

**Adults with Intellectual Disabilities' Lived Experiences of Well-being  
and the Internet: A Descriptive Phenomenological Study**

While internet use continues to increase amongst the general population, in comparison, adults with intellectual disabilities are still less likely to access the internet and benefit from the opportunities it can offer. Non-intellectual disability perspectives and assumptions, which often view the internet as a risk for those with intellectual disabilities, are considered over the everyday lived online and well-being experiences of adults with intellectual disabilities. In response, this study interviewed 8 participants with intellectual disabilities using a descriptive phenomenological approach. Seven constituents emerged: internet as a mirror; internet enables visibility and invisibility; internet as liberating; internet meets unmet needs; internet creates an active decision maker and expert; internet as friend and foe; and, the body connects to, and disconnects from, the internet. The findings gave rise to new perspectives, recommendations, and adds to the existing literature on how to support adults with intellectual disabilities' enjoyable, safe and independent internet use.

Keywords: intellectual disabilities; learning disabilities; well-being; internet; descriptive phenomenology; online gaming

#### Points of Interest

Participants with intellectual disabilities described feeling restricted and unsafe in their offline lives, but online they often felt they could do anything and more safely.

Participants did not view their intellectual disability positively. Online they could keep their disabilities hidden from others, creating a variety of identities (creative, strong, protective and helpful) that they felt represented them more accurately.

When the internet was described as a positive resource in life, this was linked to a sense of well-being with an identity emphasis. Additionally, findings point to examples of well-being in spatial, embodied, mood, sense of belonging with others and temporal ways.

This study highlights how danger was negotiated by people with intellectual disabilities in similar ways to dangers in everyday life and how these skills are transferable to off- and on-line worlds.

## Introduction

Well-being has been described as an ‘intangible’ (Thomas 2009, 11), ‘complex, multi-faceted construct that has continued to elude researcher’s attempts to define and measure’ (Pollard and Lee 2003, 60), giving rise to ‘blurred and overly broad definitions of well-being’ (Forgeard et al. 2011, 81; Dodge et al. 2008). The struggle to define well-being is not new; in ancient Greece, philosophers were also equally perplexed with the complexity of ‘well-being’ and how it should be defined, achieved and maintained (Vernon 2008). From phenomenological-philosophical tradition, well-being can be viewed as a way of being-in-the-world and how this is felt as an experience (Husserl [1936] 1970; Heidegger [1927] 1962; Boss 1979; Merleau-Ponty [1945] 1962). In this view of well-being the way in which everyday life is experienced is pivotal, rather than, in contrast, a deficit model of well-being that focuses on ‘what is missing’ from life whether that be physiological function, economic, emotional or environmental supports (Ashworth 2003; Galvin and Todres 2013). Well-being is given by the experience of time (temporality), space (spatiality), our bodies (embodiment), connections with others (or not) (intersubjectivity), selfhood and mood<sup>1</sup> (Galvin and Todres 2013). In this sense, well-being is an invisible and taken for granted state, only brought to our attention when it is disrupted or becomes absent (Vernon 2008; Galvin and Todres 2013). Well-being, as a human experience, is something a phenomenological perspective would consider beyond simplification and a one-fits-all definition (Laing 1967; Seamon 2018a, 2018b). This view opposes, what Ritzer (2011)

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<sup>1</sup> The lifeworld ‘has certain essential elements that cannot but be expected to show themselves... [Ashworth] termed such elements “fractions” because these are not independent categories or parameters or perspectives. Rather, they are mutually entailed, with overlapping or interpenetrating meanings.’ (Ashworth 2016, 23).

describes as, the McDonaldisation of health services which approach well-being and illness as calculable, predictable and sub-dividable for efficiency and controllability, consequently reducing patients to ‘merely consumers of services’ (Galvin and Todres 2013, 39). There has been a call for a more existential understanding of well-being to protect against the inadvertent dehumanisation of patients in health care, including those with disabilities or impairments, through ‘unreflectively assuming that health is just the absence of illness’ (Galvin and Todres 2013, 39; Lovell 2010).

Based on the philosophical view of being human and its ‘existential notions of freedom and vulnerability’ (Galvin and Todres 2013, 40), an existential theory of well-being was developed by Galvin and Todres (2013) characterised by a sense of adventure and a sense of homelike settling. This encompasses both the possibilities of movement (mobility) and peace (dwelling), alongside meaningful life projects, as ‘cornerstones’ to an existential and lifeworld-orientated view of well-being.

Movement (existential mobility) being the ‘capacity... of being able to move into possibilities of engagement that connects us with others, other spaces, other times and other moods’, and peace (existential dwelling), also described by Heidegger as ‘homelessness’, as the ‘experience of ‘settling’ and ‘being at home’, where one comes to rest with... how things are’ (Galvin and Todres 2013, 40-41; Merleau-Ponty ([1945] 1962, [1964] 1968, [1960] 1987; Heidegger ([1927] 1962). It is not possible to unfold the nuances of these ideas in full in the present paper, but readers are referred to ‘Living well to the end: A phenomenological analysis of life in extra care housing’ (Shaw et al. 2016), ‘Making well-being an experiential possibility: the role of sport’ (Mayoh and Jones 2015), ‘Women’s Experiences of Embodied Identity through Active Leisure’ (Mayoh, Jones and Prince 2020) where the theory and phenomenological orientation has been applied in a range of health and social care situations.

The internet is having an ever-increasing influence over our lives, including well-being, and it has become progressively interconnected with and simultaneously a creation of the online users that inhabit the internet and their interactions (Wallace, 1999). This has developed an awareness of the internet as being inherently entwined with human relationships off- and on-line, 'a new, culturally valued cognitive tool' (Young 2008, 174) and 'identity technology' where users can present their 'self' online and connect with others (Turkle 1996, 17). Virtual Environments, such as Second Life, have blurred the lines between what is 'real' and what is 'virtual', 'simulated' or indeed 'fantasy', which prompted debates over whether the 'virtual' and a person's online presence could be considered meaningful, 'real' or even surpass the 'real' (Boellstorff 2008; Turkle 2011; Graham 1999). Nevertheless, it is evident that the internet offers many participation opportunities which have been linked to an increase in the quality of life and/or well-being, for example, engagement in meaningful activities and learning, finding paid work, forming and developing friendships and sexual relationships, accessing health information and support, and increasing independence and choice (Hall 2010; Eastgate et al. 2011; Emerson and McVilly 2004; Gravell 2012; Robertson et al. 2001; Brown and Thompson 1997; Kerbage and Richa 2011; Chadwick, Wesson, and Fullwood 2013; Hall, Conboy-Hill, and Taylor 2011). These opportunities online may be more accessible for those, including individuals with intellectual disabilities, who encounter barriers to participate offline. Yet, evidence suggests that those with intellectual disabilities are less likely to access the internet compared to the general population, and those with profound and multiple disabilities rarely use technology at all (Chadwick, Wesson, and Fullwood 2013; Fox 2011; Dutton and Helsper, 2007; Kaye 2000, Lenhart et al. 2003; McClimens and Gordon 2008; Guo, Bricout, and Huang 2005; National Telecommunications and Information Administration, and Economic

and Statistical Administration 2013; Office for National Statistics 2013; Guti rre and Zaragoza 2010; Hilbert 2015; Hoppedtad 2013). The reasons highlighted for this population's digital inequality include the lack of necessary skills, training and support to those with intellectual disabilities, economic and financial barriers, the 'cognitive inaccessibility' of the internet due to its design, and restrictions and/or lack of support from parents, carers and professionals primarily due to the perceived risks of the internet (Lussier-Desrochers et al. 2017; Chadwick, Wesson, and Fullwood 2013, Chadwick, Quinn, and Fullwood 2016; McClimens, and Gordon 2008; Fox 2011; Dutton and Helsper 2007; Kaye 2000; Lenhart et al. 2003; Carey et al. 2005; Emerson and Hatton 2009; Emerson et al. 2005; Kennedy 2009; Kennedy, Evans, and Thomas 2010; Goggin and Newell 2003; Wehmeyer et al. 2004). It cannot be ignored that some perpetrators use the internet as a tool to target, abuse and exploit others, including those with intellectual disabilities, however, taking into consideration the unacceptably high instances of offline disability hate crime (Davies 2013 citing Mencap 2013; Beadle-Brown et al., 2014), one could question whether online spaces are any more dangerous than offline spaces for those with intellectual disabilities.

Previous studies hint at adults with intellectual disabilities' experiences of the phenomenon: well-being and internet (Hall, Conboy-Hill, and Taylor 2011; L fgr n-M rtenson 2008; Holmes and O'Loughlin 2014), but, until now, it has not been a primary focus of research studies. Additionally, some studies have placed participants in unfamiliar surroundings to engage in new online activities, focused on participants' disabilities to explain their failure to navigate the internet (rather than on the choice or design of the internet activity), and/or given more importance to non-intellectual disability data to describe participants' internet experiences (McClimens and Gordon 2008, 2009; Moisey and van der Keere 2007; Holmes and O'Loughlin 2014; Brewer,

Taber-Doughty, and Kubik 2010; Taber-Doughty et al. 2010; Molin et al. 2015; Hegarty and Aspinall 2006).

## **Aims**

- To gather adults with intellectual disabilities' everyday concretely lived online experiences.
- To explore and describe well-being experiences given by their lived online experiences (or conversely absence of well-being).
- Approach the research topic with openness in order to allow the phenomenon in question to reveal itself and to re-present the participants' experiences with minimal interpretation.
- To work in a way, throughout the study, that respected and valued the involvement and contribution of adults with intellectual disabilities, highlighting that they are the experts in their own lives.

## **Methods**

### ***Study Design***

Descriptive-empirical phenomenological research is a lifeworld oriented approach and was taken in order to describe the essence/structure of the participants' experience of well-being and internet. The world of experience is lifeworld (lebenswelt); 'an inevitable structure of being', created from the objects that we perceive, take for granted, create meaning from, and that which surround us (Finlay 2011, 125, 2009; Husserl [1936] 1970; van Manen 1990). Although not used as an explicit framework, lifeworld fractions; spatiality, temporality, inter-subjectivity, mood,

identity and embodiment, remained within the background as a sensitising attunement to this study because ‘we cannot but be immersed in a lifeworld... [thus lifeworld fractions] cannot but be expected to show themselves’ (Ashworth 2016, 23).

Descriptive-empirical phenomenology was also chosen for its ability to pursue participant-led multiple interviews, to re-present participants’ experiences with minimal interpretation and delineate the phenomenon. Giorgi’s (2009) methods to conduct descriptive-empirical phenomenology was closely adhered to, but, minor adaptations were made to meet the individual needs of the participants so they could participate fully. Adaptations included ensuring the language used was understandable and clear in the questions, prompts, information and publicity of the study. The opening question for the initial interview was ‘tell me about the internet’, which encouraged participants to talk about the internet in their own way and take the lead in their interviews. After the initial interview, if required, visual prompts were used to assist some participants to remember the full range of their activities. The visual prompts showed images of a range of internet activities, logos for social media platforms and search engines, and then later, personalised images (based on internet experiences described by the participant in previous interviews). An advisory group, made up of those with and without intellectual disabilities, was consulted on the design of the study before ethical approval was gained from the **University of** .

### ***Participants***

Information about the study was sent electronically (with the offer of hard copies of posters and easy read information) to intellectual disability-related advocacies, charities and organisations across the Yorkshire and Humber region in the United Kingdom. The criteria for participation was that the participant was aged 18 or over, with an intellectual disability, who had used the internet for over 2 months in the past 2



years. 8 participants were recruited for this study and given the following pseudonyms: Alex (M) aged 19, Andrea (F) aged 22, Ella (F) aged 38, John (M) aged 25, Leona (F) aged 19, Michael (M) aged 62, Steven (M) aged 22, and Yvonne (F) aged 26. Of the 8 participants, all were involved in one or more types of volunteering and all but one, Michael (who was the oldest participant and lived on his own), were living with their parents. 3 male participants had autism (Alex, John and Steven), 2 female participants had Down's Syndrome (Ella and Yvonne), 5 participants had speech and language difficulties (Alex, Leona, Michael, Steven and Yvonne) and 3 participants also disclosed they had a mental health condition (Alex, John and Yvonne).

### ***Data collection***

Participants were interviewed up to 4 times, each interview lasting up to an hour, using semi-structured interviews that were open and phenomenologically orientated. Verbal prompts (directing questions, introducing well-being as an example, and follow-up questions to clarify or invite expansion) were used throughout for all participants. Visual prompts were used in 5 participants' second interview and onwards if required. 7 participants chose to be interviewed 4 times and 1 participant decided to withdraw from the study after 1 interview. The average time for each interview was 47.5 minutes and each of the participant's interviews took place over an average of just over 9 weeks (to fit with participants' commitments and choice).

### ***Data Analysis***

It quickly became clear that the participants' unique context (although not considered, in itself, concrete examples of the phenomenon in question), was still important to consider in detail, and this helped to provide access to further insights about the phenomenon. Therefore, a two phased approach was used in this study's

analysis to pursue both sense-making breadth (based on the participants' context) and lifeworld depth (based on the participants' lived experience of the phenomenon). Data that described the lived experiences of the phenomenon was analysed using descriptive-empirical phenomenological methods set out by Giorgi (2009). Data relating to the individual participants' context was analysed using inductive thematic analysis informed by methods set out by Braun and Clarke (2006, 2013) to provide an overview of participants' life situation. All interviews were recorded and transcribed verbatim. To form an essential structure of the phenomenon the transcripts were read a number of times to gain a sense of the whole before dividing the data into meaning units. The meaning units were then interrogated to transform the participants' expressions into phenomenologically psychologically sensitive expressions, which were then subject to free imaginative variation and arranged into loose themed essential structures for each participant before being brought together into clusters. These clusters were considered and rearranged several times during a period of immersion and reflection which allowed the constituents of the phenomenon to appear and then later be settled on to enable the finalisation of the essential structure of the phenomenon. The essential structure characterises the essential features of the experience of well-being and the internet.

## **Findings and Discussion**

### ***Contextual Findings (sense-making breadth)***

Common themes among the participants included being, and/or, feeling limited, restricted and controlled offline (by those who supported them or as a consequence of negative societal views of their intellectual disabilities and impairments), and a lack of opportunities and support offline to pursue self-chosen friendships, sexual relationships, identities, meaningful activities and careers. Because of their own and others'

perceptions of them as females with an intellectual disabilities (which included being infantilized by family members), this study found that the female participants encountered more restrictions than the male participants offline, specifically where they were allowed to go and who they could spend time with.

Although many participants were busy with a range of offline activities including volunteering (often coordinated by those supporting them) they were sometimes left feeling they had little control over their own lives. Some participants described experiencing poor mental health, with 3 participants stating that they had or were currently experiencing depression and/or anxiety. These participants highlighted that multiple losses of family members and friends, anticipated losses of their current volunteering roles, not being able to secure a paid job, feeling restricted in their lives and being rejected by others, contributed to their negative emotions and/or poor mental health. Most of these participants described not wanting to share how they felt to family, friends, professionals and others who supported them, fearing they would appear 'vulnerable', dependent or a 'burden' on others, and this would also incur further restrictions in their lives, including reduced access to the internet, volunteering roles and activities.

## **Constituents of the phenomenon well-being and internet**

### ***The internet as mirror***

Many participants' access to the lifeworld was limited or restricted and they had been labelled with unwanted identities by those supporting them, health professionals, societies and systems. Examples of unwanted labels and identities participants gave included: 'vulnerable', 'wrong', 'Down's syndrome', 'pitied' and a 'burden'. The internet could be likened to a mirror in which participants saw reflections of the

lifeworld and themselves (specifically when they experienced online games and social media platforms). Experiencing the internet mirror significantly increased their awareness of their lifeworld and themselves beyond what they had experienced offline and this contributed significantly to their sense of well-being: they described feeling happy, satisfied and more in control of their lives and identities:

John: I'm considered a vulnerable adult like / I do have things that I miss, but general I'd say I'm not vulnerable but... unfortunately, the law says I am and I can't change that so [respondent looks unhappy]. / [In Final Fantasy] I'm a tank I can look like I'm the sort of person... that looks like... an actual wall... That looks like it could take an absolute pounding. / I felt like I was in a, a big strong person able to look out and protect others... / who goes into the forefront of a fight... takes the hits from the enemies... [acting as] a protector of the weaker members [and I am] built to withstand... [and] take the brunt of the beatin[g]s.

The internet mirror helped the participants to form the whole of phenomena, some of which they only had limited and/or negative experiences of, such as friend, relationship, female, male, gender roles and disability. Male and female participants' experiences and views of being female on- and/or off-line were frequently discussed in the interviews with common themes arising. Females, on- and off-line, were described as being fickle, untrustworthy, un-caring towards men, only interested in money, would cheat and prostitute themselves for money, and were more able than men to acquire things. Females were also criticised if they veered from the traditional and subservient female roles set within the design of a game:

Alex: [In the game Fable] the dad gets the money in... the mum uses the money for the kids... / [By saying] I'm a girl... people just start giving you money, free money. [I: Right] Cause you just use that at to your advantage... It's like prostitution really. / [the] guy has to pay money towards the girl... So if you divorce em, it's how they roll in the money. / [As a female] it's a lot more easier for you to get a job, obviously... / [I: ...why do you think it's a lot easier?] I think

you can get away with lies a lot more... you can get things a lot, get away with things a lot more easier...

Many participants viewed females as uncommon and not belonging in what they described as male-orientated games, such as Call of Duty and Grand Theft Auto (abbreviated to GTA by some participants). Participants observed or experienced that the mere presence of a female character in these games was highly visible, gaining attention from others, but was often unwelcome, commonly leading to male players violently, and/or, sexually, targeting female characters, something which was generally accepted as normal or unavoidable by the participants:

John: a female [in online games] will get harassed, they will get sexually harassed. / You'll have those that will just... chat up females cause they are like that or they'll just being abusing... It's not really all that different to real life you know...

Andrea: [My] character online, dressed as a girl, driving a car and they think 'Ohhhh she's a girl, let's go and kill her and bomb her orrr, do whatever to her... cause girls can't play GTA' / [I am] picked on because I'm a girl and I'm playing GTA five and cause [pause] mainly boys don't think that girls can play this sort of game and I think it's very cruel...

In comparison, males depicted in online games and social media platforms, especially YouTube, were reflected more positively. Specific attention was drawn to the male body online, reflected to the participants, in the internet mirror, as able, strong and coordinated, with a better ability to withstand pain than the female body. This led to 2 participants, Leona (female) and Alex (male), to view their own bodies, in comparison to the online reflections they saw of the male body, as disabled, uncoordinated, average, or having unwanted feminine traits.

Some of the reflections in the internet mirror were magnified, drawing the participants' attention to specific 'things': war, acts or the threat of terrorism and violence, and

criticism over the movement of people fleeing conflict, as examples. This led to some of the participants' perceiving the lifeworld as dangerous, scary, uncontrollable, threatening and conflict driven. Alex and Andrea in particular, felt helpless and had become upset, worried and/or highly concerned over their own and others' safety in their immediate world, specifically from acts of terrorism and a potential World War III. While Andrea tried to not think about it, Alex looked for ways to protect himself and others he cared for:

Alex: If people come up to my house and lined everyone up, and started killing people one by one, I feel like I'm meant to just sit there with a popcorn and just start watching. / ... [Call of Duty] helps you... because you know, in a game, you kind of realise... like if it did actually happen, you know what to do... If it did actually happen.

### ***The internet enables visibility and invisibility***

The internet enabled the visibility and invisibility of the participants in a variety of ways. Those engaged in online games and social media were aware of online visibility and what may influence this. As discussed in the first constituent, *internet as mirror*, female characters were highly visible, especially within perceived male-oriented online games. In comparison male characters were generally less visible to other players. Acting upon this knowledge, 2 male participants, John and Alex, ensured their visibility to others within online games by playing female characters. They described that as a female character they appeared more aesthetically pleasing and gained a higher status from this increased visibility (enhanced by being able to choose brightly coloured hair and clothing in some games) and abilities, such as kinetic armour. John and Alex also described experiencing more favourable encounters with other players, specifically female players, because as a female character they appeared more supportive and friendly to others. However, Andrea and John described that playing a female character

also attracted unwanted attention from male players which frustrated and angered Andrea (because she was repeatedly targeted and killed by male players in Grand Theft Auto) and led to John feeling ‘uncomfortable’ and ‘unnerved’ when he was ‘chatted up’ by a male player. While Andrea would have preferred to play a male character to increase her invisibility (she described Grand Theft Auto as choosing the gender of her character for her), John and Alex switched between playing different gendered characters, choosing male characters when they needed to be invisible to other players, often in order to escape being targeted by other players, or when they wanted to be left alone.

Many participants spoke about the times they had been unfairly judged offline, due to their appearance and disabilities, and how this had sometimes prevented them from continuing to experience aspects of their lifeworld or pursuing chosen projects offline. Alex recalled a time when he was verbally abused by two men in a public space, and, as a result, did not always feel safe offline, actively choosing to spend most of his time online because he felt safer and could keep his appearance and disabilities invisible to others and not be ‘judged’. Yvonne and Ella also chose to be invisible online, by avoiding any direct contact with others online, because they feared what others may say about their intellectual disability and/or Down’s Syndrome. Alex, John and Steven were in direct contact with others online but made themselves, or aspects of themselves invisible, by displaying minimal information about themselves on social media and gaming profiles. This was to ensure their privacy and safety online, avoid conflict and, in Steven’s case, prevent contact from certain family members. As Alex and John became closer to friends they had made online, primarily female, they sometimes chose to disclose that they had an intellectual disability, speech and language difficulties and/or autism, which resulted in varying responses:

Alex: [My online friends said to me] “you don’t sound like it...” So I pretty much sound normal to them. / [they] didn’t really abandon me, they just saw it as normal, and they just said to me obviously, they don’t think there’s anything wrong with me. Because I can speak comfortable online... than I can in person.

John: I feel like... it should just be open you know so people know [pause]. Erm, not everyone takes it very well so. / Like when I told... someone and then they just, about it, and they were just, and then they just cut me out.

### ***The internet as liberating***

Many participants felt frustrated, angry and sad because of the restrictions they experienced in their offline lives which prevented them from being able to go where they wanted, connect with those they wanted to connect with, and follow their own personal goals and career aspirations. Online, many participants felt they could ‘do anything’, be ‘reckless’ and not ‘take life so seriously’. Alex had no ‘fear’ of the consequences which were present to him offline, such as ‘pain’ and ‘dying’, because online he could ‘come back alive... [and be] reborn’ without experiencing any suffering or lasting effects on his body. Andrea’s experience of driving in Grand Theft Auto not only allowed her the spatial freedom she lacked offline, but it also brought her a sense of calmness and a welcome distraction when she felt upset at the thought of her grandfather’s death, or continually trying, and not being able, to secure a paid job:

Andrea: [I:...So why do think you spend lots of time doing this [driving in Grand Theft Auto] then? [pause, respondent thinking] I don’t know, I just, I guess it just... keeps my... mind off of stuff that I’m either thinking of or don’t want to think of and [pause]... just try and focus on... either driving round the city or driving on the motorway...

While participants acknowledged that liberation online is available to most who experience the internet, many found that at times their own liberation in online games was interrupted by others’ liberating experiences, which sometimes consisted of violent



and hateful interactions, rejection and other unwanted behaviour. Being an unwilling target in another's online adventurous horizon, or acknowledging that others may also be unwilling targets (Michael gave the example of others posting indecent photographs of children online), led to participants feeling angry, frustrated, sad and helpless.

### ***The internet meets unmet needs***

All the participants described having unmet needs: not being able to have status, friendships, romantic relationships, their own children, a paid job, money, material goods, engage in meaningful projects and live independently. Participants also described their need to escape from, or to resolve conflict in their lives, deal with loss and negative emotions, feel valued and that they belonged, cope with the unpredictability, busyness and lack of control in their lives, enact change and have control over their lives. Trying and failing to have their needs met offline led to many participants turning to the internet, which gave them plenty of opportunities to meet their own individual needs. Not only did the internet offer these participants consistency in their lives, it offered them a self-chosen routine and somewhere they could escape to, a space to relax, 'unwind' and concentrate on their own needs, which in turn made them feel happy, safe and calm. Online they could also plan, prepare, learn about, practise for and picture their futures as they wished they would be. Leona was cooking meals for herself and her family using the recipes she had found online in preparation to live independently one day. Yvonne was also searching for recipes online, copying them into a book in preparation to start her own catering business, as well as viewing houses for sale online to see what house she would choose to live in, despite currently not being supported to live independently:

Yvonne: ... me dad doesn't want me to move, cause I'm still his little girl... [I: And what do you think about it?] In my mind I will say "dad I'm not your little

girl, I'm a woman, I want to move out." / I always, I dream always, I always dream or think of moving out, but it never happens [I: Oh so you, so you dream it... when you're sleep?] No I dream it when I'm on the computer.

Alex and John described actively seeking to experience romantic relationships and getting married online, which also including getting divorced. Online, Alex had a baby with his wife, owned his own home and earned money within an online game, all of which he felt were unavailable or unattainable for him to experience offline. Online Alex had observed others, without an intellectual disability, seeking out different experiences within these online games, experiences that were unattainable for them offline, such as: 'prostitutes and... pole dancing.../ Strippers and stuff like that...'. The internet kept participants individual hopes for their offline futures alive, often against opposing, pessimistic and paternal views of those supporting them. Michael was the only participant who had not specifically sought out any online experiences to meet his needs (specifically selfhood and intersubjectivity), because, unlike the other participants in this study, his needs were being met offline through different types of volunteering, social groups and living independently.

Despite having extensive support networks, many of the participants, specifically Ella, Yvonne, John, Andrea and Alex, described longing for emotional support, someone they could talk to who would understand them without 'pitying' them or viewing them as a 'burden'. Despite these participants experiencing considerable sadness, anxiety and unhappiness, they did not often share how they felt to their family members, friends and supporters because this risked placing them further into the role of being dependent on others and needing to be cared for, which led to further restrictions on their lives. After her family had suggested that she should no longer volunteer, Ella was left feeling upset and 'stuck'. She searched for and looked at photographs of herself online supporting others as a volunteer, to validate and soothe herself after the conflict with her family

and to try to come to terms with the possibility of losing her volunteering role. Yvonne searched for poetry online and wrote these down to come to terms with the loss of people in her life, whilst Alex engaged in battles within Call of Duty to release the anger he felt from being verbally abused offline and to stop himself from damaging items in his room:

Alex: [I] Take my anger out on the game itself.../...cause I can use that to er kind of release tension.

John and Alex had developed their own support networks with others online, which was meeting their need for emotional support. John described how he and his online wife both experienced poor mental health and were both 'there for each other' when each other was feeling down:

John: ...like me she's also very tough on herself so like... We're having to constantly tell each other how good we are. Because neither of us can see it in ourselves. / cause we are both sort of person we don't like being a burden on our mothers.

Online experiences that met the participants' needs contributed significantly to their sense of well-being. However, from John and Alex's descriptions of the phenomenon, the more entwined the online experience was to their sense of well-being, the more investment of time and effort into the online activity/experience was required to maintain their sense of well-being. Once a reliance between internet use and well-being had been formed, especially over a long period of time, any interruption to, or end of, an online experience led to the participants feeling guilty, lonely, isolated, and having a sense of unwanted quietness, sadness and disconnection. John and Alex both hypothesised that this was evidence of their 'addiction' to the internet, something which had also been suggested by their family members:

Alex: I rely on it [the internet] too much... / I can't live without internet  
[respondent smiles] [I: Oh can you not?] No... I've grown too attached to it. / it's  
kind of not really a second thought.../...because it's just so normal to me.../  
[without the internet] ... it feels like the end of the world because it feels like I'm  
in nineteen fifties.

John: It's like am no longer being driven by addiction,... I've been able to take a  
step back. / [I: Is that how it used to be?] Yeah, like you always wanting to get on  
and like, I think as well it's due to the way that you had to do, you had to grind  
away at it and you know keep... playing it in order to get to the best you know it's  
like... I felt like I had to keep playing and playing and playing in order to... a, get  
my money's worth and b, just keep up so.

### ***The internet creates a decision maker and expert***

The internet offered the participants endless information in various forms to suit their individual needs, from text-based information to forum discussions and YouTube videos, and this had transformed some of the participants into informed decision makers and experts. One common area of expertise was on their own and others' physical and mental health and knowledge of certain conditions, including autism, intellectual disability, epilepsy and anxiety. Leona went to see her doctor after she had compared her own symptoms to those of a chest infection online and often offered advice to family members when they were not well from the online information she had found. Leona would guess what medication they required, recommend specific treatments and advise them when they needed time off work. Steven found and read information online about autism, to gain a better understanding of his own condition, as well as his friend's health condition, epilepsy, to ensure he could act appropriately if required:

Steven: I used to know someone who's got epilepsy so it's good like... to know, to know how, to know really about, cause they might have seizures... / [I: ... how's it [the on-line information] helped?] ... Just is better than standing there when they have a seizure I suppose.

With the help of the internet, participants embraced becoming informed decision makers and experts who could help and support themselves as well as others and this contributed to their sense of well-being.

### *The internet as a friend and foe*

The internet was often negatively perceived by the participants' families and their families' opinions and advice influenced some of the older participants' decisions around their internet use. Michael's family member advised him not to get internet access at home because it would be too expensive and complicated for Michael and there would be a risk of him getting his computer 'hacked'. Ella's family suggested to her that if she did access parts of the internet, specifically social media platforms, she would receive nasty messages centred on her Down's Syndrome, or be filmed and then displayed on the internet without her permission:

Ella: ...me mam will not let me go onto it [social media] because, reason why... I don't want other people, erm sending email, sending erm threatening message about me. So me mam's said that, that I'm not allowed to go on it, because I don't want people say something about me, that I've got Down syndrome. [Interviewer: Right, o.k., so if your mum was o.k., would you use it, for something like Facebook?] No, it'd be too upsetting for me.

For many participants, their online lives were generally private from those who supported them, unlike their offline lives. They described basic internet safety strategies they used, for example, being careful about the personal information they posted online and not accepting friend requests on Facebook from those they did not know. However, when it came to actively finding friends and maintaining friendships online, these internet safety strategies were sometimes compromised. Andrea was happy to send friend requests to those she did not know on Facebook if they shared her interest in certain bands, musicians or sports teams, as they, and also those associated with them

online, were viewed by Andrea as safe. When John wanted to meet an online friend offline and could not find a friend to travel with him to a different city, he went on his own, even after concluding that this was not entirely safe for him to do.

Verbal abuse, threats, sexual harassment, criticism, being targeted because of their gender, and/or rejection from others online were common experiences for John, Alex and Andrea. Not fully realising how restricted the participants' felt offline and how significant their online experiences were to their sense of well-being, after participants did disclose negative online experiences to family members and professionals they were threatened with disconnection or encouraged to spend time away from the internet.

When Alex and John reflected upon their negative online experiences, which at times had made them feel uncomfortable, unnerved, sad, lonely, angry, upset, frustrated and disconnected, they concluded that they were a natural and 'normal' part of the 'whole' internet experience and more preferable than experiencing something similar offline.

Alex and John often blamed themselves, and others who may be similarly targeted, rather than their perpetrator(s), attributing the online negative experience to their own lack of resilience, being weak, or their inability to tell if someone was a friend or foe.

This view was unsurprising as the participants were often blamed for their offline negative experiences, for example, after someone attempted to exploit John, his friends and mother blamed John's intellectual disability and autism for the incident, suggesting that it may not have happened if he did not have an intellectual disability or autism, or had been accompanied by someone without disabilities or autism. Alex and John both described making friends with their online perpetrator(s), either because they had come to accept the behaviour of the perpetrator(s) (perceiving that they did not 'mean any harm' to them) or after the perpetrator(s) had expressed liking them or had recognised the participant's high status in an online game. Unlike John, who continued to be

negatively affected by the numerous attacks, criticism and rejection he experienced in online games and forums from others, Alex described building up a resilience to this over many years by learning about, understanding and accepting ‘trolls’ on YouTube:

Alex: ...you got internet trolls stuff like that, you got people that, because they... are unhappy themselves... The only way to release that stress that is by hurting other people to make sure they feel bigger... which doesn't really... help others. / I have been trolled a lot of times, I get a lot time every single day. [Respondent laughs] [I: Do you?] But, because I know the history behind it, it doesn't bother me as much. [I: Did it bother you before you knew this?] It did yeah...

### ***The body connects to, and disconnects from, the internet***

To prepare his body for connection to and immersion within Call of Duty, Alex changed aspects of his immediate environment (his bedroom), by blocking out unwanted and unneeded external/offline stimuli, ingesting stimulants (coffee and sugar) and tending to his hands between games (cleaning and heating them in hot water), to ensure that his physical body could perform at its ‘optimum’ online. Alex also described that he would imagine he was the online character in the game Call of Duty so that he could fully connect to and immerse himself in the online experience, which would contribute to his sense of well-being, particularly embodiment:

Alex: It's like a little trick in my head... But it works. / ...I, I, I take, I take it like I'm in, I'm actually there... Just because obviously it kind of helps with the rush. / I mean, real life... I'm also putting that in the game as well... and because obviously I'm hyped, my fingers are moving a lot more, my eyes are moving a lot more, my, my brain's reacting a lot more faster. / ...always like get like adrenaline pumping... through me... Because I take it so seriously...

John described his immersive experience in Final Fantasy as ‘exhilarating’ because he needed to be ready for anything, which made him feel ‘on a knife-edge’. From this he

experienced the 'biggest adrenalin rush', his heart rate increased, and he sometimes felt his heart 'stopping' during the game. However, once John and Alex disconnected from the internet, a sense of embodied suffering was experienced. They described their offline bodies as becoming lethargic and exhausted, motivation was lost for any offline alternatives and their thoughts centred around their online activities. Alex simply went to sleep until the chance to re-connect appeared again and John felt lonely and could not help but think about and remember his time spent in the online game from which he had been exiled from:

Alex: ...it's kind of like more of a sad sleep / ... because... like... there's no internet, I don't know what to do, there's nothing else to do. [I: Right.] So what am I meant to do? Go outside? Do what, do what like when I go outside?... I mean there's not real anything to do, so I just go to sleep.

John: To be honest I've been feeling quite, bit lonely now because I feel like I've been...disconnected.

## **Discussion**

Although it was positive to see that many participants had their needs met and were being supported by the internet in a variety of ways, this was often through an online presence (such as an avatar or player / social media profile), which enabled participants to hide their disabilities and other unwanted traits as judged by the participants. Concealment of disability was used by some of the participants to reduce the likelihood of negative online experiences such as verbal abuse and to make them more appealing to others online, but this in turn also perpetuates the under-representation of disabilities on- and off-line, and one which is not valued and should be hidden.



For participants in this study, many of whom were not able to experience all aspects of life, the internet became a very influential component to their understanding of themselves and their world. Sometimes the 'whole' of phenomena, such as friend and female, was greatly informed by their online experiences, which led to negative and stereotypical views. Attention to, and magnification of, on- and off-line violence, conflict and chaos on the internet, led to a hyperawareness in some participants, who were left feeling helpless and worried for their own and others' safety offline.

Alongside conflict with, rejection from, and/or being targeted and abused by others online (or the potential for this), increasing their awareness of the lifeworld via the internet contributed to psychological distress in some of the participants. Yet these participants did not consider the internet as any more risky or dangerous than their offline lives, in fact many felt safer online and often concluded that their negative online experiences, such as bullying and verbal abuse, was normal and part of the internet experience, and in some cases their own fault for having an intellectual disability and not recognising the threat. This study highlights how online danger was negotiated by people with intellectual disabilities in similar ways to dangers in everyday life and how these skills are transferable to both on- and off-line worlds.

Interestingly, 2 participants, both of whom had autism used the term 'addiction' to describe their well-being and online experiences due to the time and effort these participants were investing in their online activities, their disinterest in offline activities, and the interruption to their sense of well-being when disconnected from the internet.

The general view of 'internet addiction', often associated with those with autism (Dunkley 2016), is that it often leads to poor mental health (Sarda et al. 2016; Sigerson, et al. 2017), a decrease in socialising and work, a lack of real-life relationships, an increase in stress (Griffiths, Kuss, and King 2012), loneliness, and is associated with

aggression and hostility (Caplan, Williams, and Yee 2009; Chiu, Lee, and Huang 2004; Kim et al. 2008; Mehroof and Griffiths 2010). Yet for the participants in this study these appeared to be the very reasons why they had turned to the internet in the first place. Wolfensberger's (1983) Social Role Valorisation helps to make sense of these reasons for turning to the internet, which are rooted in the participants' experience of social devaluation: experiencing rejection, segregation (and congregation with others with intellectual disabilities), devalued (due to 'impairment in body, including the brain or sense organs...'), physical and social discontinuity, de-individualisation, loss, deprivation, impoverishment and accorded low social status (107). Participants raised a common theme: their 'busy' offline lives (which were facilitated and coordinated by those supporting them rather than themselves) in an attempt to include and engage them in society, influenced by the principles of normalisation and the moving away from institutionalisation (Wolfensberger 1972). While being 'busy' could contribute to a sense of existential mobility, it often left little chance for the participants to dwell, follow their own needs and wishes, and come to terms with loss and this had negative effects on their mental health. The internet was seen to provide participants with opportunities for both dwelling and emotional support which felt safe and free from the unwanted consequences, for example, the participants feeling that they asking for support revealed that they were not independent and vulnerable, which would in turn lead to more restrictions.

### **Conclusion and Recommendations**

There was a lack of concrete lived well-being and online experiences by adults with intellectual disabilities re-presented descriptively. This study addressed a gap to offer an in-depth description of well-being and the internet through seven constituents that describe the 'internet as a mirror'; 'enabler to visibility and invisibility'; 'the

internet as liberating'; 'meeting unmet needs'; 'creator of decision maker and expert'; 'the internet as friend and foe'; and how in engaging and disengaging with the internet particular senses of embodiment were experienced 'as connecting with or disconnecting from the internet' in ways that were both wanted and valued by participants.

The internet was able to reflect and/or simulate all aspects of the lifeworld to the participants and they described how their experience of the phenomenon well-being and internet, contributed to, and interrupted their sense of well-being. Many participants had turned to the internet as way of meeting their needs and to feel supported, which, for a variety of reasons, could not be met or achieved offline. Online they described feeling liberated, independent and valued, and able to break away from, and/or conceal, given and unwanted identities centred around their disabilities to forge their chosen identities and/or how they wanted to be seen by others, which highlights some new insights about identity and selfhood in the context of the internet.

This study has given rise to new understandings (some of which had only been hypothesised or partially referred to previously) and from this a number of recommendations can be made. Many adults with intellectual disabilities, including those who participated in this study, want independent, safe and enjoyable internet use, but there must be a balance of both self-chosen and self-directed on- and off-line opportunities and experiences for this population. The findings point to many examples of well-being given by possibilities for movement and mobility in literal and non-literal ways and also for settling and willingness to reside in a valued virtual world. There were also examples of forging a way to an on-line identity that is wanted and valued. The findings indicate people with intellectual disabilities' desire to experience all aspects of their lifeworld freedoms fully (rather than ones chosen and facilitated by those supporting them) and demonstrate that people with intellectual disabilities do not

form complete reliance on the internet to maintain their sense of well-being due to their experiences of social devaluation. They negotiate both worlds; on- and off-line experiences are transferable to both ways of being. To ensure this positive resource is available to this population, especially in regards to accessing and using the internet, support and facilitation should be non-judgemental and free from any forms of punishment, for example, restricting an individual with an intellectual disability's internet access when they disclose they have experienced something negative on- or off-line, as this only leads to non-disclosure of negative online experiences. The internet presents risks for everyone, but because positive risk taking, and subsequent learning from these experiences, is not encouraged for those with intellectual disabilities, this may leave this population susceptible to negative on- and off-line experiences and not knowing what to do. There is a need for training / education that goes beyond 'internet training' for those with intellectual disabilities and their supporters, on friendships, relationships, and the development of independent decision-making, as examples, which are transferable both on- and off-line.

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