opportunity to express identity, personality, individuality and uniqueness. As one participant articulated, “I wear it round my neck and I have changed the background to bright pink!” (Participant # 1). Another enthused that:

...having [Village Networks'] Helpline just an SMS away has really improved my confidence, this means if I find myself in a sticky situation I can SMS for help straightaway, this has given me more independence (Participant # 6).

In summary, the Evangelists benefited most significantly from VilTech™ as they embraced it enthusiastically and were keen and able to incorporate it into their daily routines and to use it to enhance their quality of life.

Embarkers

Four of the participants or 27% of the sample could be defined as Embarkers in that they had begun to embrace VilTech™. They used VilTech™ for some activities such as communicating with family, either by calling them or by text, and some made calls to the 24/7HCC. However, these participants did not always use the technology to its full potential and were not overly enthusiastic about VilTech™ as the pilot progressed. One participant

explained that “when we went out I forgot to take the charger ...and I wasn’t terribly sure how to use it, but anyway, we sort of worked it out in a fashion” (Participant # 10). Another stated, “I was just pressing the green button and nothing would happen, but you have to swipe it” (Participant # 7).

These participants and their significant others wanted more training with VilTech™ so that they could develop their skills and knowledge over a longer time period. They wanted more time to get used to using the handset and to explore further the range of functions and applications available. As a mother explained how she would attempt to increase the use of the phone by getting extra training for her son.

We’ve looked at his budget with the self-managed package, and we thought because we’ve got some spare money that we’d get a speech pathologist or a speech pathology student to come and work out the voice output device because that would be a good thing to try and integrate (Participant # 10).

The 13-week introduction period was considered insufficient for the development of confidence and competence using the phone. In short, this group could see the potential of VilTech™ but needed more assistance, training and time to really embrace all it had to offer.

Discontinuers

Five of the participants, or 33% of the group, showed little interest or could not readily use VilTech™. This group terminated their involvement with mobile technology during or following the 13-week period. These participants used VilTech™ infrequently as many had previous experience with mobile phones and had maintained an alternative phone. For others, they had technical issues with the phone such as the charging and swiping mechanisms that made the handset difficult to use. For these participants, they either required more customisation or support than the pilot project offered for their continuation as one participant explains,

I can’t retrieve the messages and the service provider wasn’t able to help me either. If there’d been someone who could have spent quite a bit of time with me to actually go through and practice with the buttons that would have been something that would have been useful (Participant #15)

For some, the brand of mobile technology was as important as having mobile technology where as one participant described her preference for an alternative phone, stating that “the others have got their phones out and they have all got iPhones and iPads” (Participant # 14). For others it was just an issue of individual preference where they commented that “I’m actually thinking about returning the phone... it’s not really working out as I thought it would, I am not using it as much as I thought I would” (Participant # 11).

The Discontinuers had the least favourable experience with VilTech™ and got little out of it. They did not, or could not, appreciate and/or realise the potential of VilTech™. For some who have previous mobile use VilTech™ did not provide features that they found useful beyond standard mobile phone provision. These circumstances may have reduced their motivation and interest where their previous use provided them with a baseline to assess whether the phone provided a value-added experience to change from their current provider. In a number of cases for the Discontinuer to achieve success in using the product, far greater customisation and facilitation by Village Networks’ staff, service providers and/or family members was required.

For some of the participants, the attitude of their service provider and significant other was hostile to the VilTech™ or the level of support they needed to provide to the user. This ranged from disinterest “they weren’t particularly excited” to deliberately unsupportive. These behaviours were observed by the researchers where a lack of support outside of the Village Network support staff meant that the user could not develop the familiarity required for independent use. Even for those who became evangelists outside of formal support their family circumstance and the level of support required to assist the participant created tension within a busy household as one parent explains:

I took it off him because he had dropped it in the kitchen...he started to spiral downwards so I said, "Come out here and I'll have a go at fixing it" but as I was having a go at it he goes "I hate you", and started getting aggressive so I said, "Right, you're not getting the phone back now" and he started throwing everything, and then I ended up fixing it, I gave it back to him and I think he was still angry and he threw the phone so I said, "That's it, no phone". So then we went for two weeks without having the phone at all. He asked twice during those two weeks, "Can I have my phone back?", I said" No" (Significant other of Participant #4).

Activities and social participation

For many of the participants this was their first experience of having access to a mobile phone and for others a sophisticated smart phone with access to an array of applications. The Evangelists used VilTech™ every day with Table 2 showing that the Help Centre together with interpersonal communication, assistance with “help me to do things”, take photos, act as a reminder for other activities, playing games and listening to music being the most frequent activities.

Table 2: Reasons for Using the Phone

Use	%
To get help from the Help Centre	100%
Talking to my family and friends	86%
To help me do things	86%
To take photos	86%
To remind me to do things	71%
To play games	71%
To listen to music	57%
Talking to my family	43%
To text	14%
Other (please explain)	14%

The importance of VilTech™ to the participant’s social participation came up regularly in the interviews with participants, significant others and service providers. One parent explained that her daughter “likes the camera and enjoys photographing people in her family, especially her young nephew and her dog and cat. She showed the photos to others and [she] has some music also on her phone” (Participant # 1). In some circumstances, the use of VilTech™ was heavily influenced by the customisation of the device, the support from Village Networks’ staff and training available from family and service providers. This varied considerably across the participants. One service provider explained how she taught her participant to use the phone.

So Mike [pseudonym] had a specific training plan in terms of practising his greetings ... and a tick sheet which was ‘I’ve done it, this one on Monday, tick, tick, done’ ... then each week what we’ve been doing is adding a little bit more to that (Participant # 8).

Through the use of the phone participants had the opportunity to learn new skills such as sending SMS messages, downloading music and photography. A participant stated that “I’ve

got radio on it, I can access radio, camera, video camera and downloading music on it” (Participant # 5). This participant used these functions for entertainment but also for creating a narrative of where they had been, what they had done and as a form of conversation starter with other people.

Other participants used the 24/7HCC as a safe, secure environment to seek help and advice. It also provided peace of mind for the significant others and service providers in a number of ways. Frequently it was as a form of security where people could be contacted or contact others at any time. Another used the 24/7HCC and phone to enhance her business operations,

Mainly I use it to get the operator to make phone calls for me. Like when I need to ring for a taxi or need to renew hosting packages for my web design customers. The Help Centre has allowed me to contact anyone. Also if I have a question about my phone contract I can just SMS them (Participant # 6).

Most used the phone to communicate with friends and make arrangements. A participant stated “I use it when I’m phoning my social group” (Participant # 2). This ability to instigate social communication changed their role from one of a passive person receiving communication from others to be organised, to an active person initiating and creating their own social life. Depending upon the individual with disability there was the ability for significant others or service providers to be able to contact the individual as a reassurance that they are safe or to remind individuals of upcoming tasks. As with all mobile phones in an emergency situation the 24/7HCC is able to pinpoint where an individual is through GPS tracking. Some participants and their significant other found this option reassuring and allowed risk-taking particularly with public transport as one service provider outlined,

...the benefits have been huge for somebody who couldn’t use a phone. That young gentlemen was one that goes lost on transport and his parents will always be eternally grateful because he’s able to use his phone, he knows he always has it on him whereas before the other phone would be turned off in his bag (Service provider of Participant #2).

Disability citizenship

In the final interview, people were asked what was the main reason for their continuing the use of VilTech™? The responses included increasing independence through transport use, greater feelings of safety and support, communication with family and friends, the importance of the 24/HCC right through to increasing their levels of leisure through playing

games and listening to music. The study identified that for some participants VilTech™ allowed them more freedom and autonomy in their local communities away from their significant others, attendant carers' and service providers. For some VilTech™ provided their first chance to be alone with themselves rather than with family or attendant/carers. This individual freedom extended to innumerable activities such as shopping, banking, catching public transport, socialising with friends and working independently. VilTech™ empowered people to try new things and to risk failure as they knew help was only a phone call away. As one parent explained:

I think it's a security thing for Abdul [pseudonym], but also he can ring if he needs assistance to either the Help Centre or back to us. So I think a lot of it is around security. Previously Abdul couldn't use a mobile phone and therefore would always be dependent on somebody else. Well now, he'd like to try and be a little bit more independent, and I think that's a really good thing for him to be able to do that (Participant # 9).

The combination of the mobile phone, the customisation for an individual's impairment, standard and custom applications, together with the 24/7HCC created the conditions for empowering some participants in the study to have an increase in social participation and citizenship. Once the initial customisation and training had occurred, some individuals required no other assistance and like any person with the new smart phone developed their own patterns of use through trial and error. However, for those with significant support needs empowerment was developed through a combination of the ongoing supported environment through the Village Network Help Centre, their significant other and in some cases their service provider. This combination of formal and informal support reinforced the initial training, encouraged further skill development and became the foundation for other explorative activities beyond their home environment. As numerous participants in the study noted they were only the "red button" away from assistance.

For others their potential for engaged citizenship was frustrated and curtailed by the difficulties of using the VilTech™ or needing more training and support. Some participants required further training and ongoing customisation as they had dexterity, speech or cognitive considerations to better access VilTech™. A participant stated that "This is the only downfall of the phone, the charger connection is really small. With minimal hand function it is really hard to plug the charger in by myself" (Participant # 6). While those who had dexterity issues felt a sense of frustration with aspects of VilTech™; others questioned their own cognitive abilities to adapt to VilTech™. The 24/7HCC was specifically set up to support

people with any issues but about a third of the sample were reluctant to use the 24/7HCC for assistance for reasons of lack of confidence and feelings that their need for help was a signal of their failure to master VilTech™.

The need for more instruction was raised a number of times. One participant explained “if maybe, there’d been someone who could have spent quite a bit of time with you to actually go through and practice with the buttons that would have been something that would have been useful” (Participant # 14). This problem was exacerbated for those members of the sample not located in the city where the headquarters for Village Network was located and members of the HQ city sample were able to attend the office at any time of their choosing. While the 24/7HCC could address many issues of technology use, there was a need for face-to-face meetings for customisation where those outside of the HQ city were at a disadvantage where face-to-face support was only available every few weeks.

Discussion

The potential for people with disability to use technology to enhance independence and active citizenship previously identified by researchers in the field (Cumming et al., 2014; Pennington, 2010; Watling, 2011; Wehmeyer et al., 2006; Wise, 2012) was clearly reflected in these research findings. Furthermore the participants in the study were on the whole keen to embrace VilTech™ and this mirrored previous research involving the use of technology by people with disability (Bunning et al., 2009; Cumming et al., 2014). Participants reported a widespread enjoyment in using a range of mobile applications. These applications provided entertainment, creative outlet and facilitating communication that provide opportunity for greater levels of independence. However, as documented in the findings this starting point for some created an opportunity to feel empowered to take the risk to be more independent in communicating outside of normal social networks, wayfinding and independently using public transport. These outcomes challenged previous conception that people with disability are excluded from the digital revolution and mobile technology platforms (Goggin & Newell, 2003; Macdonald & Clayton, 2012).

This paper has heeded the call of Ellis and Goggin (2015) for research on the characteristics, potential and implications of mobile phone technology for people with disability. The study supports the value and benefits that can accrue to people with disability through using the

technology (Alper et al., 2015; Goggin, 2012). The independence that VilTech™ offered some individuals has significant implications for the cost of support where services that empower and up skill people with disabilities' social participation, independence and, hence, citizenship also provide ongoing cost savings to supporting people with disabilities and contribute towards the sustainability of family units.

Yet, the typology shows that VilTech™ was not a panacea for all people with disability in the study. The three user cohorts (Evangelists 40%, Embarkers 27% and Discontinuers 33%) demonstrated a varied level of adoption of VilTech™ and the findings point to a series of implications of the study. These findings suggest that there are substantial program sustainability issues in targeting people with disability as a homogenous market. Those who became Evangelists tended to be people with higher support needs where the value-added component of the substantial individualised customisation of both the smartphone and software programming was the major reason for the participant's successful adoption of VilTech™. This customisation of VilTech™ required significant resources from Village Networks, the individual's service provider and/or their significant other. It was these resources that led to the successful use of VilTech™, the subsequent social participation and disability citizenship outcomes for these individuals. However, the cost structure of VilTech™ treated all users as the same, which suggests that the marketisation of VilTech™ as a platform to support people with disability may need to be revisited.

At the other end of the spectrum, some of the Discontinuers could not see a "value add" of VilTech™ beyond a standard smartphone as they did not require any level of customisation. These people may have had significant disability, but both their physical and cognitive abilities allowed them to use the smartphone technology without any further intervention. Moreover, they saw no "value add" in the 24/7HCC or the security distress option. Their level of prior experience, intermediate to advanced technology use and their abilities meant that VilTech™ did not provide new opportunities for independence, dignity or disability citizenship.

The other Discontinuers were those who were actively dissuaded from using VilTech™ by their significant others or service providers. Outside of the initial support they received through VilTech™ training, these participants received no reinforcement or support to continue their engagement and thus ebbed away from the program. This supports Parsons,

Daniels, Porter and Robertson's (2008) findings that the commitment of service providers is critical in the adoption of ICT. However, this study takes our understanding of the service provider role one step further to include the influence of significant others and family members. These interpersonal factors are clearly an important influence in the continuation of the use of VilTech™ particularly if they were openly negative towards the use of VilTech™ by the person with disability.

The third group were the Embarkers and, as the description in the findings suggests, this group saw the initial value of their engagement but required a longer period of time to understand its full potential. While using the phone for a set of limited functions they did not become enthusiastic about its additional benefits beyond its current use. However, some from this group required further resources or training that was either not forthcoming or logistically could not be delivered by Village Networks. The Embarkers may have been a group with potential to become Evangelists, or at least "Continuers", if more support and time was available. From a social model and policy perspective this suggests that to reduce the digital divide for people with disability greater support needs to be provided in the acquisition, training and ongoing use of technology for people with significant support needs (Barnes et al., 2010; Commonwealth Government, 2013; Green & Mears, 2014; United Nations, 2006). To provide further insights into the implications of the study the PHAATE model is now used to consolidate the implications of the study.

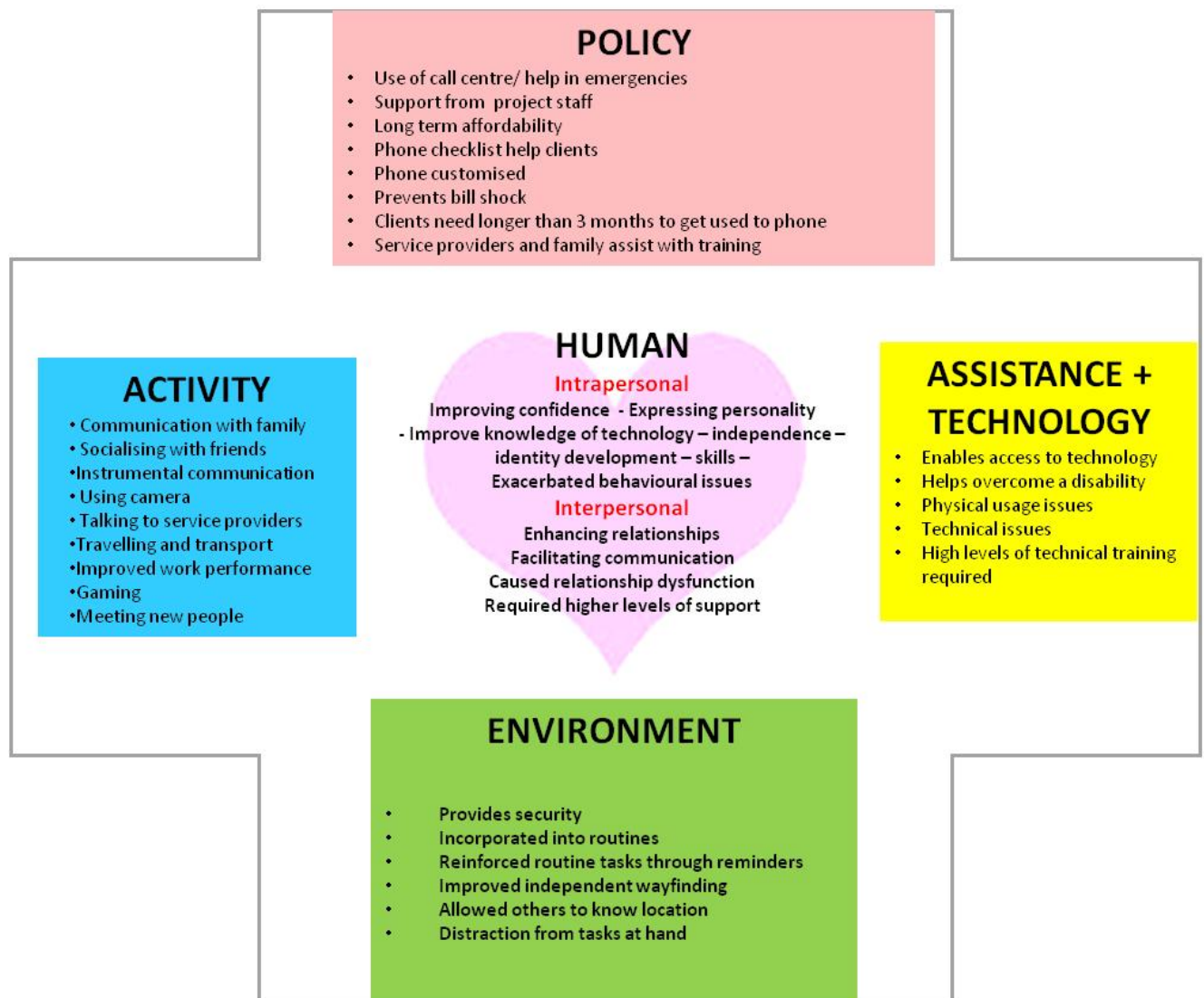
PHAATE model

In bringing a social model lens to the PHAATE model (see Figure 3) this study has expanded our understanding of Cooper's (2007) model through research in a non-therapeutic setting. In doing so, Figure 3 shows that **human** factors required a reconceptualisation from a single dimension to two dimensions of intrapersonal and interpersonal (the development of identity, new behaviours, increased independence and social interactions) at the centre of the delivery and usage of VilTech™. This extension of the Human dimension to be sensitive of the intrapersonal nature of the individual's personal circumstances and their interpersonal relationships is a significant enhancement of the model. Intrapersonal refers to the use of VilTech™ for purposes that serve the individual alone to assist with their "impairment effects" (Thomas, 2004). All people have varying abilities and the inherent nature of the

participants allowed them to use VilTech™ to assist with a variety of physical or cognitive needs. These include functions such as simulated speech, text to speech, assistive touch, alarms, reminders, photos, music and other prompts. The interpersonal are functions that assist the user in their communication and interactions with other people in their lives. These functions range from phone calls and SMS to electronically generated speech. Engagement in citizenship was also curtailed for some participants through personal factors such as difficulties physically accessing the phone and limited use due to insufficient training and support and reluctance to use the 24/7HCC.

The interpersonal identifies the influence of others on the participant's attitude and use of the phone. For people to have choice in their lives they need to develop their awareness of themselves, those around them and what they choose to make decisions on to do. The VilTech™ provided opportunities and time to master the skills required to actuate the opportunities on offer. As one disability advocate suggests 'having a real say in decisions that affect our lives. Empowerment is not something you suddenly have one day' (Martin, 2006, p. 126). In this respect, the interpersonal factor was a considerable influence. In addition to the satisfaction reported by participants in using VilTech™ for communication, the influence of significant others emerged as instrumental in both a positive and negative way. Some significant others and service providers recognised the potential for the development of independence and encouraged and supported their participant to that end. However, others did not see any potential in VilTech™ and in some cases saw it as disruptive. The attitudes, decisions and behaviours of these significant others adversely affected the participants' potential for empowerment through VilTech™. Figure 3 summarises the implications and outcomes of the study for policy, human, activity, assistance/technology, and the environment.

Figure 3. Mobile technology Research Project themes presented using the PHAATE Model



What was also interesting was that due to the variety of apps being used by different participants and the nature of the assistance they were receiving (**activity** and **technology and assistance** factors) no one participant was undertaking exactly the same activities. Yet, there was a common theme of participants gaining self-confidence, being empowered by increased choices in their life, and creating their own narrative. While this was in keeping with previous research, such as Cummings, Strnadova, Knox and Parmenter (2014), VilTech™ as a package provided an opportunity but how that opportunity was used was very different for each individual. In particular, the development of independence for people with disability in their local communities was shown through improvements in engaging directly

with their networks, independent wayfinding, public transport use, and confidence through the 24/7HCC to help with problem-solving if confronted by barriers (**environmental factors**). This led to skill development through the apps being used that aided in creating and communicating their own narratives through photos and videos (**human factors – personal and interpersonal**).

The **policy** framework in which VilTech™ operated provided opportunities for the development of the platform, the technological adaptations used on the hardware and the software that contributed to the success for the people's individual needs and interaction with others (human factors). These were set within the VilTech™' approach to overall product development, service features that included a high level of customisation and training from both technical and call centre staff. The outcomes for the participants involved meant that the phones and support systems were much more likely to be used because of the customisation, provided a more affordable package than otherwise could have been found in the marketplace, and the support of the 24/7HCC was only a one touch button away. The adaption of the PHAATE model (Cooper, 2007) to include the intrapersonal and interpersonal in the human factor and its application in the social contexts of everyday life has provided a useful tool for understanding and interpreting the research data and extends Cooper (2007). This study also provided a social setting for the research context where previously PHAATE had only been used in therapeutic settings. The two approaches complemented each other where social model understandings bring focus on the barriers to social participation and disability citizenship with an outcome seeking transformative solutions. Assistive technology provides an area of rich potential to create transformative solutions as previously identified in other research (Alper et al., 2015; Ellis & Goggin, 2015; Goggin, 2012).

Study strengths and limitations

The research project enabled the researchers and Village Networks to critique the pilot of VilTech™. The qualitative research design allowed the development of an in-depth understanding of the issues involved in the VilTech™ roll out. However, the study design had the following four main limitations. First, the timing and activation of the research process was problematic, with the researchers engaging with some participants' post-hoc

rather than being engaged in a participatory action research process from the beginning. Second, due to the dynamic nature of the project, the different impairment groups represented, their significant others, and the presence or lack of service providers meant that there were modifications to the research design over the duration of the research. Third, the research design developed from previous research experience was adapted during the research process. The interview schedule, the type of interview conducted and the number of interviews that took place for each individual varied considerably from the original project design. Fourth, access to VilTech™ reporting systems could not be provided to the researchers so this element of the study was not undertaken. This type of management information system would have given a far more accurate understanding of the use of VilTech™ than interviewing participants on their reflected use of VilTech™. Future research should consider the sample size in relation to the types of disability, levels of support needs and other considerations to provide a more all-encompassing understanding of the impact of technology on different subgroups of people with disability.

Conclusion

The research findings confirmed the belief that a regular mobile phone adapted for specific functions is an effective ICT device for training and supporting people with disability. VilTech™ acted as such a device by providing a range of applications with infinite possibilities for participants to communicate and interact with technology. However, the necessary level of training and support was shown to be essential (and not experienced by all participants in this research), together with individual customisation, if people with disability are to improve their skills and through this their confidence and level of social participation and disability citizenship. Hence, people with different types of disability with significant support needs require a level of customisation in service delivery that is rarely provided with mobile phone technology platforms that are by nature mass market low yield profit offerings.

Furthermore, the participants and their families would have benefited largely if the 13-week introduction period had been extended to six months or a year. This is so that the participants had sufficient time to develop and adjust behaviours around the use of technology and to embed the use of VilTech™ into their daily routines. Additionally more individual support, customisation and training were required so that a wider range of potential technology could

be introduced. Finally, the participants' expectations and the expectations of their significant others needed to be discussed and clarified to a greater extent at the outset so their needs could be adequately catered for and the potential benefits arising from the features of VilTech™ such as the 24/7HCC could be targeted more effectively. With these caveats, the potential of the technology can be empowering and offered participants improved understandings of the technology itself, the benefits of the applications on offer, provided support for social participation and an improved disability citizenship.

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