‘Put Yourself in the Picture’: Designing for Futures with Young Adults with Intellectual Disability

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ABSTRACT

Individuals with intellectual disability are all too often overlooked in the planning of their own support. Responding to this concern, and in line with person-centred planning, this paper outlines the collaborative development of a mobile app to support the communication, interests and goals of young adults who attend a disability support organisation. Existing technologies focus predominantly on enhancing academic abilities, such as literacy or numeracy, disregarding the potential to support personal interests and individual goals. Through a process of Reflective Agile Iterative Design (RAID), a mobile app was developed which enabled young adults with intellectual disability to produce an image of themselves achieving a certain goal. Although the app was designed for individual use in formal goal-setting meetings, participants used the app for social activities, such as taking ‘group selfies’, emailing their images to proxies and ‘layering’ selfies. The app supported the individuals beyond the planning process, contributing more broadly to enhancing overall communication, self-expression, and socialisation.

Author Keywords

Intellectual disability, communication, mobile apps, assistive technology, participatory design, person-centred planning, young adults

ACM Classification Keywords

H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

INTRODUCTION

Young adults with intellectual disability have been a marginalised population for whom conveying needs and opinions can prove difficult. As a result, others often try to communicate on their behalf. Disability advocacy agencies and government policies are increasingly recognising the need to ensure people with disability are given every opportunity to make their own decisions and to exercise choice and control. In Australia, this is one facet of the approach adopted by the National Disability Insurance Scheme (NDIS, 2014). Although this issue remains globally prevalent, there has been an increase in prominence of self-advocacy groups to ensure that people with intellectual disability have their own say (Tideman & Svensson, 2015).

Due to a number of varying biopsychosocial factors, individuals with intellectual disability very often experience great difficulty communicating (Schalock et al., 2007). This results in a cyclical process, whereby individuals who struggle to communicate their needs are further ignored or stigmatised against (Rogers & Marsden, 2013), even as members of supposedly democratic, egalitarian societies. Thus, it is essential to both investigate and provide ways of enabling communication of opinions and goals, in order to move towards a societal equilibrium in which all people are heard and valued.

We present the development and use of a goal-setting app within Endeavour Foundation, a not-for-profit disability support organisation. Goal-setting and decision-making are often undertaken primarily by proxies on behalf of the individual with intellectual disability and, thus, Endeavour Foundation expressed an interest in investigating ways in which individuals could communicate their own opinions about their future plans and goals, rather than relying on proxies. Individual support plans are determined through formal planning meetings involving staff, families, and the individual and the research was initially employed to support this planning process. However, through the iterative design process, researchers and support organisation staff alike were soon illuminated to the possibility that the app could provide support beyond the planning process, contributing more broadly to enhancing overall communication, self-expression, and socialisation.

RELATED WORK AND BACKGROUND

Intellectual Disability

The American Association on Intellectual and Developmental Disability (AAIDD) defines intellectual disability as “significant limitations in both intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills, [originating] before the age of 18” (AAIDD, 2016). Intellectual and developmental disability have an impact on not only the individual, but also their family, friends, teachers, support

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workers, healthcare professionals, and communities, otherwise known as the person's *proxies* (Boyd-Graber et al., 2006; Brereton et al., 2015).

Disability as a Social Construct

Oliver (1990) proposes the notion of *disability as a social construct*, created within society as an attempt to pigeonhole those who do not fit within its typical confines. Various authors have postulated that society as a whole instils our values and shapes our behaviours and thus dictates how we interpret disability. In recent times, however, our understanding of disability has begun to evolve from this deficit-focused concept to an ability-focused concept (Boddington & Podpadec, 1991; Keith & Keith, 2013; Kliewer et al., 2015; Mankoff et al., 2010; Schalock et al., 2007). Frauenberger et al. (2012, p.369) note that contemporary thinking challenges the deficit view of disability and advocates a "shift towards lived experiences [and] personal wellbeing" and suggest that this can be achieved through technological supports.

Diagnostic categories

Most people with intellectual disability have reduced abilities to process new or complex information and learn. Yet most do not fit a neatly labelled diagnostic category, often having a combination of underlying cognitive, communicative, motor and sensory conditions (UK Department of Health, 2001). As such, they are often overlooked in the design of new technologies, despite being, from a pragmatic perspective, the ones who can best express their own needs. This suggests that atypical impairments require individualised technological intervention, regardless of diagnostic category (Francis, 2007) and, as such, this study refrains from heavily labelling and categorising its participants based on their disability, opting to celebrate their abilities instead.

Person-Centred Planning

Person-Centred Planning (PCP) is a combination of approaches designed to empower people with disability to make their own choices and decisions. This approach is anchored in the social model of disability (Shakespeare & Watson, 1997), aiming to derail existing practice which tries to 'fix' a person with a disability, instead focussing on the principles of social inclusion, community integration, co-production of services and individual self-determination and goal-setting (Sanderson et al., 2006; Sanderson & Lewis, 2012; Wigham et al., 2008). PCP aims to facilitate the expression of interests and desires through placing the individual at the centre of the planning process, as opposed to their proxies. It is the individual who is the true expert in their own needs and who is best positioned to enable positive development and empowerment. Proxies such as families and caregivers are important to this process but are considered partners instead of primary decision-makers.

PCP is seen to actively challenge the devaluation and social exclusion of individuals with disability by adopting a holistic, person-centric approach and placing great importance on individualisation (Francis, 2007), choice and autonomy (Beadle-Brown et al., 2009) and determining a person's preferred style of communication (Moraine, 2016). In line with the United Nations Convention on the Rights of Persons with a Disability (UN, 2007), person-centred approaches advocate the right to empowerment and independence and global efforts are being made within governmental policy to integrate this approach into their service provision (e.g. NDIS in Australia, Valuing People white papers in the UK).

Communication

Communication is important for self-expression, social interaction and wellbeing, however individuals with intellectual and developmental disability may be unable to express their daily needs through typical modes of communication, such as face-to-face interaction (Magsamen-Conrad et al., 2014; Rogers et al., 2012; Scott et al., 2000). Such populations can be described as having complex communication needs (Hagiliassis, 2006).

Common approaches are used to engage with people with such needs across the disability support sector. For example, instead of using long complex sentences, information is offered in small pieces, interactively and with visual support. Importantly, interaction is tailored to the individual. In a general sense, literature shows that visual communication can be just as important as verbal communication (Lester, 2014). For example, the Picture Exchange Communication System (PECS) is a form of visual communication developed to support communication exchange in those with intellectual and developmental disability. Visual communication techniques such as PECS can in fact increase functional communication in this population (Ganz et al., 2012; Hart & Banda, 2010). This suggests the importance of using visual aids in the development of technology to enhance person-centred planning and goal-setting. Individuals with complex communication needs should have access to a wide range of strategies and techniques to enhance their communication (Light & McNaughton, 2013). Technology offers the opportunity to provide a new model of goal-setting interface that can be customised to individuals' own interests and abilities (Putnam & Chong, 2008).

Technological Intervention

Technology is becoming integrated with human existence at an ever-increasing rate and can be valuable to the enactment of positive social change (Ferrario et al., 2014). For most people, including many of those with intellectual disability, technologies such as mobile phones and tablets are now commonplace (Heyer & Brereton, 2010). It is suggested that the use of computers and mobile technologies can enable individuals with intellectual disability to better communicate, foster interpersonal relationships, and enhance wellbeing, socialisation and behaviour (Abudullah & Brereton, 2012; Alzayer et al., 2014; Frauenberger et al., 2016; Light & McNaughton, 2013; Sigafoos et al., 2013).

Assistive Technology (AT) and Augmentative and Alternative Communication (AAC) are terms for technology which "strives to accentuate strengths rather

than weaknesses, to enable expression of abilities at a level commensurate with intelligence, and, ultimately, to enhance the quality of life of persons with learning disability" (Raskind, 1994, p.152). Importantly, pragmatic AT and AAC aims to use readily available, 'mundane' technologies (such as smartphones or tablets) so as to avoid further stigmatisation (Francis, 2007).

Existing Tools

Existing technologies have shown evidence in aiding competencies such as; choice, such as the Choiceboard Creator iPad app (Stephenson, 2016); emotion learning, such as CaptureMyEmotion (Leijdekkers et al., 2013); social story learning, such as ICanLearn (Zaffke et al., 2015); communication, such as Autisay (Voon et al., 2015); early intervention, such as TOBY (Venkatesh et al, 2013); social skills, through multitouch tablet apps (Hourcade et al., 2011); digital scheduling, such as vSked (Hirano et al., 2010); learning through a mobile learning companion, such as VibRein (Toshniwal et al., 2015); picture-based instant messaging, such as SymbolChat (Keskinen et al., 2012); general learning, such as iCan (Tang et al, 2013); and socialisation through a software-based social tutor (Milne et al., 2009). However, despite the positive outcomes reported by many, current apps tend to focus on educational or linguistic outcomes, instead of encouraging the fostering of individual's own interests and aspirations, finding ways to help communicate these important human concepts to their proxies and communities. Often, traditional academic pursuits, although important in many respects, may not be of interest or of pragmatic relevance to this population's needs, wants, or competencies (Heydon, 2008; Kliewer et al., 2015).

It is important to note that excitement regarding what technology can do may lead to overlooking the needs of the very individuals we aim to help (Light & McNaughton, 2013). We must be aware that technological tools can disable as well as enable and serve to further embed issues of social exclusion, acting as compensatory mechanisms for the so-called limitations brought by disability (Goggin & Newell, 2006; Lidström et al., 2010). It is important, therefore, to ensure that technology serves to further facilitate human-to-human social contact and communication, and refrains from further exclusion in the "disability divide" (Solomon, 2000).

Theories and Analytical Lenses

Self-Determination Theory

Self Determination Theory (Ryan & Deci, 2000; 2011) is primarily concerned with the potential of social contexts to provide experiences that satisfy people's universal needs for feelings of competence (a need for challenge and feelings of effectiveness), autonomy (a sense of willingness and volition) and relatedness (social connection with others). Satisfaction of these three needs has been shown to yield enhanced self-motivation and mental wellbeing. This is important as self-determination in choosing goals and building skills and interests is believed to be critical to the education and wellbeing of people with intellectual disability (Wehmeyer & Schwartz, 1998). Ryan and Deci (2000, p.56) define two types of motivation within SDT; intrinsic and extrinsic. Intrinsic motivation is "the doing of an activity for its inherent satisfactions rather than for some separable consequence", whereas extrinsic motivation occurs when engaging in an activity for a separable outcome or instrumental value, such as reward or praise. Therefore, self-determination is seen to increase as we internalise these processes and move from being externally propelled into action to undertaking actions with self-endorsement and assimilation (Ryan & Deci, 2000). Thus, if a person has an intrinsic, autonomous, self-defined motivation to complete a task, it is much more likely that they will succeed.

Social Practice Theory

Although SDT provides a robust analytical lens through which to consider and measure the impact of technology for people with intellectual disability, it is also important to take into consideration one's sociocultural environment. Social Practice Theory is a framework which describes how individuals shape and are shaped by the cultural environment in which they exist (e.g. Shove et al., 2012). Within this theory, everyday life is defined by the rise, transformation, and fall of social practices, and researchers propose that this can inform new design approaches. Indeed, this approach is concurrent with the previously discussed concept of disability as a social construct. Further, Social Practice Theory fits with participatory design thinking as it places weight on the deep understanding of the social context of these vulnerable user groups, as Ferrario et al (2014) explain is crucial. This account of the importance of the environment, culture, and society in which this study is situated may provide useful complement to the SDT framework. It is suggested that an analytical lens which combines both of these theories will return useful analysis of the results of this study.

Critical Design Focus

Considering the literature, there appears to be increasing advocacy for the use of digital tools to support communication in person-centred approaches to intellectual disability. Indeed, in terms of socialisation, Frauenberger et al. (2012) discuss that social inclusion has become linked in many ways to digital inclusion, highlighting the need to foster this key human need through the technological tools at our disposal.

Considering that traditional academic pursuits may not be of interest or relevance, and that pursuing one's own self-defined goals suggests a greater likelihood of success, it is clear that there is increased need to provide communication support to those with intellectual disability, enabling a move towards true equality of all people and ensuring that the voices and opinions of those with disability are heard and valued. Technology that supports person-centred approaches and communicative ability could therefore be of benefit to the individual and to their proxies, communities, and societies. We propose to enhance support through technology, in this case a

mobile app, from an ability-centric perspective, as opposed to the deficit-centric perspective of historical prominence (e.g. Keith & Keith, 2013).

METHOD

The project preceding the design proposed in this paper initially sought to engage university information technology (IT) students, under the supervision of senior academics, with an organisation that provides services for teenagers and adults with intellectual disability. The service organisation in turn welcomes the opportunity to engage with students and academics in co-design projects. The project was concerned with digitizing Person-Centred Planning tools, running across three semesters and involving six teams of students across two academic year groups. Here, we focus solely on one of the designs which emerged: a mobile application that can support users with disability when expressing the goals they aspire to achieve.

Context When the people Endeavour Foundation supports and their families come to the support organisation, they have an initial meeting with staff in which they set a small number of achievable goals. According to tutors and senior staff members, these can include: being able to practice gardening, finding the courage to order a coffee and sit at a table at a cafe, being able to independently take the bus etc. These goals are reviewed regularly and can provide a sense of achievement when they are met. They also provide the staff with a framework through which to individualise learning programs for each user. However, in the absence of effective tools to support communication around such goals, it was observed by the support organisation managers that the users too often lack involvement in this very important process, in turn resulting in reduced motivation to work towards the goal.

A Reflective Agile Iterative Design (RAID) Approach

This research employed a Reflective Agile Iterative Design (RAID) approach, combining best practices of ethnography, co-design and agile software development (Heyer & Brereton, 2010) and centring on the "design and deployment of a continuously evolving exploratory prototype that is embedded within a social setting and evaluated longitudinally" (p.283). As articulated by Schön (1990), design is a reflective conversation with the problem context and the materials of the design situation, with the requirements evolving as the design proceeds. RAID emphasises the use of prototypes or concrete artefacts, which are important in working with individuals for whom abstraction of thought is difficult. For example, prior work with the support organisation found that people with intellectual disability often expressed themselves well and were empowered to try new roles through concrete use of interactive prototypes (Brereton et al., 2015). Thus, our approach engaged people with intellectual disability as full partners in collaborative design (co-design), in line with the core philosophy of collaborative design and iterative development of a concrete prototype (Simonsen & Robertson, 2012). The project employed a qualitative methodological approach in order to gain deep, narrative insights into participants' opinions on the functionality and validity of this app. Data collection methods such as direct participant observations, semi-structured interviews and environmental observations were undertaken. Ethical approval was granted through the University Human Research Ethics Committee (QUT UHREC).

The RAID process was undertaken over a period of 1.5 years, within which the technology was conceptualised, prototyped and re-iterated in conjunction with service users at Endeavour Foundation. The participants were asked for feedback, such as opinions on plans for the next iteration e.g. categorising common words, images, and interface functionality or whether to use large or small buttons. Informal observations were conducted toward the end of this period (the final two months) with particular focus on the final concrete prototype unveiling. Formal observations and semi-structured interviews and subsequent trialling were conducted in a one-off session after the university student project had concluded. The focus is on these sessions, because it was here that the concrete prototype had reached a sufficient level of usability. Observations were carried out during participant trials of the concrete prototype in four different settings; group observation of initial use (informal); researcher observation of one participant individually (formal); researcher observation of two participants (formal); researcher observation with tutor present and three participants (formal).

Participants Participants were young adults (17-35 years old) who attend the support organisation's post-school adult learning services. In the informal group setting there were 12 participants, in the formal settings there were a total of eight participants and one tutor. The cohort included 11 male and nine female participants, with varying abilities and levels of intellectual functioning. This intended to give an overview of the app's use in various settings which may arise within the participants' everyday environment. All participants were physically able to use the app e.g. swipe motion or press the button, as this was the minimum grounds for participation. All participants were familiar with and had access to technology such as smartphones and tablets, despite perhaps having little verbal or written capability. Regardless of intellectual functioning, participants displayed an interest in using the technology presented to them, both during the design stages and during the final observations in use.

An important caveat to consider; although it may seem pertinent to detail the nature of each participant's condition, we would argue here that this provides only a binary view of the person, situated in the deficit model of disability previously discussed. It is important, as discussed by Frauenberger et al., (2016, p. 130), to "go beyond functional limitations and engage with ideas, desires and problems […] in a holistic way". Moreover, we do not know the medical condition of each participant, nor would it have been appropriate or necessary to ask. Participants are encountered in a lifestyle and learning centre setting where they are

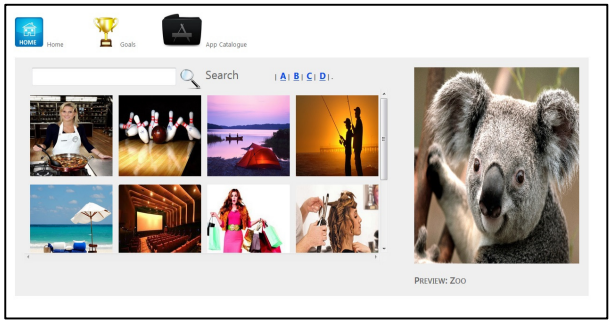
engaging in fun, social and learning activities. In line with Vines et al. (2013), we note that, although technology has the potential to enrich the lives of vulnerable people, it must also be approached with the utmost care, so as to avoid adding to stigmatisation and existent challenges. Thus we do not detail exact disabilities in a clinical sense, preferring instead to focus on the evaluation of the app and on enhancing ability, not highlighting disability.

Participation on the part of the people Endeavour Foundation supports involved discussion of ideas upon conceptualisation, subsequent sessions in which the design was discussed and refined, and finally trialling the concrete prototype. Other participants included the support organisation's tutors, who provided encouragement and support to the participants during trialling, as well as research and management staff from the support organisation, who advised on the functionalities they thought might be helpful to integrate.

Evolution of Requirements through RAID process

The following describes the iterative design process through which the final concrete prototype design emerged.

Stage 1: Early iterations revealed desire for mobile technology In early iterations of the project, we started developing a web-based application (Fig. 1) that would allow the users to express their goals using images pre-defined by the organisation and arranged into categories. Initial surveys using web-based PCP tools where users could select images from a collection of images showed that images provide an excellent level of engagement. However, often users would not like the style of images proposed or would want to import their own. Observations of the users in their environment additionally revealed that they enjoy and are capable of engaging with mobile technologies and often own mobile devices.



Stage 2: Co-design and emerging requirements

Figure 1. Early Iteration Web-based Prototype: Category Page

Prototyping and preliminary trialling were carried out in two phases. The trials enabled us to make observations of the participants and the nature of use. These trials highlighted the need for simplicity of the interface and the need for safeguarding against unintentional actions (such as deleting content or exiting the application unintentionally). Additionally, it emerged that participants preferred the use of photographs as opposed to cartoons, suggesting that photographs were more realistic and salient. Participants especially liked the use of pictures which related to their daily activities, e.g. pictures of their own garden, as opposed to any other garden or stock photo. These surveys supported the prerequisite that a digital tool must support goal-setting activity by engaging the user themselves in the process and allowing them to make choices based on their own interests (Self-Determination) and environments (Social Practice).

Stage 3: Design goals emerged Further iterations determined that the ability for the users to share the final image with their supervisor at the support organisation was required (collaborative requirements). Upon joining up the above discussed feedback - need for a simpler interface, extended choice in the pictures available, photographs instead of cartoons, and a collaborative sharing functionality - the idea of creating a mobile application through which users could create a picture of themselves achieving their goals emerged.

Stage 4: Final design requirements The mobile application was designed and built with the view of allowing people to easily create a projected selfie of themselves achieving a goal, using image contouring technologies. Informed by the surveys and co-design activities, the design was mapped to the requirements as follows:

Fig. 2 Final design requirements
Engaging: Mobile Application, Selfie action
Accessible: Can be used with icons only, development follows WAI (Web Accessibility Initiative) principles
Intuitive: Only one stream of actions possible, guided by icons and images
Non-prescriptive: Based on large public images library
User-driven: Search function available to add to prescribed icons
Collaborative: Images can be shared via email

Stage 5: Final design outcome: concrete prototype The design of the concrete prototype is presented in Figure 3. The process begins by first selecting a background image, which will depict the desired goal e.g. going on a steam train. This can happen in a number of ways. Firstly, the background image can be selected via pressing an icon leading to pre-defined queries (Figure 3 (a)). Secondly, via text input i.e. entering a query on the top part of the screen and pressing the Flickr logo (top-right icon). Finally, by selecting an image from the participant's personal gallery (top left icon). A set of background images is either found by Flickr via the query or retrieved

from the user's personal gallery, and presented to the user through the application interface (Figure 3 (b)). When the user selects a background image, it is displayed on the screen (Figure 3 (c)) and the user is able to press the camera icon to take a photo of themselves (Figure 3 (d)), which is then superimposed on the selected background image (Figure 3 (e)). The user then has the choice to save the image, email it to their proxy or share it through social media dependent upon the applications within the device and permissions (Figure 3 (f)).

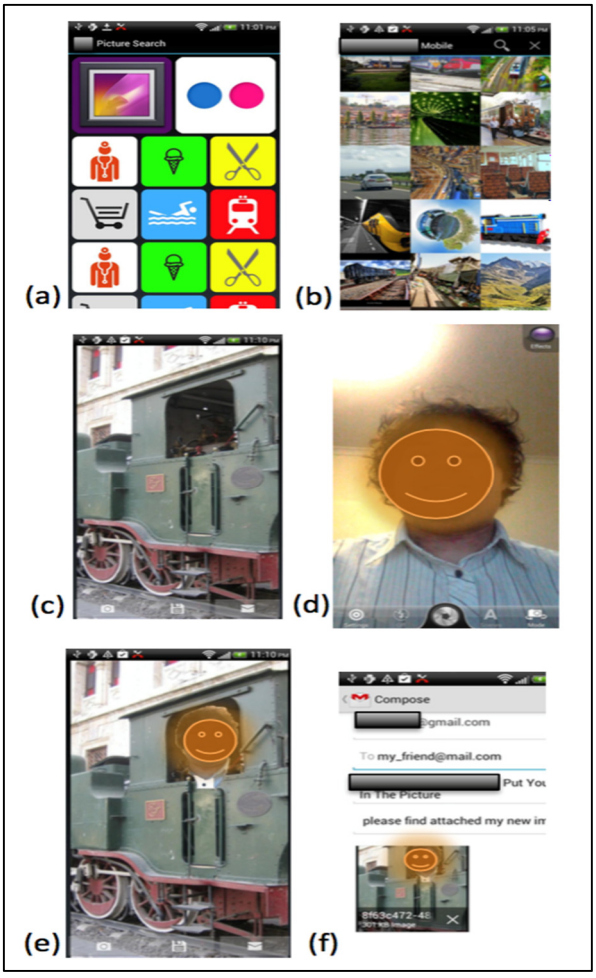


Figure 3. Final Design Prototype of '*Put Yourself in the Picture*'

The application is built for Android devices, using the open source computer vision library (OpenCV) for the contouring and superimposition of contoured face on the background image. Flickr API is used to retrieve the background images, within the safe search parameter. Sharing is enabled with all sharing applications on the user's phone. If an email application is used for sharing, then a default email set on the configuration screen of the app (for the proxy's email) is pushed to the email application, so that no typing is required.

Manned Probes Reflecting on the prototyping process, we realised that many HCI techniques would not work in this context. Techniques such as surveys and cultural probes involve detaching oneself from the situation and waiting for a response from users in their own context. As Soro et al, (2016) note, these are unmanned probes. However, many forms of design demand *manned probes* that allow intimate engagement with the participant, in order to understand how they use and interpret the probe; helping, showing, listening looking and discussing where needed (ibid). As such trialling sessions and prototypes took the form of manned probes and these were essential to the success of the project.

OUTCOMES AND FINDINGS

Users were given complete freedom in how to use and interpret the app and formal and informal observations returned the following findings:

Intuitive Use and Rapid Uptake Findings indicated that participants found the app intuitive to use and, within 30-40 minutes, could use the app independently and were confident in and excited about exploring it further, without researcher input. The tutor discussed that the participants were "*demonstrating independence. It didn't take long to learn the program.*"

Some participants even began to teach their friends how to use it, at which point the socialisation potential of the app became clear. This intuitive use is perhaps due to the concept of young adults as 'digital natives', to whom technology is a fully integrated aspect of their lives (Smith et al., 2013). The tutor expressed that *"He was really able to give it a go and that was impressive. He's showing ability to manipulate the app really well... it was really surprising"*. This intuitive design emerged through engaging in a process of RAID and explicates the benefits of collaboratively engaging in the design process with end-users, i.e. the final concrete prototype is one which inherently fits with user needs and thus can be used quickly and intuitively.

Quality One pertinent finding on the usability of the app suggested that the quality of the image and photos were of little relevance to the participants. The concrete prototype demonstrated some issues with the contouring function, in that often the contoured image of the participant's face would also include elements of the background and was of poor resolution. Despite this, none of the participants commented on the quality of the images produced nor expressed a desire for greater contouring or resolution quality. This finding attests to the importance of context, expectation and values in designing for populations with intellectual disability. For example, superior image quality may be of little to no value to an individual with intellectual disability, but may seem to be a very important issue to a neurotypical adult designer. This is a useful perspective to bring forward into further work, and serves to uphold the values of participatory design theory; that collaborative design can lead to insights unimaginable to the designer.

Socialisation Of particular interest was that participants used the app in unintended and surprising ways. When asked who they might share the images with, proxies were generally suggested by participants e.g. "*send the picture to mum and the boys",* however, despite email sharing being the only form of socialisation designed for

in the app, this was not the only form of socialisation afforded by the app.

Although designed for individual use, participants quickly discovered and immediately trialled various social ways of using the app. This included taking selfies with other participants, and immediately emailing their images to parents and friends, instead of the intended recipients (their support workers/managers). Some participants requested help to do this, while others did so without consultation. This emphasizes the element of fun that this app yields and is ultimately concurrent with the overarching aim of this study; to enhance and support human-to-human communication in those with intellectual disability. This finding shows the expression of latent needs through the app e.g. the need and desire for fun and socialisation. This fits with the increasingly discussed idea that digital and social exclusion are inextricably linked (Dobransky & Hargittai, 2006; Frauenberger et al., 2012) and thus, as we strive for the digital inclusion of those with intellectual disability, we strive for their social inclusion too. Fostering ways to include those with intellectual disability in a *digital* sense is therefore intertwined and co-dependent with more 'visible' aims, e.g. those discussed by government policy, to include those with intellectual disability in a *social* sense.

New Functionalities A further finding suggests that this unintended socialisation led to the organic development of new functionalities for the app. For example, participants layered selfies on top of one another, effectively superimposing themselves upon photos they had taken of others to create an artificial 'group selfie'. These unintended uses for socialisation and functionality surprised developers and proxies alike, serving to further underline the importance of participatory design and a RAID approach, while also highlighting the dangers of assuming that we, as designers, can fully comprehend the abilities and innovative approaches of this population without their input. This finding illustrates the innovative design possibilities which had been missed by neurotypical adult designers, but quickly anticipated and explored by the participants. Further, this finding suggests a willingness and confidence on behalf of the individuals to express ideas and new uses.

When asked about when they might use the app, participants suggested "*when you go to the shops... decide what shop you need to go to*", as well as "*when you travel to different countries, to show where you want to go or if you get lost"*. The creative thinking on behalf of the participants on the real-world application of the app demonstrates that they could imagine it as a flexible tool to integrate into their daily lives.

Trusted Proxies Observations revealed that, in the fourth observational setting (researcher, tutor, and three participants), the presence of the tutor was instrumental in encouraging engagement and excitement. Participants appeared to be more engaged when encouraged by the tutor and were guided towards using the app for its intended purpose – goal-setting. This has interesting implications surrounding the importance of trusted proxies when trialling new technology, in that these participants dutifully used the app to think about their formal personal plan and goals, but were also intent on using the app for the fun. Activities or things they felt were fun and exciting, such as *horse-riding* or *soccer,* seemed to elicit more engagement than their formal learning goals, such as *driving a car* or *cooking a chicken burger.* This suggests that there may be a disparity between what truly enthuses the individual and what is decided upon as their personal goal during their planning meetings, thus emphasising the need for such an app in the eliciting of the individual's true interests.

Additionally, some of the participants were already familiar with the researcher, and thus it was interpreted that this changed the way in which they used the app when compared to other participants. Instead of using the app to create images of themselves doing something they would like to do in future, or indeed playing with the functionality of the app as others had done, these participants instead used the app's search function to find images of things they already enjoyed and participated in (such as horse-riding or watching Disney's *Frozen*), and then shared these with the researcher. Although differing from the intended use of the app, this showed researchers that the app is also useful in supporting communication of *current* interests, sharing these with others, and in communicating the story of who an individual is, through their own unique image creation. Thus, we see a potential for such an app to support individual story-telling in all three of the main temporal tenses; past, present, and future.

Future Use After trialling with the participants, the tutor expressed a strong interest in the continued use of the app with her students, suggesting integrating it into existing classroom exercises. Importantly, the tutor also suggested using the app as a mechanism of reassurance in helping people anticipate something new, such as an upcoming and as yet unchartered activity, which may normally cause anxiety. The tutor discussed that providing a way to visualise the event or activity could reduce anxiety and clearly define expectations. This suggests that the app may be of benefit to those who experience difficulty in the abstraction of thought.

Importance of the Visual Another finding of interest is that each participant was familiar with the *flickr* icon (seen in Fig 3a), intuitively choosing it to open the photo sharing database, despite lack of written denotation, or clues about what it contained. This finding emphasises the importance of the visual in communication for people with intellectual disability, supporting the idea that icons and visual prompts such as PECS are universally understood and internalised and can provide enduring information to those for whom literacy may be difficult or impossible.

Analytic Lenses Self-Determination Theory suggests that satisfaction of autonomy, relatedness, and competence needs can yield enhanced self-motivation, mental health and wellbeing. The findings show that the app provides an increased ability to express individual

choice and interests, as well as encouraging the social sharing of both the process and the final images. Users are therefore likely to be experiencing feelings of competence (in successfully using the app to place themselves into the photo), autonomy (in choosing which photos they want to place themselves in as well as choosing with whom to share the finished product) and relatedness (in choosing with whom to share the final photo and in creating 'group selfies'). Thus, through the lens of SDT, it is suggested that the app presents a tool through which to help individuals with intellectual disability achieve greater self-determination.

From a Social Practice Theory perspective, we see that the sociocultural environment in which the study took place is of great significance. That the presence of trusted proxies changed participants' approach to the app through e.g. eliciting excitement, shows the importance of socioenvironmental structure (of e.g. the support organisation) in the interpretation of new technologies. Further, that participants took an app designed for individual use and created a social activity with it suggests that the environment in which the study was carried out engendered feelings of creativity, playfulness and innovation in the users as a group. Cultural factors which impacted on the study included familiarity with technologies such as mobile phones. By acknowledging the societal constraints and sociocultural norms at play when conducting a study such as this, it allows many important factors to come into consideration, such as; the environment in which the app is used, the quality and duration of the relationship between researcher and participants, how comfortable participants are in the research situation, and what is expected of participants. Examining this study through both theoretical lenses provides an impression that the benefits of this app come from its ability to increase both feelings of individual self-determination, and to place value on the sociocultural environment in which the individual exists.

Limitations This study represents the first step of data collection in a wider study design in which we hope to investigate the impacts of use of the app longitudinally to discount novelty factors, as well as as a more integrated technological support in the goal planning meetings at the support organisation. Within the next stage of this project, we will be able to obtain more formal user evaluation data and feedback on the long-term usefulness of the app.

Future iterations of the app might include functions to capture user interaction data, providing a quantitative view of, for example, how long participants use the app for in each session, which functionalities they use most etc. Further, a broader remit for choice of category from which to choose the background photo could be considered. Currently, these categories are static and broad (travel, sports, animals, etc.), however it may be useful to include the capacity to create categories of specific interest to the participant. As is common in intellectual disability, often individuals have particularly strong interest in one very particular item or category (Matson & Dempsey, 2009). Thus, being able to tailor the category to one of choice may serve to make the app more appealing to individual users. Findings also present opportunities for the app in supporting anticipation of future events and describing the current self through visual representation. In addition, the design may be expanded to include more search input functionalities such as voice recognition, and a version available on iOS, in order to further increase accessibility.

CONCLUSIONS

This study presents findings on use of an interest-based goal-setting app in participant-driven prototype trials. It is believed that the findings presented in this paper divulge useful information regarding the way in which people with intellectual disability interpret and use apps which aim to give voice to their personal interests and goals. Initially discussed as a design for use in formal planning meetings, through a process of RAID, it was determined that the app had potential to contribute more broadly to the self-expression and socialisation of this population.

This study has been a lesson in what can be learned from those with intellectual disability, as co-designers and otherwise. If we can provide a platform through which their voices can be heard, and their needs, opinions, and goals can be shared with confidence, we will be privy to the communicative potential of these individuals' fun-seeking natures, willingness to express ideas, and enthusiasm to try the new and the bold. Assumptions on the part of designers and proxies must be replaced by true participatory design motivations, whereby the individuals are central to the design process. It is hoped this is a step in the right direction, toward a society in which all people are heard and are appreciated as truly equal members.

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