Technology as an Extension of the Self: Socialising Through Technology for Young People with Autism

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Abstract. Technology has a profound impact on the well-being of young people with autism. Through technology, they are able to socialise, learn and gain sensory relief, creating positive communication experiences and self-conceptions. Using qualitative participatory methods, this research illustrates how The Lab, a technology club for young people with autism, enables individuals on the spectrum to socialise beyond the perceived limitations of their disability through the use of technology. The findings of this research suggest that technology can provide young people with the avenue to learn, practice and define their own sociality, defying the medicalised notion of autism.

Keywords: Autism · Technology · Video ethnography · Online participatory ethnography · Socialisation

1 Introduction

"all technologies are extensions of our physical and nervous systems… Any extension, whether of skin, hand, or foot, affects the whole psychic and social complex." – McLuhan (1964), p. 4 & 90

The well-being of individuals with autism has been closely linked to technology. From a medical perspective where disablement for individuals with autism is in part characterised by the inability to communicate and socialise, the use of technology is linked to the notion of the cyborg (APA 2013; Campbell 2009). Drawing from Haraway's (1999, p. 272) 'cyborg manifesto' where she critiques that humans have become cyborgs, a "hybrid of machine and organism" that condenses the "image of both imagination and material reality", disability scholars such as Campbell (2001, 2009) and Garland-Thompson (2015) argue that the use of technology by disabled persons is a way of internalising ableism to create the "perfect body". In Foucault's term, 'technologies of self':

"Permit individuals to effect by their own means, or with the help of others, a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality." (Foucault et al. 1988, p. 166).

A physically disabled person may, for example, require prosthetics to help them gain the ability to walk or perform specific labour – attaining a "state of happiness" in accordance to the rules laid out by our ableist society. In the case of autism, assistive-technologies such as visual learning tools aim at helping individuals with autism learn communicative, speech and social skills. In other words, the use of technology from this perspective hopes to compensate for autistic behaviours. The medical model views impairments and unusual behaviours such as those exhibited by individuals on the autism spectrum as deficits (Baron-Cohen 2002) – assuming the existence of the "perfect body" and viewing technology as a viable means for achieving this state of being. The role of technology then is to be applied and used in a directive way, similar to how perceived within education (i.e. as a tool for learning - see Sect. 4.1).

On the contrary, from a social constructionist perspective, disability is seen as a social construct where ideologies, governance and policies contribute to the disablement of people rather than their impairments. The use of assistive-technology has sometimes been regarded as a fallacious argument for improving the lives of these individuals. Instead, it strengthens the ableist rhetoric, "a set of assumptions (conscious or unconscious) and practices (e.g. use of technology) that promote the differential or unequal treatment of people because of actual or presumed disabilities" (Campbell 2009, p. 4). Nonetheless, disability scholars admit that access to technologies for people with disabilities is still important as it has the potential to incorporate inclusion and "create wide new vistas for civic engagement, education, employment, and social interaction" (Jaeger 2012, p. 33). Within the social constructionist perspective, people with impairments or unusual behaviours are disabled by the ableist culture produced and reinforced by the medical paradigm. Technology in this instance is adapted and used as a form of resistance or communication rather than compensation.

While these two perspectives seem to present polarising arguments, they demonstrate the importance of technology to people with disabilities. They reveal that impairments affect the lives of people in both tangible and intangible ways because it creates inconvenience perpetuated by discrimination. While sociality, referring to "the social processes through which [individuals] develop an awareness of social norms and values and achieve a distinct sense of self", is a constructed view, the discrimination and stigma faced by young people with autism is real and affects their state of well-being (Giddens and Sutton 2014, p. 69).

Therefore, there is a need to address both the immediate and practical means of relieving individuals with disability from discrimination while at the same time, enabling them to progressively change the disability rhetoric through the use of technology to improve their well-being now and in the future.

In this paper, I will be using the case study of The Lab, a technology club for young people with autism, to illustrate how the use of technology can enable them to socialise beyond the perceived limitations of their disability.

2   The Lab and the Research Project

The Lab is a network of technology clubs for young people between ages ten and 16 who are on the autism spectrum. It is a not-for-profit organisation which currently runs 12 sites around Australia.

Each site runs weekly two-hour sessions facilitated by two or three young and tech-savvy mentors who may be graphic designers, game developers, etc. During the sessions, participants of The Lab are encouraged to bring in their personal laptops and learn computing skills from the mentors. In the event where participants are unable to bring in their laptops, computers are made available on-site. The Lab emphasises on self-motivated, interest-based learning where the young person is responsible for his/her education. Hence, participants of The Lab are free to engage in any technology-based activities such as coding, gaming and robotics. Some young people, for example, may prefer watching YouTube videos or playing games for the week and resume learning computing skills another time. Unlike a classroom, learning and teaching (by the mentors) are casual and unstructured.

As the mentors have different skills and the physical spaces of The Labs vary from one site to another, over time, each Lab has been observed to develop its own culture. Having visited a few Labs myself and interacted with the young people, I found that while the activities differed from each lab, they showed consistent positive interactions between peers and mentors.

An evaluation of The Lab by Donahoo and Steele (2013) suggests that, contrary to prevailing knowledge, young people with autism are able to socialise within this shared environment. The evaluation found that The Lab has provided an avenue for these young people to relax and make friends, some for the first time, which has had a direct impact on their emotional and mental health. Parents have reported the reduction of anxiety and anti-depressive medication for their children since attending The Lab. In some instances, the child has reportedly reduced the infliction of self-harm or self-blame since then as well.

Two mitigating factors were attributed to the success of The Lab. Firstly, the utility of a combination of unstructured physical and online spaces gave Lab members mobility and the freedom to interact, learn and play at their own pace. Secondly, the unrestricted use of a variety of technologies brought in by mentors, parents or participants enabled young people at The Lab to explore their interests and learn through sharing with peers and mentors.

Informed by these observations, the broader aim of this research is to understand how physical, online and psychosocial spaces, theorised as *differentiated spaces*, enable young people with autism to socialise and develop interpersonal and technology-assisted relationships (Ng et al. 2015). Within which, it looks at how young people perceive themselves and their autism, learn skills to communicate and socialise through experiences at The Lab and online, as well as develop positive self-conceptions, self-esteem and identity. I will specifically be focusing on how technology and the online space enable young people with autism to communicate and define their own sociality within this paper.

3   Methodology

In this research, three qualitative methods were used to understand how young people with autism socialise within The Lab. They were namely participant observation, video ethnography and online participatory ethnography. These methods were largely used in

an adaptive and participatory manner where participants were encouraged to give input and feedback throughout the data collection phase.

According to MacLeod et al. (2014), participatory methods "sought to overcome barriers to [research] participation" for autistic people who are often deemed as "problematic" to communicate with. This was in line with an evaluation of The Lab where Donahoo and Steele (2013) found that traditional forms of qualitative research imposed stress on participants. Therefore, the choice of qualitative methods were used to mitigate this stress by building relationships with participants and placing them as equally important in their input as the researcher within the project (Mertens 2015, pp. 25–27).

3.1   Video Ethnography and Participant Observation

Video ethnography is the video recording of a stream of activities engaged by subjects in their natural setting, in order to experience, interpret, and represent culture and society (Pink 2007, p. 22). Apart from aiding the researcher in recording data, the process of video ethnography enables participants to present a specific and detailed narrative of their disability (Pink 2012; Harris 2016). While the presence of the video camera involuntarily affects the way participants react, it gives them the opportunity to present their best qualities for the recorded material (Pink 2012). Together with participant observation, it enabled me to holistically understand participants and their activities at The Lab, learning the nuances within their speech and body language.

A total of 31 members of The Lab participated in this part of the research which took place over three Australian school terms (or approximately 36 weeks). They were asked to continue with their routine activities at The Lab while I observed, interacted and videoed them. All observations and interactions were noted in a diary after each session. Together with the video transcriptions, they were analysed through critical discourse analysis. This segment was particularly interesting as the young people often negotiated with me on when and how they wanted to be videoed. They asked questions such as "Will this be published on YouTube?" or "Can you film me from a distance instead?" which brings up interesting discussions about online personas and image, and technology as a form of surveillance. Some of these discussions will be highlighted in the next section.

3.2   Online Participatory Ethnography

Online or "virtual ethnography" is an adaptive form of ethnography using digital tools within an online community (Steinmetz 2012). "Participatory" refers to two different aspects of participation in this case. Firstly, it was conducted in a consultative process through feedback sessions – even the theme of project was negotiated as a group. Secondly, instead of studying an established online environment which is often the case in virtual ethnography (Steinmetz 2012), participants were requested to build this online environment. This was in-line with The Lab's ethos of self-motivated and interest-based participation and was welcomed by the participants.

16 members of The Lab participated in this phase of the research which took place over one Australian school term (or approximately 12 weeks). Participants were asked to create an online world within Minecraft, a 3D sandbox simulation game, in teams of two to four under an agreed upon theme (e.g. Build a useful application/graphic for the specific Lab – Some participants went on to create a banner for the official Facebook page). I was given access to their worlds to observe and participate in their projects. Each fortnight, I would go around the teams to discuss their progress, some of the problems they may have encountered and understand their process of communication. The overall results suggest that members of the team had to maintain communication with each other online - beyond just the game space or the physical space of The Lab – to spark continual interest. Many teams ended their projects prematurely as they felt that there was a lack of communication and enthusiasm between team members. Generally, team members who were able to text each other over mobile phones (i.e. Older participants), or used the same online messenger programmes such as Skype were able to complete their projects – bringing into question as to how accessibility to specific technologies may affect the way young people with autism learn to communicate and socialise.

4   Findings and Discussion

The overall findings reveal that communication and socialisation through online and mobile technologies are equally important and impactful on young people with autism in comparison to physical communication which is often prioritised in understanding sociality (Giddens and Sutton 2014). Walking into The Lab, you often see young people talking to each other while texting on their phones and messaging on Discord or Skype. They travel between and within multiple spaces at the same time, learning to socialise as they communicate on different platforms. In many cases, the ways they communicate in online and offline spaces are more similar than different within the context of The Lab. Socialisation is no longer one-dimensional within the relativity of time and space but rather, it occurs simultaneously within multiple spaces and "screens" across different time zones (Merriman 2012). Therefore, there is a need to redefine sociality with the inclusion of technology. Technology has changed our attitudes, behaviours and patterns of communication, both positively and negatively, and it should be regarded beyond simply tools that are used to improve performance, enhance learning, etc. – the implication here being that they are separate rather than integral aspects to our lives. As suggested in the beginning of this paper, technology has become an extension of the self. This is supported by the findings of this research presented below.

4.1   Learning Through Simulation

Young people with autism have been observed to emulate behaviours and speech from what they learnt online.

Learning by simulation or simulated-learning is not a new concept. It has been used in education, particularly in higher education, to "replace and amplify real experiences with guided ones, often "immersive" in nature, that evoke or replicate substantial aspects of the real world in a fully interactive fashion" (Lateef 2010, p. 248). Lateef (2010) argues that it is a "technique" as opposed to a form of "technology" – although he acknowledges the role of technology in enhancing this technique. This is similarly implied by Clayton and Gizelis (2005) and Zigmont et al. (2011) where simulation, a form of role-playing that can occur within physical or online settings, is used as a method of teaching. It assumes that learning through simulation is directive rather than organic. Similar to the medical model of personhood, technology is seen as a specific tool built for an explicit purpose: teaching. However, the results of my research at The Lab reveal that young people with autism learn social and communication skills through simulating gameplay. This is often constituted under the behavioural effects and impacts of gameplay; a common rhetoric, for example, is that playing violent games lead to aggressive and addictive behaviours (Griffiths 1999; Anderson 2004). While these behavioural changes may be seen as consequences of playing games, they are nonetheless a form of learning – albeit not with the common, positive connotations of learning.

During one of the sessions, I sat with a 10-year-old child playing Emily is Away, a narratively-based chat game where you either pick preprogrammed lines or type in personal responses to engage in a conversation with the computer-generated character, Emily (Fig. 1).

This child developed a romantic relationship with Emily within the game through choosing lines that he did not seem to fully understand. At some point, he turned around and asked me if these were speech you would normally use to pursue a girl.

In other instances, young people at The Lab often speak in a similar fashion to the way they communicate online. Aside from shorthand such as "LOL", "BTW" or "BRB", they also learn to negotiate through trading online. On Minecraft servers, for
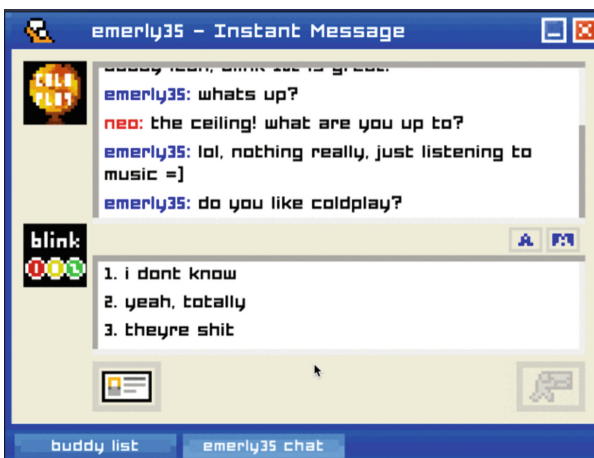

Fig. 1. An ongoing game of "Emily is Away"

example, young people at The Lab learn simple sentences and phrases through reading ongoing chats online (e.g. "You sell armor?", "How much?", "You trade weapons?"). This is sometimes reflected in their conversations at The Lab where they speak in a relatively condensed and abrupt manner.

These examples illustrate the impressions online conversations and communication may have on young people, especially those on the spectrum who may be unable to discern between what is acceptable speech on a day-to-day basis. Some young children with autism have been reported to have negative or very little interactions with their peers face-to-face (Donahoo and Steele 2013). Thus, they may begin to speak or behave through simulating their positive experiences online, injecting shorthand into their speech or engaging in conversational styles similar to that of their online communication. This will be further explored in my next point.

4.2   Network Sociality and Beyond

Inspired by Manual Castell's work on network society, Wittel (2001) conceptualised the term 'network sociality' – a form of socialisation enabled by technology that is largely interest-based and requires lower commitment in comparison to traditional notions of socialisation and communication. It enables people to socialise within extensive networks focused on individual connections rather than membership-based, exclusive communities. Wittel's 'network sociality' suggests that we communicate at high levels of intensity on a need basis, similar to that of a social contract between two or more people. He argues that this is because of the way we connect with each other online which is largely through networks rather than communities.

This is evident not just within the online space but also the physical space of The Lab. While some young people develop friendships that extend beyond The Lab, most interact solely within the sessions based on the activities they are engaged in.

A group of young people, for example, have been working on their Minecraft world for over a year now. While they continue doing so in their own time, my conversations with them indicate that do not communicate with each other much except through in-game messaging when necessary. However, when they are at The Lab, they converse intensely, discussing issues from their personal lives to their individual progress on the world with much enthusiasm, comparable to the likes of what we traditionally understand as "best friends". Within The Lab sessions, they have also drawn up plans, lists and sketches for what needs to be built in their Minecraft world. However, in-game building is often worked on individually and anyone who is trusted by the players are free to join.

This form of physical and online interactions mirror Wittel's concept of network sociality. Any form of communications is done in short-bursts (i.e. at The Lab sessions) and with great intensity. They communicate base on common interests or on a need-basis, concerning him- or herself to individual activity or person rather than a group or community. However, beyond the weekly meetings, members keep to themselves and have low commitment to each other.

This re-enactment of Wittel's 'network sociality' within both physical and online spaces urges us to rethink the definition of socialisation once again.

4.3   The Physicality of Technology

Unlike other spaces, the online/digital space is mediated and requires a physical medium. Therefore, in understanding sociality through technology, the physicality of medium must be considered.

Disability geographers Davidson and Parr (2010, p. 72) argue that the online space is enabling because individuals with autism are able to interact without the nuances of physical communication such as body language, eye contact and emotional cues. Similarly, within the physical space of The Lab, young people with autism have used their screens as a way to avoid these nuances of physical communication. For instance, two young people may be sitting beside each other but interacting silently through online means. In other instances, the young people may be chatting without ever looking directly at their peers. Instead, their eyes are concentrated on the screens in front of them. One young person often talks to someone in between talking to his console or laptop – he would comment on his game (e.g. Come on! You can win this Pikachu) and interject with a reply to someone else's comments or conversations then return to talking to himself/the console or laptop.

The physicality of technology creates a form of distraction for these young people who gain sensory relief (i.e. keeping eye contact to the minimal) while simultaneously engaged in conversations. It enables them to express themselves within a physical setting without having to comply with the general rules of physical communication. This form of communication is not limited to young people with autism and demands a redefinition of the social norms guiding communication. When some parents enter the room, they demand their child to look at them or the mentors while talking to them. In their perspective (and many others within mainstream society), making eye contact while speaking to someone is polite. However, for individuals on the spectrum, the presence of the technological medium enables them to overcome some of the physical discomfort from sensory overload and effectively converse or communicate to others in their means. Therefore, we need to expand and rethink what we understand to be socially acceptable, or "polite", forms of communication so as to create a more inclusive society.

On another front, the physicality of technology may also impede communication. While I was videoing the sessions, some participants were visibly nervous or unusually quiet and composed. Others asked questions about what I was using the footage for and if I could delete certain sections of it. The video camera hence became an imposition on their freedom; it became a surveillance tool. According to Davidson and Parr (2010) as well, the physicality of technology and the online space may also restrict people with autism from wanting to learn and communicate with others who are not on the spectrum as they may retreat into their comfort zones, creating exclusive groups and communities rather than trying to be included by others who are different from themselves. The intricacies and complexity of technology call for more considerations to be taken into account when analysing their use as a medium for communication.

5   Conclusion

In McLuhan's (1964) most influential works, he discusses technology as an extension of the self and the human body. Although McLuhan wrote his research 30 years before the World Wide Web (WWW) was created, he prophesied the potential of web technology as an "extension of consciousness" that would include "television as its content, not as its environment", where information retrieval and communication would be enhanced and "speedily tailored" (cited in Guertin 2012, p. 39). He implores us to understand technology beyond simply a tool, but an amplification of ourselves that have broader social consequences. McLuhan's theories were exemplified at The Lab where technology has become an integral part to its members' ability to communicate and socialise – beyond the perceived limitations of their disability imposed by the medical view of their differences.

In my research, technology has demonstrated itself to be an extension of these autistic youth's individual psyche and mode of communication and expression. Through technology, they are able to learn and emulate patterns of interaction and create different styles of communication that are both comfortable for themselves and their peers around them. In the process of which, they illustrate how Wittel's concept of 'network sociality' can transcend between physical and online spaces, calling upon us to rethink and reconceptualise notions of sociality with the inclusion of technology as an integral part of communication and life.

Ringland et al. (2016, p. 1259) similarly found through their analysis of an online gaming platform and forum dedicated to young people with autism that "members of the [community] search for, practice, and define sociality". This view is confirmed by my research at The Lab.

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