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I'VE GOT A MOBILE PHONE TOO! HARD AND SOFT ASSISTIVE TECHNOLOGY CUSTOMISATION AND SUPPORTIVE CALL CENTRES FOR PEOPLE WITH DISABILITY

Abstract

Purpose: the purpose of this article is to examine the use of a mobile technology platform, software customisation and technical support services by people with disability. The disability experience is framed through the participants' use of the technology, their social participation. *Method*: a qualitative and interpretive research design was employed using a three stage process of observation and semi-structured interviews of people with disability, a significant other and their service provider. Transcripts were analysed to examine the research questions through the theoretical framework of PHAATE - Policy, Human, Activity, Assistance and Technology, and Environment. **Results**: the analysis revealed three emergent themes: 1. Engagement and activity; 2. Training, support and customisation; and 3. Enablers, barriers and attitudes. Conclusions: the findings indicate that for the majority of users the mobile technology increased the participants' communication and social participation. However, this was not true for all members of the pilot with variations due to disability type, support needs and availability of support services. Most participants, significant others and service providers identified improvements in confidence, security, safety and independence of those involved. Yet, the actions and attitudes of some of the significant others and service providers acted as a constraint to the adoption of the technology.

Keywords: Community independence, PHAATE Model, mobile technology, social participation, mobile phone, assistive technology

Introduction

Mobile phone technology is so seamlessly integrated into everyday life that its assistive potential for people with disability has often been overlooked. This paper adopts the United Nation's Convention on the Rights of Persons with Disabilities (2006, np) definition of disability that includes "those who have long-term physical, mental, intellectual or sensory impairments". Yet, the literature suggests that it has proved challenging for people with higher support needs to access mobile or smart phone technology². Assistive technology (AT) is defined as "any item, piece of equipment, or product system, whether acquired commercially off-the-shelf, modified, or customised, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities". Advances in AT have been far ranging from manual and power wheelchairs, Cochlear implants, voice recognition systems and text to voice software. Closely linked to assistive technology developments have been advances in information and communication technology (ICT). Since the advent of the Internet, the digital revolution has required assistive technology to integrate with online systems in a two way form of communication. Computers, digital cameras, handheld personal digital assistants (PDA) and mobile phones create integrated platforms for people to enhance their interactions with the physical environment through access to the virtual environment 24 hours/7 days a week. As one commentator observes,

Recent developments in mobile technology, including the introduction of the iPad and other smartphone and tablet devices, have provided important new tools for communication. The wide availability of these portable, powerful, networked technologies has changed how we work, learn, spend our leisure time, and interact socially. ⁴

Yet, these technological advancements in mobile platforms have largely been unused by people with disability amongst others because of cost factors ², the lack of involvement of people with disability within the design of the technology³ and the attitudes of community and allied health workers that people with disability with higher support needs could not use such devices. With respect to defining higher support needs, the World Health Organization's International Classification of Functioning (ICF), records categories for disability type, level of disability and activity limitations. Disability is measured by body function and structure (e.g., loss of limb), and the level of limitation is termed as none, mild, moderate, severe or profound ⁵. Many national-level surveys (e.g. ABS ⁶) include this measure as an important

variable for understanding social participation. In both medical and social model conceptualisations, activity limitations have been classified by the level of support a person requires to participate from independent, low, medium, high and very high. Literature reviews over the last 25 years of ICT use with people with disability with higher support needs identified the potential of ICT 7-11 and that ICT for people with disability required a more considered approach to education, training and support ^{12,13}. It was also recognised that the commercial hardware and software available required customisation together with a greater understanding of disability on the part of web development companies¹⁴. Nonetheless. the rapidity of expansion in ICT is unprecedented ¹⁵ and the possibilities of new products for people with disability with higher support needs continues to be explored with the benefits substantial when the technology is correctly matched with hardware and software customisation ^{4,9,16}. These developments include products for people with spinal cord injury using mobile technology ¹⁶, people with autism spectrum disorder for the purposes of realtime communication ¹⁷, prompting systems to facilitate decision making for people with intellectual disability ¹⁸, and systems to assist participants with increased social participation, independence and promptness ¹⁹. Yet, these studies and others identify problems with hardware and functions suggesting that they require greater customisation to be reliable for people with disability ²⁰.

The adoption of mobile phone technology by people with disability gives access to a world that the general community regard as essential to be "cool" and connected ^{21,22}. While the coolness factor has not been a major consideration of the rehabilitation community, it is a major factor in the choice and use of mobile phones for users in general ¹. Notwithstanding, the accessibility and assistive potential of smart phones for people with disability has been a focus for developers, regulators and providers ²³. Messaging, GPS navigation and location, speech directions, landmark identification and the wealth of other apps have and continue to be explored for their assistive potential ²³. From the perspective of people with higher support needs cognitive or intellectual disability, the problems associated with highly complex interfaces and confusing instructions have been made far easier to understand as smart phone technology became more "user-friendly" ²⁴. This is evidenced in the use of mobile phones for personalized task prompting with picture, video, and audio instruction supporting users in

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Factors Affect Mobile Phone Brand Choices – Studying the Case of Jordan Universities Students Muhammad Alshurideh 1, Abdallah Bataineh 2, Barween Alkurdi 3 & Nedal Alasmr 4

personal, vocational and educational tasks ¹⁸. These improvements have seen the adoption by young people with intellectual disability who relished the opportunity to use the technology and express this through the creation of "their stories" and self-concept development ²⁵. Using ICT featured in the narratives of their lives and in their self-concept inside and outside of work ²⁶...

Researchers have started developing instruments to measure the potential of people with disability with higher support needs to use everyday technology ²⁷ and their retention of ICT skills ²⁸. Research to date has identified that some users require a significant time investment to understand the demands of the ICT tasks and the complexities of the interface²⁹. Some factors critical to success were a positive attitude on the part of those working with users, that those assisting the users needed a level of technical understanding to instil user confidence and develop their skill competence and that training programs need to incorporate support people to ensure a commitment to the gut roles of the technology and social participation outcomes of the person with disability ³⁰.

This paper reports on the findings of research that examine the uptake of mobile technology with a pilot group of 15 users. The research was positioned within social approaches to disability ^{31,32} adopted under the United Nations *Convention on the Rights of Persons with Disabilities* ¹ and the systemic policy change driven by the introduction of the National Disability Insurance Scheme (NDIS) in Australia ³³. To assist in contextualising assistive and information communication technology frameworks within social approaches to disability, the PHAATE model (policy, human/person, activity, assistance, technology and environment) ³⁴ is used to analyse the results of the mobile technology service delivery.

The research sought to address three questions:

- 1. What was the engagement, uptake and activities that people with disability used the mobile phone technology for?
- 2. What training, support and customisation were required to use the mobile phone technology?
- 3. Were there any intrapersonal, interpersonal, socio cultural barriers or attitudinal influences on the uptake and use of the mobile phone technology?

Method

The research involved assessing the effect of the mobile phone technology platform on the education, training, and support of participants with disability. The not-for-profit organisation based the project on an experiential learning conceptual approach ³⁵. This approach took the project into real time as an adjunct to, the personal support provided by families/carers and service providers. Moreover, it gave users the opportunity to bolster their personal experiences enabling them to understand the consequences of their choices and decision-making.

The research design adopted the principles of participatory action research with the not-for-profit strategic planning documents [reference withheld for anonymity] which is suitable for working with the not-for-profit sector and people with disability^{36,37}. Within this approach, the research design implemented an inductive interpretive approach where the voices of the stakeholders (people with disability, their significant others² and their service providers/support workers) guided the findings of the research. The project was designed for a staged implementation over 12 months across the individual and organisational contexts. The research used three distinct populations: participants with disability; the significant others of the participants with disability; and the disability service support managers of the participants with disability (where applicable). This research design created a triangulation of data sources to study the phenomena.

Theoretical Framework

The 'PHAATE' model ³⁴ was adopted to understand how mobile technology was delivered and how it contributed to the lives of the participants with disability. Given the policy context of the NDIS and National Disability Strategy policy it is important to capture social approaches to disability that incorporate considerations of the individual, broader policy context, environmental and social participation activities. While assistive technology has always engaged with the technology itself and the impact on the individual in a medical, psychological and behavioural context, it has not always done so by understanding social approaches to disability outlined under the UN Convention and national implementation of such approaches. PHAATE has its roots in the rehabilitation sector ^{38,39} and provides a comprehensive conceptualisation of the integration of assistive technology in service

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² "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.

planning and service delivery. In many ways it integrates very well with the previously mentioned World Health Organisation classification system that seeks to move from medical and rehabilitative environments to create a greater biopsychosocial understanding of disability ^{5,40}. PHAATE represents the factors for consideration in service design which are: policy, human/person, activity, assistance, technology and environment.

The PHAATE model recognises the interaction of factors that contribute to an individual's functioning in a given context. However it differs significantly in that it is not based on a medical premise but a social premise. The model is human centred where assistive technology is matched to assist a person to become more independent in their environment, dealings with others and empowers them to be more socially engaged in undertaking activities. The model stresses the importance of policy in facilitating social outcomes for people with disability. The 'PHAATE' model has had relatively limited operationalisation in rehabilitation engineering ^{41,42} where this research provides an opportunity to operationalise the model for a different type of assistive technology and tested in a social setting rather than a medical rehabilitation setting.

System development

Village Networks (pseudonym) is a not-for-profit disability service organisation that developed a mobile phone technology platform. The platform consisted of:

- A mobile phone or tablet device, case, charger and lanyard;
- All standard android based mobile applications;
- A suite of customised Android based mobile applications (apps) and ICT technology adaptions for people with disability including a one touch 24/7 Help centre program app;
- A customer service system which included a 24/7 Help Centre for assisting people
 with disabilities. The Help Centre was linked to a software and app development
 team; and
- hardware and hardware interface customisation to allow people with disability to
 mount the technology to their wheelchairs if needed. It also included assistance with
 pointing devices, switches, wheelchair controls and joystick control systems.

The system was developed by Village Networks and a government department (which provided seed funding), working in conjunction with a commercial telecommunications company. These funding arrangements for the project development were separate to the research grant application process between Village Networks and the University research team. The outcome was a customisable mobile phone technology platform provided at no cost to the participants. The partnership arrangement was the direct outcome of the Australian policy environment which is undergoing radical change. The National Disability Insurance Scheme (NDIS) is a no-fault insurance cover for Australians with severe or profound disability ⁴³ that changes the funding process from block funding organisations to provide services for people with disability to individually funding people with disability to purchase services of their choice ^{33,44}. The result is user-controlled budgets and direct service purchasing ⁴⁵. It will give choice, flexibility, control and purchasing power to the person with disability as the program moves from a pilot to full rollout from 2016-2018. People with disability can decide what they need and want, and buy it from the provider they choose ⁴⁶. Yet, critics of individualised funding and marketisation of care also point out issues associated with people with different types of disability, higher support needs, and the lack of an evidence base as to how well the policies are working ⁴⁷⁻⁴⁹. It is reasonable to predict that in this new NDIS context, a technology that is universally seen as 'cool' and that can provide support in an unobtrusive way will find a market if it can be shown to reduce the cost of attendant care and other support services through empowering and up skilling people with disabilities' social participation.

Research Design

Population and sample

The selection of participants involved drawing a sample of 15 from 152 people with disability involved in the pilot project. The sample of users was determined by the total population included within the study and those who self selected to become part of the research. The organisations through which the sample was recruited covered the spectrum of those with physical/mobility, cognitive and sensory impairments. Further, the organisations (names withheld for anonymity) specialised in individuals with higher support needs requiring complex inclusive practices for social participation.

The information sheet prepared for the research was distributed to prospective users by the mobile technology team. Those who were interested contacted the research group and a time was organised to meet with a member of the research team. Table 1 provides a detailed breakdown of the demographic variables including a relatively even gender representation, two thirds of the sample having intellectual disability, eight identifying as having multiple disabilities and representing the continuum of support needs from independent through to very high. As such, there was a high level of people identifying as having multiple disabilities that constituted being classified as having higher support needs with complex considerations for social participation. The participants were recruited between March and December 2013.

Insert Table 1 about here

Participants and observation

To match the mobile technology to people's needs and to understand how these can be met in an effective way, a 13 week trial was undertaken. This included either some modification or customisation to hardware technology and software technology. The interfaces (which included one touch connection to the Help Centre and icons for a variety of services) and the devices (Smart phones and tablets) used were modified (for example enlarged or the 'home' screen modified) according to individual requirements. The individuals came through a number of service providers and families from the Sydney area, regional NSW and Tasmania. Village Networks facilitated the pilot or trial by deploying staff at no cost to the participants. Each participant received a mobile phone, case, charger and lanyard and the phone was connected to a mobile phone plan (covered by Village Networks). Each participant received two familiarisation sessions in which the staff introduced the technology. The sessions involved personalising the phones to maximise their effectiveness for participants. Members of the research team were observers to the familiarisation and customisation sessions held at Village Networks office or at service providers in some cases.

As part of the soft technology offering, each week throughout the pilot the Help Centre staff contacted each participant at random intervals in order to familiarise the participants with the process of answering calls on the phone. Participants were also asked to contact the Help Centre on a daily basis. The staff at the Help Centre were recruited with one of the key criteria being previous experience of working with people with disability. While the individuals may or may not have had professional qualifications, they were also provided with on-site training of working with individuals with disability in a call centre environment.

Village Networks has a long history of providing disability service training for employees of their organisation and this training expertise was mobilised through induction training for all staff across mobility, sensory and cognitive disability. This training was also enhanced through call centre specific training by a manager with extensive call centre management experience.

Interview schedule

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 semi structured guide allowed the interview to be conducted in language that accommodated individual differences and recognised industry practices which took into account the experience of the participant, significant others and the organisation. The interview guide included questions about the participants' current social participation. Other questions asked about supports (parents, friends, direct care workers), assistive technology (prompt cards, reminder devices, signs), and ICT (e.g. the use of computers, phones and tablet).

Data collection

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 sets of interviews were held where possible before the pilot project commenced. The participants subsequently took part in a 13 week pilot project. The second interviews where possible was conducted after six week (approximately in the middle of the 13 week period) and then the third interviews was conducted at the end of the pilot project. Field and reflective notes from meetings with interviewers, Village Network staff, researchers and participants were used to understand the broader context in which individual participants were using the phones that included past experiences, relationships with carers, established behaviour patterns, motivation and expectations.

Data analysis

The interviews were tape-recorded, transcribed and spot-checked for accuracy. The transcripts were then analysed with Nvivo (v9). The typological analysis is created by first reading transcripts for keywords, phrases and concepts. Categories or groups are created '...

on the basis of some canon for disaggregating a whole phenomenon' ⁵⁰. The transcripts are electronically coded and textually analysed ⁵¹. The analysis then used constant comparison between pre-and post-interviews to look for changes or differences ⁵². The social approach to understanding disability that seeks to promote social participation through independent, dignified and equitable inclusion and participation ^{31,32} was used as the lens through which the data was viewed. Initial coding was conducted of emergent themes arising from the social model approaches to social participation. These related to community access (e.g. enables communication with friends), use of ICT (e.g. provides an opportunity to access a range of technology) and usage constraints (e.g. lack of confidence using the phone). Following the initial round of coding the transcripts were further analysed using the 'PHAATE' model.

Trustworthiness strategies

Four trustworthiness strategies were employed to strengthen the rigour of the study.

- 1. Village Networks, the three researchers and the service providers supporting participants, engaged in discussions regarding the selection of participants and the willingness on the part of carers to participate in the interview process.
- 2. As far as possible, it was important that the participants had a genuine interest in the use of the phone long term beyond the free pilot period and willingness to participate in the interview schedule. In order to achieve this Village Networks and the researchers decided that participants should self-identify and self-select. A detailed description of the pilot project and participant involvement was given to all people who signed up for the mobile technology.
- 3. Two of the researchers independently analysed the data on an ongoing basis identifying and comparing themes. Regularly all three researchers discussed, critiqued and challenged the progressive analysis. Agreement was required by all three researchers for themes to be included.
- 4. The three researchers kept reflective notes on their past experience and expectations which were share in progress meetings to identify potential biases and influences in the research process.

Ethics

Ethics clearance from the University human research ethics committee (HREC approval #2012 000 063) ensured that people with disability were only exposed negligible risk (i.e. negligence, inconvenience, discomfort, harm or pain). It was acknowledged that participants may not have been able to use mobile technology and that they could experience frustration, disappointment and a sense of failure. It was also possible that the experience would be emotional for the significant other. It was identified that both fulfilled and unfulfilled expectations can elicit emotions and memories that are painful. All participants were interviewed in a supported environment with on-call assistance and support from the not-for-profit experienced and qualified staff.

Results

Analysis of the interview transcripts and the observation notes revealed that twenty two themes emerge for the three research questions (see Figure 1). There were substantial links between and across themes and subthemes. This is illustrated in Figure 1 where the twenty two themes are clustered according to the PHAATE Model.

Insert figure 1 about here

In the following sections the emergent themes are presented in relation to the three research questions along with representative quotes. Table 2 shows the connection between the themes and the research questions, through Nvivo analysis states the frequency that the themes were identified by those interviewed, the number of interviews in which the themes were identified and provides an example quote from a participant with disability, a significant other or a disability service providers/support worker. Each question and the emergent themes will now be discussed with a brief narrative due to the word restrictions of a journal article.

Insert table 2 about here

Research Question 1 - engagement and activity

This research question concerns the use, engagement and activities of the mobile technology, by people with disabilities, in relation to a variety of purposes. Five themes were identified:

communication with family; socialisation with friends; using the camera function; talking to service providers and accessing a range of technology. Communication with family involved using the phones to talk and text with a range of relatives which included parents, siblings, cousins, grandparents and aunts and uncles. Socialising with friends consisted of using the phone to communicate social arrangements and to share news. Using the camera function on the phone primary consisted of taking photos and sharing these with family and friends. Talking to service providers involved participants communicating using their new phones with their localised, individual service providers. Accessing a range of technology involved participants using their phones to gain entry to technology for communication, playing games, sharing photos, listening to music, texting, using alarms, finding out about the weather and using calendars for timetabling activities and events. In particular the phone was often discussed as a social asset for contacting family and friends. Andrea's mum explained she rings my sister who lives down in Victoria and she rings her and she rings her cousin, so they have chats. They chat about the football. John's mother said that he would text me a message occasionally, "Mum, I'm here in the park with all my friends having fun", you know and that was beautiful. As can be seen by the quotes, the social facilitation was a two-way process where the technology provided an opportunity for individuals to maintain, reinforce and expand their social networks within and external to their current social situation.

The mobile technology was considered an assistive technology enabling communication and participation in a range of leisure activities. Tony told us *I love playing games on the phone*. Dan's service provider described Dan's mobile phone as 'a socialisation tool'... So he and his friends, because they're all around the same age, were able to bond and just kick back as normal blokes. Just because one doesn't speak verbally it doesn't matter, and that was really pleasing. So he's really connected with it, which is also really good for him and the gentlemen that he shares a house with who loves music too ... they get up and dance to it.

Social communication through the use of the camera, narrative and photo voice was particularly popular activities. Different individuals developed their "storytelling" that was digitally enhanced for those that they were communicating to with a real "skill" development through these technologies. For example, Jill who used her phone for business as well as leisure explained

I use the phone camera weekly usually to take photos of myself as I am shooting landscape photos or family portraits using my Canon camera. Then I upload these photos of myself to my business Facebook page. People are curious how a disabled person can be a photographer so by posting photos of me on a photography shoot is the little slice of proof people need to understand.

Research Question 2 - training, support and customisation

This research question described the importance of training, support and customisation of the mobile technology for the people with disability using it. Four themes were identified: use of the Help Centre; staff support; training checklist; and customisation of the phone. The four themes involved assistance with "soft technology" while the customisation of the phone also included some "hard technology" customisation including switches and physically fixing the platform to wheelchairs or other structures to allow easier use by people with disability. These themes will now be examined.

Use of the Help Centre involved using the 24/7 Help centre for advice and help with security. The security aspect of the phone having a built-in "help or panic button" was a significant "selling point" of the technology. At any time a user could speak with the support staff, which were recruited on the basis of having experience with disability and then provided with further training on both disability and working in a call centre environment. The support consisted of the telco assisting the participants to effectively use the technology for their specific needs. For some people with disability they called the 24/7 Help Centre because their speech was difficult for others to understand and the 24/7 Help Centre staff were able to assist by either acting as an intermediary tree in a three-way conversation or contacting people on behalf of the person with a disability. The training checklist comprised an inventory of items which were designed to enable participants with easy access to a range of phone functions. Finally customisation was identified, which involved specific adaptations to suit the requirements of individual participants.

This last theme of the individual customisation of the hardware (handset) and the software particularly the Big Launcher (home screen) was what separated the mobile phone technology platform from standard Telco organisations. Quite simply the participants would not have been able to use the mobile technology without the "soft" or "hard" customisation.

Customisation for some people was non-existent, for others involved a few hours or a few days, while for some people it was ongoing for the duration of the pilot. For those who required extensive or ongoing customisation, this was due either to their impairment considerations, support needs or through them pushing the boundaries of the technology as they imagined and under talk new uses for the technology. The customisation process was considered critical in enabling usage. As Mia's father described we've just got my photo on a button that she clicks and it just calls me, which is good. Apps were added to the phones according to individual need. For example Dan's service provider explained that Dan has a travel application which is excellent... so if you want to buy a ticket to go home it actually will say 'pick your station', and it will actually say 'I would like to buy a ticket to Central station'. This voice activated function enables independence and communication when catching public transport for individuals with speech impairment.

Formalised training programmes were identified as useful enablers, as was the support provided by the 24/7 Help Centre. As Dan's service provider described *he had a training plan in terms of just practicing in his static device, so that was his greetings, his transport, his playing games, and a tick sheet which was yeah I've done it ... so that a support worker could work with him. Other sessions were held with people with disability and their service providers. Ethan's father explained <i>we've had two good sessions... we went back the other day and tried a few things, fixed all the issues up, and we were there for an hour again. Paul did a video for Ethan to be able to look at to see what he has to do.*

Not all the support provided was formalized, a lot was informal backup or even just encouragement, from the 24/7 Help Centre, family and/or service providers. This is very different to a standard Telco model and, hence, has significant resource implications. For instance, Alf stated that *I would ring the Help Centre and talk to somebody about my weekend and stuff, and tell them how I went, and that's its going okay.* Ethan's mother explained that the biggest problem at the moment with Ethan is that, just at the moment, he still has a bit of a strong finger and needs to be a little bit more gentle with the phone. She continued to support him with this issue. Nonetheless, some participants, parents and service providers were not satisfied with the level of support provided during the roll out of the mobile technology. Kim stated that she thought that it would be simple but I think, we needed the process to be explained in the folder and this should have been done it in the first place.

This suggests that a great deal more needed to be undertaken to manage the expectation of those involved.

Research Question 3 - enablers, barriers and attitudes

This research question defined the enabling experience of using mobile technology for people with disability in terms of facilitating their enjoyment, allowing themselves to express their identity and to develop new skills and at the same time acknowledges the potential for structural and attitudinal barriers. Thirteen themes were identified in relation to this research question and included: affordability; bill shock; the pilot period; overcoming a disability; technical usage issues; physical usage issues; behaviour usage issues, security; incorporation into routines; distraction; assistance from family and/or service providers, development of identity and independence.

Many of these themes can be considered as enablers. Under the affordability theme there was an acknowledgment that participants valued the three month free trial period. Yet, on the flip side there was concern about the long term affordability of the mobile technology once the pilot period had ended. Under the NDIS, there is a component for assistive technology but whether ongoing costs of telecommunication are included is still under discussion. Closely linked to this theme is bill shock. Depending upon the individual, bill shock involved was being able to monitor the mobile phone usage and charges to prevent the surprise of unexpectedly large telephone bills. Of course, this is one aspect of mobile technology use that affects all people whether having a disability or not but can be more critical for certain individuals and certain types of behaviours. The themes of help overcoming a disability indicated that the use of the phone could compensate for a disability faced by a participant. For example, the use of the speech simulation that the phone provided assisted people who were non-verbal to be able to undertake simple tasks as identified previously like purchasing a ticket at the railway station. Security related to the potential of the phone to ensure wellbeing of participants through the use of the 24/7 Help Centre and the GPS tracking device inside the phone. The security aspect provided the individual with a touch point if anything went wrong, they became disorientated or were physically threatened whilst going about their daily duties. The security aspect of the platform also provided significant others and service providers with the "peace of mind" to know that they could contact the individual when needed or have a backup for the individual to go to if they were not available. The

phones became ubiquitous in being incorporated into the routines of everyday life of the individuals, this significant others and for some service providers/support workers.

In contrast to these enabling themes a number of themes emerged around barriers. These included technical usage issues involving technological problems which made phone use difficult and physical usage issues related to difficulties caused by physical impairments faced by some of the participants. There were also a number of instances of the behaviour of some users becoming obsessive in overusing some aspects of the technology and contravening what would be regarded as accepted phone and social media etiquette. In most cases, these behaviours could be addressed with further training and expectation management but in one case led to the discontinuation of use of the technology. For some people, the mobile phone technology became a distraction where participants use of the phone diverting them from other tasks. The need for a longer pilot period was also identified, this was based on a concern that adequate phone usage could take a lengthier period of time than the three month trial period allowed under the scheme

While the enablers and barriers are significant considerations, what became apparent was the empowering nature of aspects of the technology on the development of identity (the opportunity to show personality, as well as the chance to communicate individual values) and the development of independence (greater freedom in their local communities) of those involved. Jill enthused that *having the phone has really improved my confidence and has given me more independence*. Joel's father outlines this development of independence and identity, describing Joel as

really experienced with technology since babyhood. He had the first Apple Classic and was playing games and using a voice output device since the age of two and a half, or three years old I think. So he's really comfortable with technology and I think that's why he wanted a mobile. And that's why we thought, 'Maybe this will bring a few of the things that we've tried to address together.' You know, the communication, the independence, the keeping in touch with the networks he's building up.

John's Mum also identified the empowering function of the phone and explained that he *used* text extensively. This was very useful as Johns' enunciation is poor. He used text at home to communicate with Martha between rooms and to negotiate behaviours such as bedtime.

However the enabling function of the mobile technology was countered by barriers which were defined as obstacles, challenges or constraints in accessing the mobile technology and its benefits. These barriers included physical issues such as button size, controlling volume and the swipe action which for participants with poor fine motor skills were a major issue and source of frustration. Alf described his experience stating that *my hands couldn't hit the buttons and I'm a bit slow in answering it, I'm still having problems, I can't always connect with the person that's ringing me.* Other issues also arose around compulsive behaviour with the phone as illustrated by a mother's concern about her son's behaviour. *John was always ringing his father when, you know, he shouldn't have been ringing him or just ringing random numbers or ringing my phone... Like his compulsion just overrides everything. Like, even with the home phone I haven't got that plugged in at the moment ... he's pressing 1234. Not getting any service but just 1234. You know, he thinks that's really funny!*

Attitudes held by parents, carers, families and service providers in relation to participants' capabilities acted as both enablers and constraints in relation to the use of the phone. There were concerns about appropriate phone etiquette but on the whole participants, parents and service providers had a strong belief that the use of the mobile technology could provide an additional source of confidence and independence. Amy's Mum suggested that it had:

given her confidence, that if Amy's on the bus and something happens then it's only one button, so it's not like trying to dial a number, or even if it's another phone and something has been already pre-set it doesn't matter, it's one button, she knows someone is always going to be there and she's quite comfortable with ringing that number

The attitudes of some of the attendants or support workers to the way the mobile technology was introduced and rolled out influenced whether or not some of the participants continued using the phones after the pilot. In some cases significant others or support workers actively discouraged the use of the phone. Outside of the one person who was compulsive in their behaviour phoning of others, the reasons for the negative attitude towards supporting people were not apparent. This affected the users experience and ultimately whether the technology could have assisted their independence. This accounted for some of the discontinuance. Yet, examining Table 1, with a sample of 15, it is very difficult to establish any causal or spurious

relationships between the uses of the technology after three months.. While frustrations with the technology, issues with undertaking physical action, others requiring continued training or reinforcement due to cognition or complexity of the tasks there did not appear an explanation for those who became high, medium or low users. While others required far more sophisticated support in order to realise the potential of the technology yet could be identified as high uses of the technology. As Ashlee's mother explained that while Ashley was considered a higher user of the technology,

it's self-learning and I think in some respects too it's more who is the phone best for. It seems to be geared a lot at those with say an intellectual disability and whereas someone like Ashlee is able to use things in a more sort of complex level but the help manual didn't help me work out what to do... It's was almost like we needed to go to a deeper level and that information wasn't there so it needs time to fiddle to understand the technology. Because there's not actually enough training there beyond that sort of initial surface level of how to make a phone call, how to charge it type of level.

Discussion

Interpreting the data using the PHAATE model (see Figure 2) illustrates the themes in relation to the **human** factors (the development of identity, enabling behaviours and increasing independence) and that these human factors are at the heart of the mobile technology experience for the participants. Freedom of choice for people with disability in the words of a disability supporter can be defined as 'having a real say in decisions that affect our lives. Empowerment is not something you suddenly have one day' ⁵³. The potential for the development of independence was recognised and described by family members and service providers alike. However, as previously mentioned, engagement in social participation was curtailed for some participants, who had difficulties physically accessing the phone, or who needed more training and support and for those who were reluctant to use the 24/7 Help Centre. This is in keeping with previous studies that identified similar training and support requirements for optimum retention and technology use ²⁹.

The potential for people with disability to use technology to enhance independence and social participation previously identified by researchers in the field ^{11-13,21,54} was clearly reflected in

these research findings. Overall the participants in the study were keen to embrace the mobile technology which mirrors previous research involving the use of technology by people with disability ^{21,25}. Yet there was still a discontinuance of a third of users and an ambivalence by another third of users in the pilot that is also consistent with previous understandings of the adoption of assistive technology ³. Moreover, participants reported widespread pleasure in using their mobile applications. By using a range of communication applications (activity and technology and assistance factors) participants could be seen exhibiting signs of increased self-confidence, empowerment and self-determination which is in keeping with the findings of other researchers ²⁶. In particular many of the participants developed greater independence in their local communities which was evident in an increased independent use of public transport, increased communication with relatives and friends, use of the Help Centre (environmental factors) and the development of new skills and activities such as taking photos, storytelling and sharing these with family and friends (human factors).

The environmental, technology and assistance and human factors were each shaped by the **policy** structure in which the mobile technology operated at the organisational level. Quite simply, without the NDIS, the National Disability Strategy and a move to individualise funding frameworks the likelihood of the project moving forward may not have occurred ^{33,44}. The mobile technology project, features and procedures involved support and training from Village Networks' staff, hard and soft technology customisation, and service providers assisting with training, affordability, prevention of bill shock and a Help Centre for ongoing daily assistance. While the NDIS has been rolled out in demonstration sites, the incorporation of technology allowances within an individual's package may determine whether people are able to afford the ongoing cost of this technology from both a hardware, software and customisation process. Hence the PHAATE model outcomes illustrated in Figure 1 provided a useful tool for understanding and interpreting the research data.

Limitations

While the research was successful in many ways, there were five key limitations identified from the study.

1. The timing and commencement of the study process was challenging, with the researchers engaging with many participants' after rather than at the start of the pilot.

- 2. The variety of participants and their service providers or lack thereof required different methodologies to be employed as the project progressed.
- 3. Hence, elements of the research design had to be modified during the research process. For example the order of the interview schedule, the type of interviews carried out and the number of interviews that each individual participated in varied from the initial research design.
- 4. Access to the reporting systems Village networks and the detailed telco data usage by those included in the sample or the pilot could not be provided to the researchers so this element of the original study design was not completed.
- 5. Without access to the reporting systems the research team were not able to identify the most frequently used features and how this equated to the self-reported assessment of what participants regarded as the most useful and enjoyable features of the system. This comparison would have been an interesting one to undertake as some features that become ubiquitous to a person's life are sometimes overlooked by the person in doing self-reported reflection.

Conclusion

The results of this study support the findings of previous studies that ICT use with people with disability with high support needs has significant potential⁷⁻¹¹ and that a purpose focussed, considered and in some cases individualised approach is required in training and supporting users^{12,13}. Those participants who reported the greatest satisfaction had significant ongoing support that included further adaptations and training from their carers and/or service providers. They were also adept at using the Help Centre.

This raised two issues from the study the first was the pivotal role that significant other play in the ongoing use of and skill development with the mobile technology. This was particularly the case for participants with intellectual disability and high support needs. It suggests that engaging significant others with an expectation that their involvement will be central and ongoing is essential. The second and related issue is that of unpredicted challenging behaviours with the use of the phone. The more research into smart phone use by

people with disability the more data can be collected on common challenging behaviours such as constant phoning for no reason. Moreover, the more strategies can be developed and tested for managing these behaviours and circumstances. Greater time spent understanding users with disability before they take up their smart phone could allow trainers and significant others to predict possible challenging behaviours and have plans and strategies prepared in advance. In this case the removal of the phone need not be the solution.

Finally this study has identified the clear potential for smart phones to increase independence and community participation for people with disability with high support needs. Furthermore it has identified key areas for future research as indicated above that could potentially take this form of ICT use into the everyday for a group of people who have been traditionally excluded from it. Yet, as this paper has shown the business model for people with disability with high support needs requires a greater level of customisation, extended training period and ongoing support that needs to be incorporated within the overall support approach if the potential to increase social participation is to occur.

Declaration of interest

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Figure 1: The PHATTE model which includes policy, the person, activity, assistance, technology and the environment

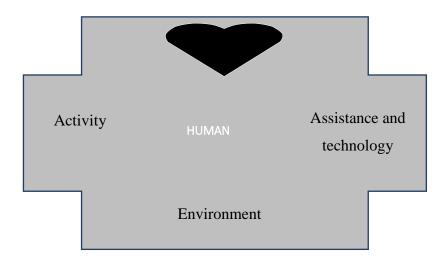


Figure 2: Research themes presented using the PHAATE Model

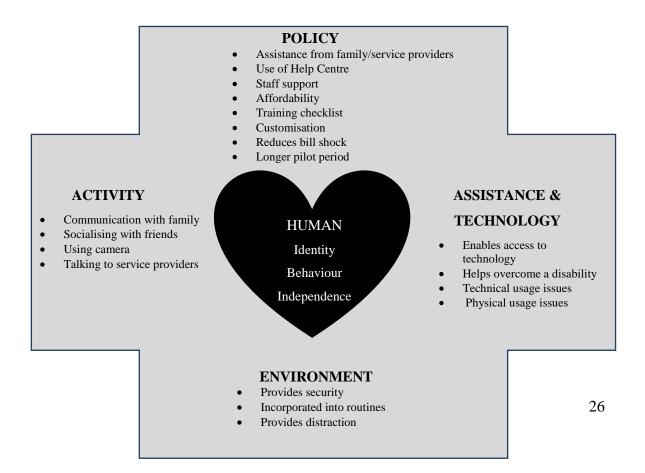


Table 1: Details of research participants

Pseudonym	Gender	Age	Disability Type	Support	Access in the community	Support needs	Usage constraints	Phone use prior	Technology use prior	Adoption after three months
Andrea	F	18–30	Cognitive	Service provider	Training centre	Medium	None	Yes	Frequent	High
Amy	F	18-30	Cognitive	Service provider	Training centre	Medium	None	Yes	Frequent	High
Ethan	M	18-30	Cognitive/Mobility	Service provider	Part-time work	Independent	None	Yes	Frequent	High
John	M	18–30	Cognitive/Mobility	Service provider	In company	Very high	Compulsion	Yes	Frequent	High
Ashlee	F	18-30	Cognitive/Sensory	Service provider	School	Independent	Vision	Yes	Frequent	High
Jill	F	18-30	Mobility	Independent	Working from home	Independent	Speech	Yes	Frequent	High
Tony	M	31–64	Cognitive	Service provider	Living in community	Independent	Physical	Yes	Frequent	Medium
Dan	M	18-30	Cognitive/Sensory	Service provider	Training centre	High	Speech	No	Frequent	Medium
Alf	M	65+	Mobility	Independent	Retired	High	Physical	No	Frequent	Medium
Joel	M	18-30	Mobility/Sensory	Supported Living Fund	With service provider	Very high	Speech	No	Frequent	Medium
Steve	M	18-30	Cognitive	Supported Living Fund	Part-time work	Medium	None	Yes	Infrequent	Low
Mia	F	18-30	Cognitive	Service provider	Training centre	Medium	None	Yes	Frequent	Low
Kylie	F	18-30	Cognitive/Sensory	Service provider	Part-time work	Medium	Vision	Yes	Frequent	Low
Kim	F	18-30	Cognitive/Sensory	Service provider	Training centre	Independent	Speech	Yes	Infrequent	Low
Rob	M	65+	Cognitive/Sensory	Service provider	Retired	Very high	None	Yes	Infrequent	Low

Research	esearch Theme		Number	Example quotation
Question		of theme	of sources	
Question 1 –	Communication with family	33	23	He uses it with prompting to speak with his grandma
Engagement	Socialising with friends	11	7	I share my experiences with my friends
and activity	ctivity Using camera		6	I take photos of myself!
	Talking to service providers	26	11	He arranges when they come to the house to pick him up using the phone
	Access to technology	68	28	Back in April I said 'No, I can't use a mobile phone', and look at me today!
Question 2 –	Use of Help Centre	23	16	I mainly use my phone to contact the help centre, they can tell me where I am!
Training,	Staff support	9	6	I have a specific training plan in terms of practicing greetings, transport and games
support and	Training checklist	5	4	He has a checklist which he ticks off
customisation	Customisation of the phone	15	6	They changed the size of the buttons and made them a little bigger
Question 3 –	Affordability	3	3	The free pilot allowed us to be involved
Enablers,	Reduces bill shock	4	4	As the internet is locked out that's going to minimise the bill shock
barriers and	Longer pilot period	5	3	He needs a longer period of time to get used to things
attitudes	Helps overcome a disability	4	3	You just press a button and it goes straight through to her hearing aids which is very good
	Technical usage issues	45	20	I can't always connect onto the person ringing me
	Physical usage issues	24	12	I have trouble with the swipe action
	Provides security	7	5	If I need him and he needs to contact us it's not going to put more pressure on us
	Incorporated into routines	10	5	He charges the phone before he goes to bed each night
	Provides distraction	3	3	She wanted to engage all the time with the phone rather than actually engaging in the activity
	Develops identity	12	7	She feels pretty cool because she's got a phone
	Promotes independence	3	3	If the phone rings she's not frightened, she can do things with it now
	Behaviour hinders usage	12	7	He was always phoning his father when he shouldn't have been ringing him or just ringing random numbers
	Assistance from	26	11	They made a video so that he can see how to use the phone and what he has to do
	family/service providers			