Submission to the HUMAN RIGHTS AND TECHNOLOGY PROJECT 2018

PREPARED FOR

Australian Human Rights Commission

PREPARED BY

Australian Rehabilitation and Assistive Technology Association (ARATA)

participation through technology

October 2nd, 2018

Australian Human Rights Commission

GPO Box 5218 Sydney NSW 2001
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Dear Mr Santow,

Re: Human Rights and Technology Project

Please find enclosed our detailed responses to the questions in the Human Rights and Technology Issues Paper.

Yours sincerely,

Dr Natasha Layton, President, ARATA

Emma Friesen, David Harraway, Valerie Watchorn ARATA Members

EXECUTIVE SUMMARY

The Australian Rehabilitation & Assistive Technology Association (ARATA) is a national not-for-profit membership association of assistive technology consumers and practitioners. ARATA is focused on enhancing the lives of people of all ages and abilities through the best use of assistive technology.

The Association is a forum for knowledge sharing between the range of people who are involved with the use, prescription, customisation, supply and ongoing support or training in the use of assistive technology. ARATA represents skilled practitioners, consumers, and suppliers Australia wide and is linked to sister organisations worldwide through the International Alliance of Assistive Technology Professional Associations and the CREATe ASIA Agreement (ARATA, 2012). ARATA has made previous submissions to government:

http://www.arata.org.au/education-resources/publications/

Assistive Technology (AT) is an umbrella term for any device or system that allows individuals to perform tasks they would otherwise be unable to do, or increases the ease and safety with which tasks can be performed. [1] Assistive technology can be anything from a simple device in the kitchen to a wheelchair or a computer application. Assistive technology is vital in enabling participation in society despite the presence of disability. Assistive technology not only minimizes the impact of impairments, but it enables people to:

- enhance their independence
- work and volunteer
- care for themselves and others
- engage in cultural, social, educational, recreational and spiritual lives alongside the rest of the community

ARATA greatly welcomes the opportunity to contribute to the discussion around Human Rights and Technology.

1 World Health Organization (WHO). (2004). A glossary of terms for community health care and services for older persons. Geneva: WHO.

Human Rights and Technology

1. What types of technology raise particular human rights concerns? Which human rights are particularly implicated?

People with disabilities are impacted upon by technology both directly (through their use) and indirectly (through contact with others, service systems, and businesses) throughout their day to day lives.

AI and related information technologies are pervasive across many domains of human endeavour. The move towards AI and Machine Learning (ML) systems and processes has been rapid and appears likely to continue due to both pull (perceived need/usefulness) and the push (underlying market forces) factors.

Areas of great change include Financial Services, Healthcare, Retail, Manufacturing, and increasingly, our own homes and workplaces via the use of Smart Digital Assistants.

These consumer grade technologies and services (which include Social Media and Internet of Things connected devices) are of particular interest to many people living with a disability as they have the potential to provide them with easier access to functions they might otherwise have difficulty performing. While appearing to hold much promise to enrich and enable the lives of disabled Australians, there are also clear implications for individual human rights of smart digital assistants and related technologies.

A September 2018 online survey of ARATA members titled “Experiences of persons with a disability using smart digital assistants and related technologies” was conducted in order to examine member opinions on human rights and assistive technology. The survey consisted of both open and closed questions and sought to identify which systems people were using, what they were using them for, and their concerns (if any). 18 members responded of which approximately half chose to express concerns (via a text field) in relation to Privacy, Personal Safety, Informed Consent, undisclosed third-party use of personal data (for commercial purposes), being manipulated by smart systems (loss of real autonomy of decision making), and (potentially) being profiled by so called “Social Credit” type systems which might eventually lead to access to services and finance being curtailed.

40% of respondents had already experienced a perceived breach of their personal information through use of smart systems, social media and related technologies. This was mostly experienced via unwanted and intrusive advertising of goods and services; but also through more serious breaches of confidential personal information released without consent being provided.

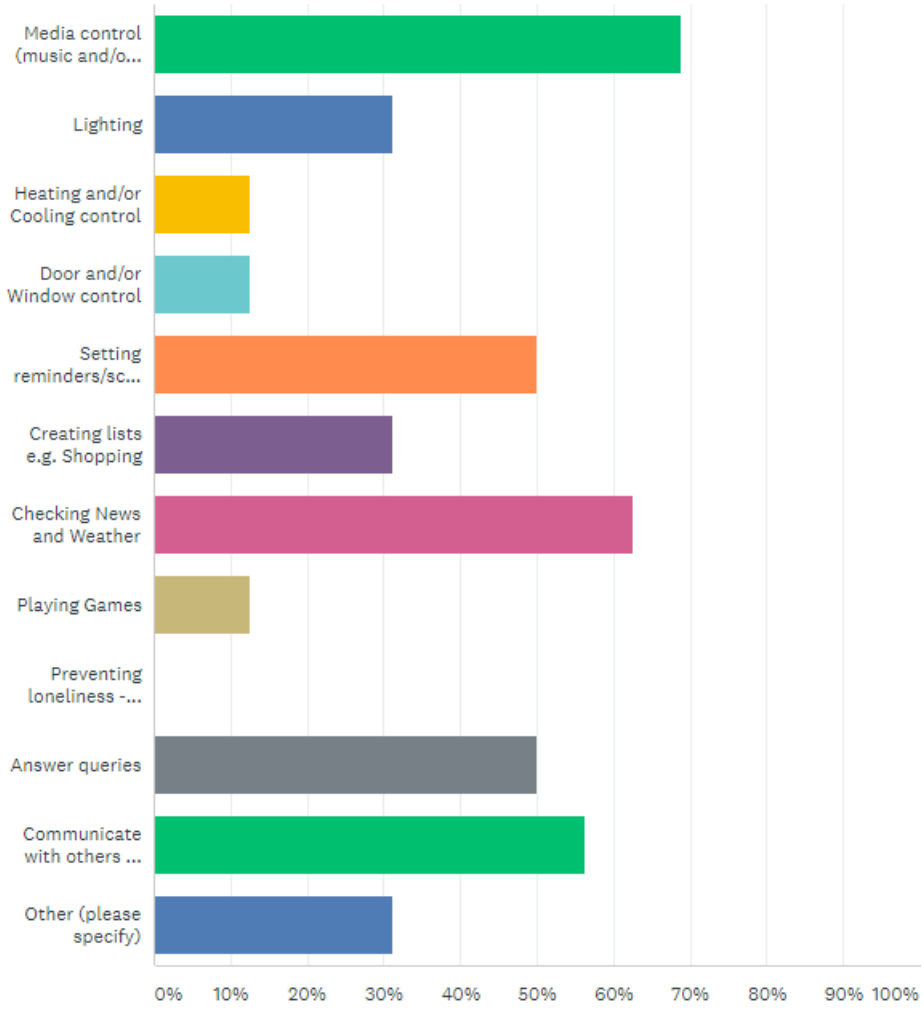
Two people reported negative experiences with their Google Home Mini and Siri. The Google Home Mini user observed their device to be listening without the wakeup command phrase being issued. The Siri user received advertising in their social media feed directly relating to a conversation in their presence of their iPhone the day before.

Despite these concerns, many members reported using their smart digital assistants at least daily (35%) and a few times a week (24%). Google Home/Google Assistant had the largest user base in our community (65%) followed by Apple Siri (32%). In terms of what people did with their smart digital assistants, the following results were obtained.

Q3

What functions do you perform with your digital assistant ?

Answered: 16 Skipped: 2



It was interesting to learn that no respondent reported using their device to prevent loneliness or enhance social inclusion as there is a growing body of evidence that chat bots and similar systems

may have beneficial effects for older people, people living with Intellectual Disability, Autism Spectrum Disorder, Depression and Anxiety. [2,3]

The Right to Informed Consent

Best practice in AT involves the person and their team being consulted and their wishes considered at every step of the AT acquisition process. Informed Consent is a principle ARATA members see as a core tenet of both their practice as allied health practitioners or as consumers and recipients of these services, as articulated in ARATA's Position Papers.[4]

Allied Health Codes of Ethics (AHPRA[5] and NASRAP[6]) all incorporate a requirement for explicit consent to be obtained before commencing with the provision of care for the person. The AT literature also frequently references this as necessary to developing trust as essential component in an effective process of AT exploration.[7]

Companies who provide AI & ML based services require access to the user's personal information. This is typically achieved by the person providing consent in the form of signing an End User License Agreement (EULA) or App Permission by ticking a box at the end of all too frequently opaque long and legalistically worded online form.

Clearly, this form of "consent requirement" may be particularly problematic for people who experience difficulties with comprehension of written language - as their capacity to understand fully what they are signing up for; and to monitor and respond to breaches of their privacy resulting, is often constrained.

ARATA recommends a code of conduct is developed to ensure optimal disclosure, framed for accessibility across diversity types, and adopted by all stakeholders.

The Right to Privacy

As the HREOC discussion paper reports and our members indicated, Privacy is a major concern for many Australians.

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2 Cotten, S.R., Anderson, W.A., & McCullough, B.M. (2013). Impact of Internet Use on Loneliness and Contact with Others Among Older Adults: Cross-Sectional Analysis. Journal of Medical Internet Research, 15(2), doi: 10.2196/jmir.2306

3 Khosravi, P., Rezvani, A., & Wiewiora, A. (2016). The impact of technology on older adults' social isolation. *Computers in Human Behavior, 63,* 594-603. doi.org/10.1016/j.chb.2016.05.092

4 http://www.arata.org.au/education-resources/publications/

5 https://www.ahpra.gov.au/

6 http://nasrhp.org.au/

7 Federici, S., & Scherer, M., J (Eds.). (2017). Assistive Technology Assessment Handbook. Boca Raton, FL: CRC Press.

Several ARATA members expressed concern about the "slippery slope" of erosion of privacy in relation to their use of AI, Social Media etc; and how their personal information may be linked together by government and corporations without the person being made aware of this happening. There are limited protections to the onselling of data in Australia; but these may not apply to overseas companies.

In relation to AT, passive and active monitoring systems in a healthcare at home or residential care setting raise privacy issues. These may utilize a combination of sensors, cameras, and devices.

Monitoring systems may collect data both on the person with a specified need, eg. cognitive impairment but may also collect data on other users of the same environment, eg. personal care staff or visitors.

Movement monitoring systems such as location devices may be used to monitor people's geographical location and may raise concerns around the right to privacy.

ARATA recommends co-production and deployment of an ethical framework for monitoring systems.[8]

The Right to Access AT

Currently AI based Smart Digital Assistant technologies are primarily available in the mainstream / consumer grade end of the marketplace. While this can sometimes have advantages in terms of cost and availability for some people with disabilities and their families, the situation on the ground may more complex for several reasons.

Traditional specialized AT solutions are provided via local expert suppliers. These companies have typically entered the field due to the lived experience of disability (either within their own life or that of a family member or friend). As the AT marketplace in Australia is relatively small (although anticipated to grow to over $1B with the full roll out of the NDIS), expert AT suppliers have needed to adopt a highly customer focussed service model to remain viable. This means that they, almost without exception, know their product range inside and out - required to make solutions work effectively in the lives of AT users. As ARATA members know all too well, AT provision is always more than about the product aka the "hard technologies", the support systems around solutions aka "the soft technologies" are frequently just as, if not more, necessary for the desired outcome to be obtained.[9]

[8] Chung, J., Demiris, G., & Thompson, H. (2016). Ethical considerations regarding the use of smart home technologies for older adults: An integrative review. . *Annual Review of Nursing Research., 34*(155-X10). doi:oi:http://dx.doi.org/10.1891/0739-6686.34.155.

[9] Waldron, D., & Layton, N. (2008). Hard and Soft Assistive Technology: defining roles for clinicians. *Australian Occupational Therapy Journal, 55*(1), 61-64.

Another important aspect to access is awareness of options so an informed choice is able to be made. Historically in Australia this role has been fulfilled well by the Independent Living Centres who provide impartial information and advisory services for AT to the whole of the community. They have a long and proud history of building community capacity and connecting various parts of the AT world together. They do this in various ways:

1. by providing advice over the telephone or email to people with disabilities, their families and friend, novice and expert AT practitioners, and even supporting those who are wishing to enter the AT marketplace with a new product or AT related service;
2. by contributing to the National Equipment Database[10] which provides up to date information on AT products and services and where to get them;
3. by educating novice and experienced AT practitioners in AT process and practice via various training events and workshop;
4. through co-production with consumers of AT.

Unfortunately, these services are now under threat because of the way they are funded by the States in the context of the transition to full NDIS roll out. Without adequate funding to sustain operations, it is conceivable that what has been a highly regarded and effective service to all Australians who choose to use it, will be either greatly diminished or disappear.

Unless Australians have access to high quality unbiased and impartial information services, their awareness of options will be limited to just an internet search or what someone near to them may have liked; and their decision making and access to best possible solutions is restricted.

Assistive Technologies are variously funded by over 50 separate entities across Commonwealth, State/ Territory and other levels of government within Australia (see ARATA's AT Funding Map[11]). This complexity itself leads to the need for information and referral by expert assistive technology services. In addition, historically mainstream technologies have actually relatively been more difficult to obtain via State based AT funding schemes (as they are seem outside the remit of these Schemes) than specialized solutions. The NDIA test for what is reasonable and necessary is being interpreted by some as restricting access to what may be the most appropriate system as mainstream solutions used as AT are sometimes considered to something the person should just purchase for themselves. While ARATA members appreciate that the NDIA is required to operate according to the legislative guidelines established by the Act - we are also wanting to see the widest range of AT choices available to people with disabilities.

AI based systems require connection to the internet. People with disabilities are known to experience a lower rate of internet connectivity for various reasons including ongoing cost. Funding bodies have been reluctant to fund internet access for people with disabilities, as this is seen as general cost of living. Internet access in Australia is still impacted upon by geography and is patchy or very expensive still in many places. The reports of recent attempts by the NBN to alter how

[10] https://ilcaustralia.org.au/search_category_paths
[11] http://www.arata.org.au/access-&-funding/funding-your-at/

people in rural and remote areas receive access (when compared to higher density urban areas) were of concern to ARATA members as we are aware that when someone relies on their device to maintain participation in life; and has no other means of doing so, the lack of internet access by people with a disability is experienced in a disproportionately greater way than by other citizens without a disability.[12]

The Right to Accessible Environments and Information

As a signatory nation, Australia has international obligations under the UN Declaration on the Rights of Persons with Disabilities (Article 9). The definition of Accessibility includes information systems (b) as well as the physical environment (a) in which Australians live their lives. These obligations typically refer to public spaces and services; but there are also requirements to

b) ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities; and

f) promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information.

Smart Digital Assistants may in fact be more accessible for some users; however it is ARATA members experience that this is certainly the case not for all. Many devices and system utilize voice input as their primary means of control to get to necessary functions. This partially or wholly excludes people with complex communication needs (CCN) who experience difficulties with their intelligibility of speech and/or underlying receptive or expressive language. While alternatives such as keyboard entry (eg Type to Siri or into Google Assistant exist), these also may not work for some folk, due to the physical access or cognitive barriers presented.

ARATA therefore recommend the Federal and State governments continue to fund impartial and expert information services (Independent Living Centres) into the future as it is our experience that the need for these has never been greater

12 Thomas, J, Barraket, J, Wilson, CK, Cook, K, Louie, YM & Holcombe-James, I, Ewing, S, MacDonald, T, 2018, Measuring Australia's Digital Divide: The Australian Digital Inclusion Index 2018, RMIT University, Melbourne, for Telstra.DOI: https://doi.org/10.25916/5b594e4475a00

2. Noting that particular groups within the Australian community can experience new technology differently, what are the key issues regarding new technologies for these groups of people (such as children and young people; older people; women and girls; LGBTI people; people of culturally and linguistically diverse backgrounds; Aboriginal and Torres Strait Islander peoples)?

As stated above, being able to understand exactly what signing up for a service may be a challenge for many prospective users. The allure of these technologies can be very compelling however. Many ARATA members can recall the early days of iPads and how often these were seen by some as a universal solution for their issues; and were attractive in part because many others had them. This wanting what others have is a common experience for many people regardless of their disability and in some cases, the iPad and other tablets have been transformative in what they have offered for communication, education and to manage important functions such as calendaring, reminders, and scheduling.

ARATA propose an evidence based approach to Assistive Technology seek to balance a range of considerations, of which psychological factors are seen as significant; but also needs to be viewed in context.

c) What principles should guide regulation in this area?

Universal/Inclusive Design - design of technology for the use by the greatest number of people despite differences in ability, size or age. [13] The principles of Universal Design must be embedded within the design of online tools and environments. Federal Government agencies such as the NDIA could adopt purchasing and procurement policies that promote flagship examples of excellence in local inclusive design. This would require some of the current well-known restrictions on the agency (overly restrictive budget and staffing caps) to be addressed. Other large governments departments would need signals to move from a lowest cost to a best quality local product and services approach also.

4. In addition to legislation, how should the Australian Government, the private sector and others protect and promote human rights in the development of new technology?

Ongoing government consultation with a diverse range of users with differing sensory, physical, communication and cognitive abilities is needed to ensure that their requirements are represented in decision making that shapes the AT marketplace.

One of the key tenets of the NDIS AT Strategy was to encourage the development of a vibrant and diverse marketplace for AT. Establishing specific incentives for companies to utilize inclusion

[13] universaldesignaustralia.net.au/

strategies for workers with disabilities (eg. in consultancy roles where they could use their lived experience to inform the design of new AT) would serve to encourage and educate the marketplace. More workers involved in AT achieves cultural change throughout and promotes consideration of Inclusion as the starting point in product and service design.

5. How well are human rights protected and promoted in AI-informed decision making? In particular, what are some practical examples of how AI-informed decision making can protect or threaten human rights?

A well-designed AI could assist with consent by a range of users by configuring its interface to match requirements, actively asking and confirming understanding throughout the setup process, and providing notifications/calls for more information to human advocates or assistants where these may have been allocated. It is possible that an AI might be able to do this in a more impartial and less "attached to outcome" way than a human mediator. The AI could record this exchange and save it off site which may serve as an objective record in case of dispute.

Threats to human rights may be around limitation of choice- the AI menu may not be sufficiently robust to appreciate nuances of human interaction.

Accessible technology for people with a disability

8. What opportunities and challenges currently exist for people with disability accessing technology?

ARATA members either work with, provide services and support to, or are part of Australia's diverse disability community themselves. As such we are often at the coal face of how people with disabilities are navigating the changing world of technology.

Chris, one of our members asked to share his story for this submission and reported he is happy to be contacted at a later date if this would be helpful to the Commission:

> "I am a C3 quadriplegic so I automated the entire house. Lights (including dimmer settings), fans, air conditioner, elevator, air conditioning and audio visual equipment. The AV equipment includes TV, DVR (including navigating menus and recording shows), home network hard drives, Netflix, YouTube etc. By automating I mean everything is controlled by voice through Google home and currently working on Amazon Alexa (Alexa needs a VPN for some options which drastically reduces the speed and accuracy, so I have mainly been using Google home). everything can also be controlled by my smart phone by tapping icons all by scrolling through the menus using a single switch scrolling method. We also tested my home using the Apple watch which worked really well. The differences automation makes to the lived experience is huge. Instead of having to call people I can just ask Google to do

whatever I need. This is particularly important in the middle of the night. If I wake up feeling hot I can turn on the bedroom fan or air conditioner I can turn on and off the TV, movies or music if I can't sleep. “

Another member shared this practice story of Nick whose system was also working well for him and his family :

> “Nick is 78 yrs old. Lives in family home with his wife who is his main carer. Limited literacy with English and Greek. Has Progressive MS. Uses a powerchair, drives via joystick controller; but limited hand function now. Fatigues rapidly. Speech is mildly dysarthric; but remains intelligible to familiar partners throughout his day.Family set him up with Google Home & Chromecast,Logitech Harmony Hub, Philip Hue lights. With this system Nick is able to turn his Smart TV on and off, change channels, play radio stations, turn lamps in the lounge and bedroom, on and off, and make shopping lists. His family set scheduled voice reminders for him to remember to have a drink from his straw as well and use the broadcast feature to send him a message of reassurance so he doesn’t worry so much about when they are coming home. “

Another recent experience is how some Speech Generating Device (SGD) users in Australia and overseas have been able to operate their Smart Digital Assistants successfully via voice output from their speech generating devices when setup to do so by their support people(as these can store the required command words and the person can speak them out but selecting them from the SGD). This novel solution for Accessibility is an excellent example of how people with disabilities wish to be included in the mainstream technology they see around them, and how resourceful and expert supports can make such inclusion possible.

While those are clearly success stories, there are still structural barriers and inequalities for many people.

These are well known to ARATA members in their day to lives. Typical issues faced in the AT Sector are:

- Lack of resources (money and time);
- Reduced access to service systems such a funding bodies due to lack of transparency and consistency of approach (different people are affected differently depending on location and local interpretation of rules eg people’s NDIS experience around AT has varied and continues to do so greatly);
- Workforce capacity issues due to lack of retention of experienced staff, geographic isolation (city - country divide) and demographic change;
- Long wait times for equipment to be funded, sometimes so long that the person’s needs or living circumstances have changed and the equipment is not longer suitable or required. This can be expensive; and
- Lack of ready and continuous access to quality information and advice to drive informed choice (see previous point about threats to State Independent Living Centres.

There is scope within the new technologies to enable improved access by people with intellectual and other cognitive and learning disabilities. For example, it seems likely that AI based smart digital assistants will eventually be calibrated/ able to calibrate themselves to better match specific and individual requirements. Potentially over time the AI "guide" will learn to adapt and guide the user based on their interactions. As with human partners now, this process needs to be carefully managed and provide scaffolds of tasks which are sensitive and responsive to a wide variety of factors, including learning preferences, affective and sensory changes, and safety. Other exciting possibilities include context specific assistance menus push delivered via Augmented Reality glasses to aid people with autism and other learning disabilities to negotiate and navigate challenging situations with more confidence. An AI "guide" could level the playing field for people with cognitive, communication or print disabilities. These functions are currently possible (eg. Microsoft's Seeing AI app) but still in the early days. It may be that a human backup or alternative to the AI is preferred. The Be My Eyes app uses a network of human volunteers; but one day soon could be AI assisted. Although this service is pitched towards blind and vision impaired users, it is also available for people with severe print disabilities or major literacy difficulties.

9. What should be the Australian Government's strategy in promoting accessible technology for people with disability? In particular:

a) What, if any, changes to Australian law are needed to ensure new technology is accessible?

Accessibility tools are already available to many developers but sometimes aren't used because of ignorance of need or attempting to save money or time. Mobile apps can vary greatly in quality.

Therefore, ARATA proposes a national education campaign with IT industry stakeholders around Accessibility. This could be auspiced by the NDIA in partnership with others.
Big tech companies already employ Accessibility teams; but many smaller developers and manufacturers do not. This would be an opportunity for employment for some people with disabilities to serve in the role of expert consultant/ peer mentor and a resolution would feed into greater legislated requirements for app developers to comply and maintain compliance with Accessibility Standards.

We also propose that there be mandated requirement for Plain English and/or Symbol supported or Voiced explanation of App Consent EULAs with clearly detailed explanation of risks and consequences along with an extended cooling off period for paid apps and services to allow users to opt out without adverse consequences.

Conclusion

ARATA appreciates the opportunity to contribute to the national discussion on this very important topic. We hope our submission assists HREOC in establishing an appropriate and measured response to the promise and challenge of advanced technologies such as artificial intelligence (AI) for Australians living with a disability and those providing supports to them. It is ARATA's position that access to well considered and implemented Assistive Technology is in accord with the human rights of people with disabilities in order to lead full participatory lives