

Digital Citizenship and Young People with Intellectual Disabilities: A Review of the Literature

Introduction

This literature review was initiated to inform Hohepa Canterbury's digital framework project. The literature review aims to identify how young people with learning disabilities are currently using digital technology (particularly social media), and what programmes and supports have been demonstrated to assist them to do so as good digital citizens.

The report below summarises information from the academic literature pertaining to how young people with intellectual disabilities currently use information communication technology (ICT), the benefits and risks and challenges associated with this, and how learning in this area is currently being addressed. The report concludes with recommendations drawn from the analysis of the literature, to guide Hohepa's project.

Digital citizenship

Before continuing, it is important to define what is meant by being a good digital citizen, as this informs the detail of the report. The concept of digital citizenship is evolving and has varied meanings, sometimes referring to using on-line activities to engage in the political world or to make a contribution to the community (Pandgrazio et al, 2021), while others use it to mean being knowledgeable, skilled, and responsible in on-line environments (Ribble, 2017; Fishes et al., 2021). The definition used by Netsafe in Aotearoa New Zealand fits with the intent of Hohepa's project and is therefore the definition being used for this literature review. This identifies that good digital citizens are discerning and responsible and are "able to confidently conduct themselves when connecting to people, resources and information in real-world contexts" (<https://netsafe.org.nz/digital-citizenship-and-digital-literacy/>). In addition, Netsafe says that digital citizens:

- are confident and capable users of technology
- use technologies to participate in educational, cultural, and economic activities
- use and develops critical thinking skills in cyberspace
- are literate in the language, symbols, and texts of digital technologies
- are aware of information communication technology (ICT) challenges and can manage them effectively
- use ICT to relate to others in positive, meaningful ways
- demonstrate honesty and integrity and ethical behaviour in their use of ICT
- respect the concepts of privacy and freedom of speech in a digital world
- contribute and actively promotes the values of digital citizenship.

Use and Barriers

The majority of the available literature on this topic relates to the current use of ICT by people with learning disabilities, and discussion of the barriers and risks involved in this. This information is not directly related to the project topic, but provides useful background and highlights factors of relevance to the project. The two key points made in the literature relate to 1) the digital divide between people with intellectual disabilities and non-disabled peers, and 2) the barriers and risks that influence the limited on-line engagement of people with intellectual disabilities. Both of these key points are discussed below.

The Digital Divide

A number of studies have explored how people with intellectual disabilities use ICT, all of which have similar findings. These studies note that, overall, people with intellectual disabilities do not access nor use ICT to the same extent as non-disabled people (Fisher et

al., 2021; Chadwick et al., 2013). Furthermore, authors note that although people with intellectual disabilities may have access to several devices each, this does not necessarily lead to those devices being used. For those who are using the internet, the most common purpose is for social media/social networking and entertainment (largely games) (Glencross, 2021). In comparison to the non-disabled population, people with intellectual disabilities rarely use ICT for activities such as listening to podcasts, reading, dating, or sexual expression (Glencross, 2021).

The digital divide means that many people with intellectual disabilities are missing out on the full range of benefits that can be gained via ICT and on-line engagement. The social isolation and loneliness that is a well-documented experience for many people with learning disabilities, can be somewhat mitigated in the on-line world – the internet can be a great leveller, enabling people with intellectual disabilities to interact with others without disability being a feature (Chadwick et al, 2018), and providing opportunities to build connections with others more easily than in physical settings. As with all other people, the internet can also be an useful source of information, can help with learning and skills development, and can facilitate fun and recreational activities.

Barriers and Risks

The digital divide appears to be influenced by the following factors:

- *Lack of education.* Young people with intellectual disabilities, particularly those whose education occurs outside of mainstream classrooms, do not receive the same digital education that is provided in both incidental and planned ways on a regular basis to non-disabled young people (eSafety Commissioner, 2020). As a result, their digital literacy skills and understanding of how to be responsible and safe on-line is therefore limited.
- *Literacy and communication difficulties.* These cognitive difficulties can make it hard for young people with intellectual disabilities to use ICT effectively (Alfredsson et al., 2020).
- *Unavailability of support to enhance access and safety.* The majority of parents and caregivers report that they do not have the skills and experience to provide guidance or assistance with ICT matters (Rouchelau et al., 2021). Conversely, in some situations, parents underestimate what young people can do on-line, and therefore omit to provide guidance or oversight (Caton et al., 2016).
- *Concern about risks.* The literature identifies possible risks such as increased risk of cyberbullying, scams, and grooming (eSafety Commission, 2020), though these are largely discussed as opinion or theory, without prevalence data or evidence to support these notions. Although it is likely that being vulnerable to abuse in 'real life' may also extend to on-line life (Buijs et al, 2017), the risks to people with intellectual disabilities are not currently evidenced, and may be over-stated. Concern about risks often leads to a tendency by parents/caregivers/organisations to err on the side of caution, restricting access to devices and the internet (Chiner et al., 2018; Rouchelau et al., 2021; Caton et al., 2016). This in turn leads to people with intellectual disabilities missing out on the benefits, of ICT engagement and risks them being left behind in the modern world.

Strategies and Programmes

Research to address the risks and barriers via strategies and programmes is only now emerging and is very sparse. This section discusses existing programmes, factors and strategies that have contributed to successful on-line programmes, who support could and should be provided by, and the content that could be included in a digital citizenship programme.

Existing Programmes

The literature provides little evidence of people with intellectual disabilities being provided education or programmes to help them learn to live in a digital world (Anderson et al 2019) (other than with school work), despite this frequently being recommended as an important strategy.

An exception to the lack of programmes is presented in a 2016 study by Usoro et al. The authors of this study developed a prototype on-line game (unfortunately not available for public use) to help young people with intellectual disabilities learn how to stay safe on line, and to help their parents and carers learn how to supervise, monitor, and support them. This type of games-based learning (GBL) has a strong research basis in the mainstream literature and is described as a “dynamic educational motivator, able to provide users with immersive experiences, provoke reflection and improve cognitive capacity” (Usoro et al pg. 1), as well as being highly motivating, repetitive, and providing deep immersive learning experiences. Such visual tools are thought to help address the memory/information-retention challenges that many young people with an intellectual disability face.

Useful Strategies

Several other authors have investigated the factors and strategies that have helped on-line learning (unrelated to digital citizenship) to be successful. Although not directly relevant to Hohepa’s project, these could have value if incorporated into an on-line learning programme related to digital citizenship. These include:

- Using modelling (demonstration), role-play and practical scenarios to work through real-life on-line issues (Fitzpatrick et al., 2022). Sitting alongside the person to guide them as they ‘practice’ was demonstrated as useful in a study by Chiner et al. (2018), and in the eSafety Commissioner (2020) research, one family hired a young support worker to teach their teen gaming etiquette and safety skills (while gaming) and reported a great deal of success.
- The use of index cards that include images and screen shots to explain procedures, as these can be referred back as needed and have a low literacy requirement (Cihack et al., 2015).
- Providing immediate feedback on progress (Rouchelau et al., 2021).
- Peer interactions that allow time for debate and discussion, and that emphasise praise and encouragement (Fitzpatrick et al., 2022).

Who? Provision of Support

Regarding who should provide guidance, education, and assistance, there is some clear detail within the literature. Chiner et al. (2018) found that parents and caregivers think that organisations should provide training to young people, and that they feel largely unequipped to provide this themselves. Library services are often recommended as ideal organisations to assist with this, as they often have community ICT development as part of their remit (Whiteside et al., 2022). Having said this, parents and caregivers who attend education sessions about digital citizenship themselves are more able to provide support (such as using content control filters and encouraging use of privacy settings) to young people with intellectual disabilities (eSafety Commissioner, 2020).

In addition, an important study by Andersson et al. (2019) notes that young people with intellectual disabilities are not eager to be educated on this topic by adults, or in traditional learning environments. In fact, the young people in the Andersson et al. (2019) study expressed strongly that it would take something special (a pizza party, payment, other teenagers as tutors) for them to even considering attending a learning event. Several of the participants in the study said that nothing would encourage their attendance. Within the

context of Hohepa's project, finding out what young people want is imperative if they are to be guided and supported to develop their digital citizenship.

Content

Given the lack of established programmes, there is consequently little information available regarding what specific content should be included in digital citizenship training for young people with intellectual disabilities. The information that is available (Alfredsson et al., 2020b; Chadwick et al., 2018; Chiner et al., 2018) is based on opinion, rather than on researched outcomes, and there is little agreement regarding what this content should be. As with many aspects of supporting people with intellectual disabilities, the answer may be to adapt reputable evidence-based materials that have been developed for the general population.

Recommendations

Based on the evidence from the literature, some general recommendations can be made to guide Hohepa's digital citizenship project going forward. These include:

- Find out what young people with intellectual disabilities want and what would encourage them to engage in a programme to develop their ICT skills. Engaging young people in developing ICT skills may be challenging, but informal peer-led approaches appear to have the most promise. A wide range of options should be considered and discussed with young people, and co-design of the elected method may assist in tailoring it to their preferences.
- Explore ICT/digital citizenship programmes that are evidenced based and have demonstrated positive outcomes for non-disabled young people in Aotearoa New Zealand. Adapting such a programme to suit the needs of people with intellectual disabilities could be a good option. In doing so, seek to incorporate the factors listed in the 'Useful Strategies' section above, as these are demonstrated to assist people with intellectual disabilities in learning new skills on-line.
- Prioritise parent and Support Co-ordinator education. Supporters need to have the skills to work alongside young people and guide them in their on-line interactions.
- Develop policies and practices that balance benefits and risks. Potential risks should not be avoided or ignored, but instead acknowledged and managed, so that people with intellectual disabilities can have greater control of their lives and a chance to enhance their well-being. In this context, young people should not be overprotected but, work must be undertaken to share decision-making and agree on actions and requirements related to ICT use.
- Consider that any approach that is developed is likely to be costly and time-intensive. Although young people are the focus of this project, all people with intellectual disabilities are likely to benefit, and there will be advantage in developing tools and approaches that have broader use.
- Consider partnership opportunities with community agencies that have a remit for developing ICT skills. Organisations such as libraries or Hagley Adult Literacy may be in a position to assist.

Conclusions

The literature review identified that there is little research on the topic of developing digital citizenship with young people with intellectual disabilities. What is evidenced, however, can be summarised as follows:

- Many people with learning disabilities have access to a range of devices but often lack skills to use these, and use these less than their non-disabled peers

- Risks (such as grooming, cyber-bullying, radicalisation, being scammed) are perceived to be higher due to cognitive impairment, but there is no actual evidence of this.
- Most people with learning disabilities have had little ICT education
- There are no disability-specific available programs or comprehensive tools to teach digital literacy to young people with learning disabilities, though the research encourages the development of these.

As such, the path forward is likely to rely on adapting evidence-based materials that have been designed for and used with non-disabled young people in Aotearoa New Zealand to meet the needs of those with intellectual disabilities. Success will ultimately depend on the active engagement of young people with intellectual disabilities. In order to ensure that the approach is engaging, it is recommended that potential participants are involved in sharing their views and shaping and co-designing the programme.

Bibliography

Alfredsson Ågren, K., Kjellberg, A., & Hemmingsson, H. (2020). Access to and use of the Internet among adolescents and young adults with intellectual disabilities in everyday settings. *Journal of Intellectual & Developmental Disability, 45*(1), 89-98.

Alfredsson Ågren, K., Kjellberg, A., & Hemmingsson, H. (2020a). Internet opportunities and risks for adolescents with intellectual disabilities: A comparative study of parents' perceptions. *Scandinavian Journal of Occupational Therapy, 27*(8), 601-613.

Alfredsson Ågren, K., Kjellberg, A., & Hemmingsson, H. (2020b). Digital participation? Internet use among adolescents with and without intellectual disabilities: A comparative study. *New Media and Society, 22*(12), 2128-2145.

Anderson, A., & Phillips, P. (2019). "Getting Basic Information Isn't as Helpful as the Nuanced Advice We Can Give Each Other": Teens with Autism on Digital Citizenship Education. *Journal of Research on Libraries and Young Adults, 10*(3), 1-27.

Buijs, P.C.M., Boot, E., Shugar, A., Fung, Wai Lun, A., & Bassett, A.S. (2017). Internet safety issues for adolescents and adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 30*(2), 416-418.

Caton, S., & Landman, R. (2020). Internet safety, online radicalisation and young people with learning disabilities. *British Journal of Learning Disabilities, 50*(1), 88-97.

Caton, S., & Chapman, M. (2016). The use of social media and people with intellectual disability: A systematic review and thematic analysis. *Journal of Intellectual & Developmental Disability, 41*(2), 125-139.

Chadwick, D.D., Quinn, S., & Fullwood, C. (2017). Perceptions of the risks and benefits of internet access and use by people with intellectual disabilities. *British Journal of Learning Disabilities, 45*, 21-31.

Chadwick, D.D., & Fullwood, C. (2018). An online life like any other: Identity, self-determination, and social networking among adults with intellectual disabilities. *CyberPsychology, Behavior & Social Networking, 21*(1), 56-64.

Cihak, D.F., Wright, R., McMahon, D., Smith, C.C., & Kraiss, K. (2015). Incorporating functional digital literacy skills as part of the curriculum for high school students with intellectual disability. *Education and Training in Autism and Developmental Disabilities, 50*(2), 155-171.

Chiner, E., Gomez-Puerta, M., & Cardona-Molto, M.C. (2017) Internet and people with intellectual disability: an approach to caregivers' concerns, prevention strategies and training needs. *NAppEdR, 6*, 153-158.

Chiner, E., Gómez-Puerta, M., & Mengual-Andrés, S. (2021). Opportunities and hazards of the internet for students with intellectual disabilities: The views of pre-service and in-service teachers. *International Journal of Disability, Development & Education, 68*(4), 538-553.

Choudhary, H., & Bansal, N. (2022). Addressing digital divide through digital literacy training programs: A systematic literature review. *Digital Education Review, 41*, 224-248.

eSafety Commissioner. (2020). Online safety for young people with intellectual disability. *Australian Government and eSafety Commissioner*. <https://www.esafety.gov.au/sites/default/files/2020-12/Online%20safety%20for%20young%20people%20with%20intellectual%20disability%20report.pdf>

Fisher, K.W., Williamson, H.J., Guerra, N., & Kupferman, S. (2021). Digital citizenship: Technology access and use for youth with and without intellectual and developmental disabilities. *American Association of Intellectual & Developmental Disabilities Inclusion*, 9(4), 263-275.

Fitzpatrick, I., & Trninic, M. (2022). Dismantling barriers to digital inclusion: An online learning model for young people with intellectual disabilities. *British Journal of Learning Disabilities*, <https://doi-org.cmezproxy.chmeds.ac.nz/10.1111/bld.12494>

Glencross, S., Mason, J., Katsikitis, M., & Greenwood, K. M. (2021). Internet use by people with intellectual disability: Exploring digital inequality – a systematic review. *CyberPsychology, Behavior & Social Networking*, 24(8), 503–520.

Good, B., & Fang, L. (2015). Promoting Smart and Safe Internet Use Among Children with Neurodevelopmental Disorders and Their Parents. *Clinical Social Work Journal*, 43(2), 179-188.

Lough, E., & Fisher, M.H. (2016). Internet safety and online use in adults with Williams syndrome. *Journal of Intellectual Disability Research*, 60(10), 1020-1030.

McCarthy, M., Bates, C., Triantafyllopoulou, P., Hunt, S., & Milne Skillman, K. (2019). “Put bluntly, they are targeted by the worst creeps society has to offer”: Police and professionals’ views and actions relating to domestic violence and women with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 32(1), 71-81.

Mazurek, M., Shattuck, P., Wagner, M., & Cooper, B. (2012). Prevalence and correlates of screen-based media use among youths with autism spectrum disorders. *Journal of Autism & Developmental Disorders*, 42(8), 1757-1767.

Molin, M., Sorbring, E., & Lofgren-Mårtenson, L. (2015). Teachers’ and parents’ views on the Internet and social media usage by pupils with intellectual disabilities. *Journal of Intellectual Disability*, 19, 22–33.

Pangrazio, L., Sefton-Green, J. (2021). Digital Rights, Digital Citizenship and Digital Literacy: What’s the Difference? *Journal of new approaches in educational research*, 10(1), 15-27.

Phillips, P., & Anderson, A. (2020). Cyberbullying, digital citizenship, and youth with autism: LIS education as a piece in the puzzle. *The Library Quarterly*, 90(3), 264-282.

Rocheleau, J.N., Chalghoumi, H., Jutai, J., Farrell, S., Lachapelle, Y., & Cobigo, V. (2021). Caregivers’ role in cybersecurity for aging information technology users with intellectual disabilities. *CyberPsychology, Behavior & Social Networking*, 24(9), 624-629.

Usoro, I., Connolly, T., Raman, S., French, T., & Caulfield, S. (2016). Using games based learning to support young people with learning disabilities to stay safe online. *European Conference on Games Based Learning*, 704.

Verberg, F., Helmond, P., Otten, R., & Overbeek, G. (2022). Effectiveness of the online mindset intervention 'The Growth Factory' for adolescents with intellectual disabilities *Journal of Applied Research in Intellectual Disabilities*, 35(1), 217-230.

Whiteside, N., Cooper, V., Vo-Tran, H., Tait, E., & Bachmann, B. (2022). Digital literacy programs in support of diverse communities – an Australian public library approach. *Journal of the Australian Library and Information Association*, 71(4), 388-407.