The Digital Life Project

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ABSTRACT

The Digital Life Project is a joint initiative of the NSW Government Department of Family and Community Services (FACS) and The Samaritans Foundation (a non-government organisation which delivers a range of human services). It has been designed to support people living in Large Residential Centres (LRCs) through a period of unprecedented reform in disability services. The project is part of a much larger Transition Program that includes a wide range of projects designed to enhance community inclusion for such people.

By and large, such people experience barriers to social participation because they have moderate to profound levels of intellectual disability, and a range of physical and mental health support needs. They are also moving through a period of unprecedented change to the way in which they are supported to live meaningful lives.

This project is successfully introducing digital media as a new way to support people with complex barriers to society participation and inclusion. This is because the videos being produced by the project:

- are created through active participation by the person and/or their supporters
- contain unique information about themselves they have chosen to share
- belong to the person and they are supported to exercise control over how that information is stored and shared.

Author Keywords

Large Residential Centres (LRCs), National Disability Insurance Scheme (NDIS), profound intellectual disability, moderate intellectual disability, augmentative and alternative communication (AAC),

ACM Classification Keywords

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

INTRODUCTION

The disability reform period in NSW is dominated by three key changes to policy and service delivery:

- The Australian Government is incrementally rolling out the NDIS across Australia, with full implementation planned by 30 June 2018. For people who live in LRCs in NSW this means moving from an integrated health, accommodation and disability support model to individually funded disability services and self-initiated use of a range of mainstream health services.
- The NSW Government is transferring its share (40%) of direct disability service provision over to the non-government sector.
- The NSW Government is providing contemporary community accommodation for people currently living in LRCs (about 1,000 people over 3 years) and permanently decommissioning those services.

These reforms are all premised on protecting the rights of people with disabilities, including ensuring the support that is required to enable those rights to be enacted is provided. The primary mandates can be found in the following conventions and legislature:

- United Nations Convention on The Rights of Persons with Disabilities (CRPD) - of which Australia as a party aims to promote, protect, and ensure the full enjoyment of human rights by people with a disability.
- National Disability Insurance Scheme (NDIS), in conjunction with other laws, gives effect to Australia’s obligations under the CRPD.
- Disability Inclusion Act 2014 (NSW) is aligned to the rights stipulated in the CRPD.

FACS is committed to upholding the rights and principles of equality, independence, choice and inclusion that underpin these mandates. Indeed, the Department’s Lifestyle Planning Policy promotes personalised approaches to supporting people with disability to develop and maintain their own unique skills and capacities, and to have a lifestyle based on their own interests and aspirations. However, in times of significant reform, this approach needs to be adapted to include more innovative strategies for community inclusion and participation.

The Digital Life Project is one such innovation, as it seeks to introduce digital participation as a means of enhancing information creation, custodianship and dissemination.
RATIONALE FOR THE PROJECT

The objectives and principles espoused in all of the above mandates are all relevant in the context of supporting people with intellectual disability to acquire a level of digital literacy and participation. For most of these people, digital participation is a new concept, although an undeniable human right. This is especially relevant in this period of major reform in the disability services sector and to the ubiquitous use of information technology throughout multiple aspects of community and business life.

Community participation for people with intellectual disability has long been defined as attending daytime activities, often in small to large groups of people with similar levels of disability. People who reside in LRCs in NSW typically have moderate to profound levels of intellectual disability, as well as multiple complex physical and psychological support needs. This project is unique in that it explores community participation through the use of digital media for people with moderate to profound levels of intellectual disability.

The Digital Life Project is part of a larger change initiative called the LRCSSL Transition Program, which includes a wide range of projects designed to enhance the transitional experiences and quality of support for people living in LRCs. This project is focussed on enhancing community inclusion by introducing digital communication as a new way in which they participate in creating information about themselves, as well exercising control over how that information is stored and shared.

In addition, and due to a range of complex health and behaviour support requirements of a large contingent of this group of people, it is also imperative that detailed information is made available to a new disability support workforce in a way that is accessible for people who may have lower levels of digital literacy and English proficiency. This is required to ensure there is an unbroken continuity of appropriate support as people move away from an institutionalised nursing model of supported accommodation towards authentic community living.

The inspiration for exploring the possibility of information sharing and communication through digital participation came by attending a digital story exhibition at the Newcastle Museum in early 2015. The “Home to Home” Digital Story Exhibition, presented by The Summer Foundation provided a glimpse into the often hidden lives of nineteen young Australians with disabilities who live in aged care homes. The Summer Foundation’s digital stories can be found at: https://www.summerfoundation.org.au/documents/digital-stories/.

The exhibition featured a collection of digital stories created during a series of workshops across Australia in 2014. The storytellers were the people themselves, who were supported to develop scripts, narrate voice-overs and collate images and footage to produce insightful videos about their unique experience of living in a nursing home. The emotions of grief, frustration and sadness were deeply pervasive in this collection of stories, as were themes of perseverance, strength of character and hope.

Following the securing of funding, FACS partnered with The Samaritans Foundation to co-design and co-implement an approach for enhancing communication and information sharing through the use of digital media for people moving from LRCs to community living in NSW.

PROJECT DESIGN & IMPLEMENTATION

Participants

Initially, the project was targeted to people living in three LRCs in the Newcastle, Lake Macquarie and Port Stephens areas, but has since expanded to work with people living in an LRC in Western Sydney.

Outcomes

The project has been designed to achieve two key outcomes for this cohort of people:

- People have the opportunity to develop their own stories and support plans using digital presentation as a means of communication, education and expressing personal creativity.
- People have a means to own, store and share information about themselves with their informal and formal support network.

Outputs

To date, the project has employed a co-design approach to refine three distinctly different kinds of video productions:

- Introduction Videos (IVs), which aim to capture and convey a personalised impression of the person as a means of introducing the person to new acquaintances and support services. These videos are being produced by a professional media production company, Storyhaus.
- Individual Support Videos (ISVs), which aim to capture key aspects of the person’s daily and long term support needs. These videos can be used to inform new support services and staff members about how best to support the person. These videos are being produced by a FACS media production team.
- Clinical Support Videos (CSVs), which aim to capture specialised practices and procedures essential to a person’s health and wellbeing. The FACS media production team works closely with allied health and medical staff to design the content of these videos to ensure they are able to be understood by support staff in the future.

Each type of video is designed to provide a specific kind of communication and information exchange to enhance understanding of the person, and to develop rapport with those around them. The information imparted through digital storytelling and digital support planning will help to provide continuity in the provision of support, but
more importantly, ensure that new supporters are well-informed to provide personalised support.

Almost all videos produced are between 3 and 6 minutes long. Through trial and error, it was found that this is the most effective timeframe for retaining the viewer’s attention and imparting vital support information to new audiences.

At this stage in the project, all participants receive their video products on USB drive and DVD media. However, the goal is to go beyond this rudimentary approach and to introduce mobile technologies to participants, the majority of whom have never owned or used these technologies before. In June 2016 the project team commenced an exploration into the development of a person-centred mobile application for persons with moderate intellectual disability. However following several months of discussion with academic and private developers, it was determined that the overall cost, resource and time commitment exceeded our project limitations. It was also clear to the project team that many of the facilities and functions suitable for our participants, were already present in the operating systems of popular mobile devices. For example, photo and video storage, planning calendars, contacts lists, a journal facility, and other means of recording and presenting an individual’s experiences and lifestyle preferences. In many respects, the device itself is able to act in similar ways to the mobile application we had conceptualised.

Consequently, the project team is now investigating options for funding Android tablet devices to complement their current communication support equipment. The devices would need to be customised to suit each individual’s communication preferences and abilities to ensure they have easy access to their information, including their own video productions. For many people, this will give the person a means of being the custodian of their own digital information.

A key achievement for the project was the recent success in winning the Anglicare National Award for Innovation and Excellence in Darwin on 5 September, 2016. This has given the project team a boost of enthusiasm to maintain momentum and to continue to explore new ways for enhancing digital participation for people with intellectual disability and complex needs.

CONCLUSIONS

During the last five or six years, disability service providers around the world have witnessed very significant changes in the lives of people with physical and intellectual disabilities through the use of mobile technologies and applications.

Indeed, a range of devices are now being used by people with disabilities in a range of augmentative and alternative communication (AAC) modalities for social networking, long distance communication, as well as enjoying music, games, capturing photographic images, online shopping and many other transactions. These are significant contributors to addressing the inequity of access this population has to digital participation. This project is also contributing to this by providing a catalyst for the person’s journey of discovery into digital participation and inclusion.

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- Production Team (FACS): Spiro Pappas, Paul Kelman, Tracey Adams and Norman Favor
- StoryHaus Producer/Director – Karl Brandstater

REFERENCES

Legislation

1. Disability Inclusion Act 2014 (NSW), NSW State Government
2. National Disability Insurance Scheme Act 2013, Australian Government

HIGHLIGHTS FROM THE PROJECT LEAD

Video-making has been a serious hobby of mine since 2008. Working as a support worker in disability group homes, I often used to think about the potential video might have as a means of training staff to be better support workers. Not in the general sense of training workforces in industrial practice and policy implementation, but in an individualised sense, as a means of capturing and conveying the nuances of a person’s character, communication and support needs.

There are so many subtle things we learn about an individual through supporting them over a period of time. And there is so much knowledge held within the minds of support staff in the Large Residential Centres; knowledge that often isn’t written anywhere or recorded in any plan.

Video teaches on a very different level to the written word. Text, of course, is still the most effective way to impart detailed information on an intellectual level, but video is able to engage audiences on an intuitive and visceral level, and this can make information more memorable and impactful, as long as the video work is authentic and well executed.

The potential of video isn’t limited to teaching its audience a series of facts about the individual’s support needs. It has the ability to inspire supporters to work well with the person; to work compassionately with the person and to come into the position of support for that person with a mind that is better prepared for the work ahead.

We’ve learned many lessons since the project started in mid 2015. What we’re doing is quite new. It’s been a collaborative effort and process, with the involvement of
innumerable FACS and NGO staff members, family members, public guardians and members of the community.

I think I can safely say that most if not all of the people with disability that we’ve had the pleasure of working with have enjoyed the process of making their videos. When the Digital Life team is filming, all attention is upon the person. It’s a new and interesting experience for most of the participants and we hope that the process, as well as the end product, has been a positive and rewarding influence in their lives.

Geordie Anderson, October 2016.