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Digital mental health and intellectual disabilities – state of the evidence and future directions

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ABSTRACT

Abstract

The use of digital technologies in the management of mental illness, and more generally in the promotion of wellbeing and mental health, has received much recent attention and is a focus of current health policy. We conducted a narrative review to explore the opportunities and risks of digital technologies in mental healthcare specifically for people with intellectual disability, a sometimes marginalised and socially excluded group.

The scope of digital mental health is vast and the promise of cheaper and more effective interventions delivered digitally is attractive. People with intellectual disability experience high rates of mental illness and could benefit from the development of novel therapies, yet seem to have been relatively neglected in the discourse around digital mental health and are often excluded from the development and implementation of new interventions. People with intellectual disability encounter several barriers to fully embracing digital technology which may be overcome with appropriate support and adaptations. A small, but growing, literature attests to the value of incorporating digital technologies into the lives of people with intellectual disability, not only for promoting health but also for enhancing educational, vocational, and leisure opportunities.

Clearly further evidence is needed to establish the safety and clinical efficacy of digital mental health interventions for people with and without intellectual disability. A digital inclusion strategy that explicitly addresses the needs of people with intellectual disability would ensure that all can share the benefits of the digital world.

Digital mental health and intellectual disabilities – state of the evidence and future directions

Introduction

The development and adoption of digital interventions into mental healthcare has generated much excitement.[1] Service users, professionals, and policymakers alike have embraced the 'digital revolution' and the NHS in England has made a clear commitment to expand and further integrate digital healthcare into the routine delivery of services.[2] Digital mental health is the application of technology in the promotion of mental wellbeing, and assessment, monitoring, and treatment of mental illness (Table 1).

- Online and mobile phone interventions for practical and organisational tasks (booking appointments online; web-based personal health records; SMS medication or appointment reminders)
- 'Telecare' (remote consultations via video link; monitoring and alarm systems that alert carers or professionals to abnormal physical parameters or high-risk behaviours)
- Smartphone and tablet apps (symptoms tracking; passive data collection of sleep and activity patterns)
- Online information resources (psychoeducation)
- Social media and online social networks (peer networking; support groups; online chat rooms)
- Traditional psycho-social therapies delivered electronically (computerised Cognitive Behaviour Therapy; guided relaxation or mindfulness apps)
- Novel therapies built with technology (avatar therapy; virtual reality; serious games)

Table 1 – The scope of digital mental health interventions

Most mental health services in the UK now subscribe to a recovery-oriented model that emphasises service user collaboration, values personal goals, and recognises the importance of social inclusion and supportive relationships.[3] The intelligent integration of digital technologies into mental healthcare can support a cultural shift to the recovery model and increase service user empowerment.

Approximately 1 million adults in England have an intellectual disability.[4] People with intellectual disability have lifelong deficits in cognitive and adaptive functioning that impinge on a variety of everyday activities.[5] As clinicians working with people with intellectual disability we are interested in the potential of digital mental health to deliver improved methods of engaging with service users and managing mental health. This clinical review explores the opportunities and risks inherent in the wide-scale uptake of digital mental health specifically for people with intellectual disability. We also consider how technology might be designed and implemented to achieve maximum benefit for all, ensuring that no-one is left behind. Relevant literature published in English was identified by Medline and Google Scholar searches up to May 31st 2016, supplemented by additional Google searches to retrieve pertinent material (such as reports, guidelines, and policy documents) from the grey literature.

Use of digital technology by people with intellectual disability

Use of digital technology has become an important aspect of modern life and is a marker of community integration. In 2016, ninety percent of all adults used the internet every day and over 7 in 10 owned a smartphone.[6] There is consensus that digital technologies are under-utilised in people with intellectual disability.[7-9] Best estimates indicate that between a quarter and a half of people with intellectual disability access the internet.[10,11] The use of mobile phone is lower amongst people with intellectual disability than in the general population and people with intellectual disability tend to use the basic functions of devices rather than more sophisticated operations.[12] Uptake of newer devices (such tablet computers and smartwatches) by people with intellectual disability has not been studied in

any depth but is likely to similarly lag behind use in the wider population. The gap between those who have access to information and communication technologies and those who do not has been termed the 'digital divide'.[13]

Current digital health interventions for people with intellectual disability

Numerous automated but 'low tech' interventions have been used in the care of people with intellectual disability for many years. These include alarm systems that monitor behaviour and activity, for example, a door sensor that triggers an alert when a vulnerable person leaves the house at night. Tele-consultation (remote communication using video link) using real-time or asynchronous appointments has been shown to increase access to specialist advice[14] and is acceptable to carers.[15] This approach is especially useful in intellectual and developmental disabilities where specialists may be relatively few in number and dispersed geographically, and where travelling is difficult. Tele-monitoring and remote management has the potential to harness newer technologies (such as wearable 'smart' devices) to help people with intellectual disability to manage their physical health.[16]

At the time of writing this review there are two apps within the 'learning disabilities' section of the NHS apps library (https://apps.beta.nhs.uk/). 'My Health Guide' is an electronic health passport that supports information sharing and understanding. The app, which is currently being trialled in clinical services in the UK, enables users to build a personal profile including health information, communication preferences, and more general aspects of their life and personality. Initial feedback from staff and service users has been positive (https://www.myhealthguideapp.com/press/digital-health-app-trial-extended/). 'My Choice Pad' is an app containing several thousand signs and symbols that can be used to support communication. The seven apps that are currently listed in the 'mental health' category of the NHS apps library are designed predominantly to support self-management of mood and anxiety symptoms and make no mention of suitability for people with additional needs.

A large number of digital apps are available that aim to augment communication in children with autism spectrum disorder and limited verbal abilities, often with the use of pictograms or more sophisticated 'word trees' and branching pathways. Similar apps exist to increase

vocabulary or are used in educational settings, often as part of a formal skills development programme. A number of these might also be helpful for some with other cognitive impairments but very few of the new generation of digital mental health interventions have been specifically designed or targeted to people with intellectual disability. Interventions which use digital technology in other domains have been developed for people with intellectual disability and might give insight as to how these approaches could be repositioned for used in the field of mental health (Table 2).

A smartphone app supporting physical activity

A randomised controlled trial to evaluate the role of a simple smartphone app that provides reminders to exercise is being undertaken in adults with mild-moderate intellectual disability as part of a multi-modal intervention to improve physical health.[17]

Varied applications of Virtual Reality

Virtual Reality is the computer simulation of a three-dimensional environment within which the user is immersed and can interact. In an exploratory study of 20 participants of varying ages and with mild-severe intellectual disability, Hall et al (2011) showed that it is feasible and acceptable to use Virtual Reality and a simulated healthcare environment to deliver health information.[18] Virtual Reality has also been successfully used in vocational training, in everyday activities ranging from cooking[19] to navigating a 'virtual city'.[20]

Serious gaming for money management

Serious games are interactive programmes with educational as well as entertainment value and where the incentive to complete the game is used to motivate learning. A serious game developed for tablet computers has been shown to be enjoyable and enhance money management skills in a group of adolescents with intellectual disability.[21]

A mobile app to communicate pain

An computer/mobile application (STOP-ID!) designed with pictograms and graphic images to help people with cognitive limitations to report pain has been tested in 40 adults with Down's syndrome.[22] Although the majority of users needed assistance, the authors conclude that the tool shows promise as a new means to facilitate communication of pain in this group.

Table 2 – Digital interventions have been used to support people with intellectual disability in different domains

Barriers to use of technology

There are several barriers that might act to limit the use of digital technologies by people with intellectual disabilities and could account for the digital divide (Table 3).

• Cognitive limitations
• Physical and sensory impairments
• Lack of appropriate training
• Lack of ongoing support
• Lack of permanence and frequent changes in interface and usability
• Economic barriers
• Self-exclusion
• Attitudinal barriers and desire to shelter from harm
• Organisational culture

Table 3 – People with intellectual disabilities may experience barriers to accessing technology

People with intellectual disability have cognitive and linguistic limitations that can limit access to complex and text-heavy resources. They are likely to require more time to learn new skills necessary for using technology. They might be discouraged by unsuccessful prior experiences with using technology or by frequent changes in the interface and navigation systems of digital programmes. Despite this, several authors have demonstrated that with appropriate training and support most people with a mild-moderate degree of intellectual disability can learn and retain basic computer skills.[23,24] People with more severe and profound intellectual disabilities, often without verbal communication, may still make use of limited computerised interventions with appropriate support.[25]

In addition to the cognitive obstacles faced in accessing digital technologies, many people with intellectual disability have physical limitations that can affect fine and gross motor skills

and the ability to use keyboards or a traditional computer mouse. Sensory impairments are common and can hinder the viewing of information on the small screens of mobile devices.

People with intellectual disability are often materially disadvantaged and only 6% are in paid employment,[4] therefore, financial constraints are often a barrier to accessing technology. New devices can cost upwards of several hundred pounds and require ongoing investment, for example, to access the internet or update software.

A proportion of people who make an active choice not to adopt new technology are termed 'self-excluders'.[26] However, people with intellectual disability, on the whole, seem interested in new technology,[27] and our experience is that many are keen to explore the opportunities that technology brings. For example, the using the internet can give considerable freedom including the opportunity for self-expression, allowing people to expand their social circle beyond their usual contacts, and can act as a means for people with niche special interests to pursue their favoured subject.

The attitudes and behaviours of family members or carers might either enable or discourage technology use as people with intellectual disability are often dependent on others for at least some degree of care and support.[28] Carers and paid support staff, who themselves may embrace technology to a greater or lesser extent,[29] seem to hold mixed views about the place of technology in the lives of people with intellectual disability. Whilst they recognise its value in promoting independence, they also express fears about increased vulnerability and victimisation, particularly in the context of social media use.[30,31] There is a potential conflict of interest for paid care staff between increasing independence by facilitating use of the internet for people with intellectual disability and working in risk-averse conditions that can inadvertently act to prioritise safety over opportunity.[32] There may also be practical and organisational barriers that limit the uptake of new technologies, such as the requirement for staff training and procurement of new equipment.[33]

Overcoming barriers to use of technology

Universal design (alternatively known as "design for all") is the design of products and environments usable by all people, to the greatest extent possible, without the need for adaptation.[34] Principles of universal design are well established and apply equally to electronic devices and the virtual world as in the physical domain (Table 4). However, even those websites created specifically for people with intellectual disability have been found to apply the principles inconsistently.[35]

Universal design principle	Examples
Equitable use (usable to people with diverse abilities)	- Controls are adequately spaced and large enough for users with limited dexterity - No 'time outs' that penalise slower users - Simplest language possible, supplemented by icons/pictorial information and audio - Brief information summaries - Built-in safety and security measures
Flexibility in use (choice in methods of use)	- Allow keyboard access methods as an alternative to use of a mouse (e.g. enable the cursor to be used with arrow keys) - Enable users to adapt settings and change preferences - Compatibility with a range of devices
Simple and intuitive use (easy to understand regardless of experience, knowledge, language, current concentration)	- Interface is stable across different functions and time points - Linear, logical ordering with limited options - Reduced on-screen clutter - Training and support are available and accessible - Allowing the user to choose rate at which information is provided to avoid information overload (links to new information rather than lengthy scrolling)

	- Static page elements, avoiding flashing content
Perceptible information (provides different modes of communication)	- Clear typography and sans serif fonts - Contrast between different elements on the screen - Captions for video - Screen magnifier option
Tolerance for error (minimises hazards and adverse consequences of unintended actions)	- Quick consecutive presses of the same key are ignored - Allow user to adjust amount of time a key should be pressed before command is accepted
Low physical effort (design can be used with a minimum of fatigue)	- Operation requires minimal strength, grip, twisting
Size and space for approach and use (appropriate size and space provided)	- Ensure fixed equipment (e.g. screens) are viewable to users of different heights

Table 4 – Principles of universal design can be used to optimise accessibility of digital technologies

Electronic devices and educational software are now in routine use in mainstream and specialist schools.[36] There may be a natural cohort effect whereby those in younger generations ("digital natives"[37]) will not only be capable of, but also expect to use digital technology in most aspects of their lives. However people with digital skills can lose them if they transition to adult services which do not actively promote digital use.[38]

The opportunities for digital mental health in people with intellectual disability

Owing to a combination of biological susceptibility and exposure to adverse social and environmental factors, adults with intellectual disability experience high rate of mental ill-health.[39] Autism and behaviour problems are common in this group and the potential for

digital interventions to provide benefit across a range of domains (health, social, educational, vocational) is significant.

With the research literature around digital mental health in its infancy, people with intellectual disability have often been excluded from the development, implementation, and evaluation of digital mental health interventions. Our review shows that people with intellectual disability are capable of engaging with digital technologies given the right opportunities. Preliminary qualitative work shows that people with intellectual disability and clinicians are amenable to incorporating digital interventions into routine treatments for mental disorders.[40]

The evidence base for digitally-supported therapies for people with intellectual disability is slowly developing. An adapted version of a computerised psychological intervention for anxiety and depression has been tested in a controlled trial of adults with mild-moderate intellectual disability.[41] The programme, *Pesky Gnats: The Feel Good Island*,[42] delivers simplified Cognitive Behaviour Therapy (CBT) concepts as a social story with different game characters teaching different core skills, and is used in sessions alongside a therapist. Mindfulness or relaxation exercises are presented as a video at the end of each session. This study is the first formal evaluation of computerised CBT in people with intellectual disability and demonstrates that digital mental health interventions can successfully be delivered in this group.

A 'blended care' (or 'hybrid') approach, where digital therapy is combined with traditional face-to-face meetings,[43] may be more acceptable than exclusively online treatment.[44] People with intellectual disability are a highly heterogeneous group and even those with comparable scores on standardised cognitive testing can have greatly different profiles of strengths and needs, sometimes complicated by the presence of other neurodevelopmental conditions such as autism or attention-deficit hyperactivity disorder. Blended care augments rather than replaces the role of the therapist, allowing for tailoring of standard digital interventions, and maintains the benefits and continuity conferred by 'in person' relationships.

Some digital mental health interventions are aimed towards families and carers of people with intellectual disability. Many organisations now provide online information resources (e.g. https://www.mind.org.uk/ and http://www.rcpsych.ac.uk/healthadvice/atozindex.aspx). Others host virtual communities, such as Mencap's 'Family Hub' where carers can make connections and post on discussion forums (https://www.mencap.org.uk/familyhub); this may be extended through organisations such as 'Contact a Family' (https://www.cafamily.org.uk/).

Challenging behaviour is a term used to describe abnormal behaviour that threatens the physical safety of a person or others and that can restrict access to ordinary community facilities.[45] The physical, emotional, and economic impact of challenging behaviour can be considerable and affects both the person with intellectual disability and the network around them, and is a common reason for referral to specialist psychiatric services. Challenging behaviour is an example for which an array of digital health interventions could be utilised. First, mobile apps could provide a means of augmented communication that helps people with verbal deficits to effectively convey their needs without resorting to challenging behaviour. Second, apps to monitor and record the behaviour in real time (e.g. 'Behavior of Concern' https://pedagogisktkapital.se/english/) could be helpful in recognising patterns and trends and in facilitating a functional behaviour analysis. Third, families and carers of people with intellectual disability and challenging behaviour could use social media and online discussion forums to gain support and advice from others with similar experiences and reduce feelings of isolation and burnout.

Creative solutions are needed to ensure that people in socially disadvantaged and marginalised groups are not further excluded by experiencing barriers to using technology. The UK Government 'Digital Inclusion Strategy' aims to increase participation with digital technologies, particularly in groups at risk of marginalisation, although there is no specific mention of people with intellectual disability (https://www.gov.uk/government/publications/uk-digital-strategy/2-digital-skills-and-inclusion-giving-everyone-access-to-the-digital-skills-they-need). Other initiatives for ensuring that people with intellectual disability have access to new technologies are, free use

of computers and the internet at local libraries, dedicated community technology centres, and schemes for loan of digital devices.

Risks of digital mental health in people with intellectual disability

As with any intervention, there are potential disadvantages to digital interventions for mental health. Several of these may disproportionately affect people with intellectual disability.

Online health information is largely unregulated and may be of poor quality. This is relevant to all who seek information online but people with intellectual disability may be more credulous and vulnerable to misinformation. Unmoderated social media can present risks of cyberbullying, online grooming, identity theft, and exploitation. People with intellectual disability are more susceptible to online victimisation due to impairments in understanding social communication, impulsivity, elevated levels of trust, and increased rates of social isolation and loneliness.[46]

All digital mental health interventions suffer from a lack of formal evaluation and neither their clinical nor cost effectiveness have been demonstrated to the level that would be expected of orthodox interventions.[47] In the absence of evidence from clinical trials, clinicians are reliant on anecdotal reports and judgements based on face validity of interventions and resources. Simple rating scales and checklists have been developed for quick appraisal of the basic elements of digital tools.[48,49] Quality evaluation tools can be applied to online health information, although none has achieved pre-eminence.[50] The UK National Information Board have developed a hierarchical process for appraising and accrediting health apps, from Stage 1 (self-assessment) to Stage 4 (independent evidence of clinical safety and effectiveness).[51]

Apps and wearable devices for health often store and transmit large amounts of sensitive personal information. A review of health apps listed in the NHS Library found systematic gaps in compliance with data protection principles, including lack of encryption of data and absent or inadequate privacy policies.[52] There is potential for third parties to accrue significant

amounts of information and use this for commercial purposes (e.g. in targeted marketing); users with intellectual disability may find lengthy privacy policies more difficult to understand.

Conclusions

Modern technology has the possibility to radically change the landscape of mental healthcare. Digital interventions in their many forms promise more effective, and cheaper, treatments. However there is a paucity of empirical data to support the effectiveness and safety of digital mental health interventions and it is concerning that the application of new technologies for people with intellectual disability seems to have been largely neglected.

People with intellectual disability are able, and willing, to use digital technologies but experience barriers in access that can lead to exclusion and perpetuate the health inequalities already experienced by this group. Using principles of universal design improves access not only for people with intellectual disability but also for those with other cognitive limitations, sensory impairments, and reduced literacy or technical know-how. Development and further research on digital interventions should include people with intellectual disability and their carers at the development and evaluation stages of the innovation pathway. The UK Equality Act protects individuals from unfair treatment and requires providers of services to anticipate and respond to the needs of people with physical or cognitive disabilities.[53] It is important that evaluation of digital mental health products includes an assessment of accessibility and usability by people with intellectual disability. Statutory and third-sector services must take a positive stance towards digital technologies and enable people with intellectual disability to realise and share the benefits that digital technology can bring.

Conflict of interest declaration
Rory Sheehan reports no conflicts of interest.

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