Facebook use by people with learning disabilities: The case for facilitated, guided autonomy

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Abstract

Facebook is a worldwide phenomenon. However, for people with learning disabilities, the platform presents many challenges. These relate to social skills, self-expression and avoiding exploitation or other hurtful experiences. This study explores factors relating to Facebook use or abstinence by this cohort; how these may be influenced by their learning disabilities, and how supporters can help mitigate any difficulties or barriers. In-depth interviews (*n* = 115) and observations of usage were conducted. The findings revealed that themes elicited centred around passive consumption of content, supporter controls, virtual connectivity, vicarious enjoyment and aspects concerning the projection of self. Factors related to non-use included a lack of knowledge or access to the platform. A case is made for supporters practicing 'facilitated, guided autonomy' by working with those whom they support to help evaluate 'friend' requests, compose posts and generally, emphasising their subservience to those whom they support, act as 'Facebook assistants'.

Keywords: Social media, Facebook, learning disabilities, inclusion, autonomy.

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1. Introduction and purpose

Social media has been defined as 'forms of electronic communication (such as websites for social networking and microblogging) through which users create online communities to share information, ideas, personal messages and other content (such as videos) (Merriam-Webster, 2019). It 'includes blogs, social networking sites (e.g., Facebook), virtual social worlds (e.g., Second Life), collaborative projects (e.g., Wikipedia), content communities (e.g., YouTube) and virtual game worlds references' (Caton & Chapman, 2016, p. 125). According to Darragh, Reynolds, Ellison & Bellon (2017: online), social media has 'changed the way humans communicate, interact, … grow, maintain and develop relationships'. Facebook users 'can access, share information, photos or videos, and upload/download information at any time frequently from online groups and communities to fulfil shared interests'.

Despite this apparent revolution in communication practice, Darragh et al. (2017: online) point out 'for some of society's most marginalised people, … social media remains inaccessible due to the design and functionality of various applications, lack of computer or device access, as well as poor or limited literacy skills which were not acquired or developed during formative years of education'. In addition 'parents and careers … may control access to Internet-based social media and personal electronic devices', thus restricting access further. Shpigelman and Gill (2014) opine that people with learning disabilities may have 'restricted social networks in real-world settings and may experience social isolation [thus] Social media can serve as a supplemental environment to maintain relationships with friends after school or job hours and to provide and receive social support (p. 1612). Thus, there appears to be an imperative to explore this issue and, in particular, the barriers that may be faced by this cohort, and how usage may be best facilitated. This paper addresses attempts to address these issues.

2. Prior literature

Despite the huge popularity of social media (Caton & Chapman, 2016; Statista, 2017), there is a paucity of research into the experiences of the phenomenon by people with learning disabilities, including the uses, benefits and barriers of the various systems and services. Holmes and O'Loughlin (2014) explored the positive and negative experiences of three people with learning disabilities using social networking sites. One participant had difficulties because of her 'concrete understanding of the word 'friend' as used by Facebook. Because of this, she 'would attend parties … arranged on Facebook by 'friends' whom she had never met before, placing her in potentially … vulnerable situations' (p. 5). Another suffered from 'social anxiety'. For her 'Facebook provided … a medium in which to increase her social circle without having to meet anyone. She … enjoyed using Facebook as people messaged her and commented on her status' (p. 5). The third participant also enjoyed Facebook as 'she was able to keep in touch with people she had been to school with, and update them on what she was doing now' (p. 6).

Shpigelman and Gill (2014, p. 1601) examine 'how adults with intellectual disabilities participate in social media, and in particular, Facebook as the most used social networking site'. A self-report 'accessible' online survey was undertaken (distributed through Facebook pages, and recruiting people with 'an intellectual disability … that make(s) learning hard or slower'), regarding the experiences, capabilities and preferences of Facebook users. There were 58 respondents. Results suggested that this group of Facebook users was older than for the population overall: the majority were 30 years and older while 'the majority' of the general population of Facebook users (at that time) were aged 18–29 years. This was explained by 'differing rates of cognitive and language development' between the two groups, especially considering the 'relatively high literacy demands' on users. Study respondents were also less-frequent users of Facebook—'at least once a week' as compared to 'at least once a day' for the general population of Facebook users (Hampton, Goulet, Rainie & Purcell, 2011, cited in Shpigelman and Gill, 2014). This is said to be due to problems with reading and writing and the usability difficulties of the web in general and of Facebook in particular. Perhaps surprisingly, there

were no significant differences between the frequency of using Facebook between those who lived alone or with others. When comparing the Facebook experiences of respondents who use the platform alone or with help, the former tend to look for people they know, to ask for help from someone and to chat with a friend on Facebook' (activities of those who prefer or need to get help were not explicitly outlined). Sixty-eight percent of the respondents said that making new friends is easier on Facebook than in person (face to face). Similarly, 82% said they felt more comfortable talking with people on Facebook than face to face, and 26% reported that by using Facebook, they feel 'like everyone else.'

Other research has been somewhat peripheral. Didden et al. (2009) examined the types, prevalence and associated variables of cyberbullying among students 'with intellectual and developmental disability' attending special education settings. Results suggested that the phenomenon occurred less often than other online activities, but there was nevertheless a positive correlation between being a victim of Internet bullying and depressive feelings and a negative correlation between being a victim and self-esteem. Kydland, Molka-Danielsen and Balandin (2012) documented the experiences of (12) adults 'with intellectual disability' who were trained to use Flickr. They enjoyed, in particular, the social functions, which let them express themselves and communicate with each other. However, there were problems with understanding and entering text and concern about control over photo-sharing.

3. Methods

This was a qualitative study, even though the number of participants was large, with group and then individual interviews, conducted at the college or other institution attended by the participants. The former as Daems, Dekelver, De Vliegher, Smets & Martens (2015) point out, can 'build confidence, …. environments that are not threatening or intimidating and [generate] peer support and validation, all enabling people with learning difficulties to contribute to research discussions' (p. 76). As the topic of Facebook (and social media in general) formed part of a larger study of the use and impact of mobile devices, themes such as the experiences, benefits and difficulties of the technology were asked, in addition to exploring participants' use (and non-use) of Facebook. After the group sessions, participants were invited to chat more on a one-to-one basis. This was to explore in more depth views expressed in the group sessions.

Interviews with supporters were very open and centred around interviewees' experiences of the use of mobile devices by and with the people they support. The impact of the latter's use of Facebook was a major topic of conversation.

3.1. Participants

Participants were adults, ranging from 18 to 64 years and had 'mild' LD. This cohort is generally able to 'hold a conversation, and communicate most of their needs and wishes …. They usually have some basic reading and writing skills'. They can usually undertake supported employment, although needing 'support with tasks such as budgeting and completing forms [and] find abstract or complex ideas difficult (BILD, n.d.). In total, 114 people participated in the group sessions, of whom 72 were interviewed individually. These latter sessions were with fewer people mainly due to time constraints although in some cases it was clear from the group sessions that certain individuals were either not engaged at all with the technology or were not able to follow the themes discussed. Only five people chose not to move from the group session to a one-to-one chat. They were recruited from adult Day Centres for people with learning disabilities, 'Functional Skills' departments at Further Education colleges, voluntary groups and other organisations supporting people with learning disabilities, mainly around London and the South East of England.

3.2. Data analysis

Interview transcripts were 'framework' analysed (Richie and Spencer, 1994; Ritchie and Lewis, 2003, Qualitative Research Practice London: Sage Publications). The writer has discussed using this method in prior work (see, e.g., Williams, 2017; Williams and Cendon, 2019) Suffice to say here that the method entails eliciting key themes within the data and labelling them appropriately; collating together material relating to each theme, and scrutinising these to discover the range and nature of the phenomena elicited and find associations and explanations.

4. Findings

4.1. Introduction

Before discussing results in detail, it is worth pointing out why the data haven't been quantified, to read, for example, '10 people said…,' etc. This is for two reasons. First, the sample was very heterogeneous in terms of the level, frequency and type of support; experience with and knowledge of social media, etc. and a range and other demographics. Thus, even where many people made the same point they were doing so from very different circumstances and perspectives. The focus was more on the issues raised regardless of how many participants raised them. Nevertheless, it would be impossible to discuss a particular point without using phrases such as 'some participants', 'one gentleman', 'several people,' etc., unless the subject was removed by use of the passive voice throughout ('it was stated that …'). Hence, these quantifiers being used in the research.

As would have been the case with any cohort of users, a wide variety of attitudes, behaviours, needs and interests were elicited with regard to the use of Facebook. It is therefore difficult, if not impossible, to try and attempt any comparisons between 'people with learning disabilities' and 'mainstream' cohorts. Shpigelman and Gill, (2014) attempted this, as documented above, although their research examined demographic and situational differences rather than comparing actual use behaviour, and the authors used a quantitative method to generate comparable metrics. The current paper explores the issue by examining how reported use, attitudes and behaviour may be influenced by, if not directly attributable to, a learning disability.

4.2. Factors affecting Facebook adoption

Taking the approach of focusing on factors that may be, at least in part, be attributable to or impacted by a learning disability, various themes emerged. These are:

- Passive consumption
- Controls and constraints
- Virtual connectivity and vicarious enjoyment
- The projection of self
- Factors related to non-use

Each of these is discussed in turn below.

4.2.1. Passive consumption
Much literature discusses the concept of what is rather disparagingly described as 'lurkers', defined as 'non-contributing, resource-taking members' (Kollock & Smith, 1996, quoted in Brandtzæg & Kiem, 2011). It appears that 'most social media users' generally, are 'lurkers', albeit less so on Facebook and other social network groups than in information exchange communities (Amichai-Hamburger, 2016). Gazit et al. (2018) reviewed the literature on active and passive social media users and found factors related to the latter to include personal preference, need gratification, self-efficacy, individual-group relationship, time constraints, usability and security considerations.

Results from the present study suggest that many reasons for passive consumption (a term the writer prefers over 'lurkers' because of the latter's negative connotations) appear to be strongly related to learning disabilities. Among these was that of an awareness (or perception) of own's own poor spelling, grammar or self-expression generally (the 'self-efficacy' factor very prevalent in literature around technology use, and very strongly exhibited here). These factors were explicitly stated as reasons for non-contributing and are similar to that reported in prior studies. McClimens and Gordon, (2008), for example, in their study of online blogging, identified a cocktail of inexperience in self-expression, problems with written language and even poor IT skills mitigating against active social media participation.

In other cases, the simple declaration that 'I don't have anything to say' or 'I don't know what to write' appeared to also indicate a lack of self-confidence or, perhaps as commented upon further below, poverty of activities undertaken. In this regard, Overmars-Marx et al. (2012) found in a review of the literature that people with learning disabilities participated less in community and friendship groups and undertook more passive and solitary activities, such as computer games or TV watching.

In addition, and sadly, a small minority stated that they wouldn't post photos of themselves because—although their words were more direct—they had a very negative self-image. This is a reaction that also reflects the literature, which has shown that an awareness of one's own disability negatively affects one's self-esteem (e.g., Cosden & Noble, 1999; Zeleke, 2004). One of the supporters interviewed said that in her experience, Facebook was not well-used and that many of the people she supports 'would not really understand social media [and] many would not know what to say', suggesting possibly more a lack of social skill than confidence, for some participants. Another supporter claimed that even 'very outgoing people don't post', as illustrated by the example of a 'very confident and vociferous' gentleman who has a Facebook account, but 'hardly uses it'.

4.2.2. Controls and constraints

The disinclination to actively contribute to Facebook is not only related to a lack of self-confidence or negative self-image. Another factor, related very much to participants' learning disabilities, is that of the controls and constraints imposed—for the very best of intentions—by people in a support capacity. The writer has already documented in general terms the barriers faced by people with learning disabilities (Williams, 2019), many of which were the result of interventions by supporters. Purely in terms of social media, many supporters indicated that they impressed upon the people they supported the 'dangers' of Facebook, and in particular, befriending people they don't know 'in real life'. Constraints are also imposed by college tutors and others because parents of the people they support 'don't want their offspring to use social media because of the possibility of online bullying and because of their more general vulnerability'. Another aspect of this problem is that, due to what was described by supporters as a lack of empathy or of social skills (supported in the literature: Ouherrou, Elhammoumi, Benmarrakchi & El Kafi, 2019; Wiener & Schneider, 2002), people 'say what they think about photos and posts [and] do not understand the hurt they can cause'. One supporter said that she had to deal with 'upsets' caused by Facebook 'almost every day'.

4.2.3. Virtual connectivity and vicarious enjoyment

Following from the above, it is perhaps not surprising that much research shows that people with learning disabilities have difficulties making and keeping friends (Lafferty, Mcconkey & Taggart, 2013). Both the literature (e.g., Pockney, 2006) and supporter interviewees in the present study suggest that for many people their support worker is considered to be one of their closest companions. One supporter interviewee described both the online and offline efforts of a person in her care to befriend her as 'almost like stalking'. It may not be surprising, therefore, that study participants greatly enjoyed feeling a connection with their virtual Facebook connections. Several interviewees said they liked looking at photos and posts of others, despite not commenting themselves (and therefore acting as 'lurkers'). For some, Facebook was an excellent way of keeping in touch with family. In this context, photos posted by various relations were greatly appreciated. Some participants said that they did not

see their family often enough—perhaps not surprising when one considers the problems the cohort have with transport (Mackett, 2016; Wormald, McCallion & McCarron, 2019). It was, therefore, particularly important to feel a sense of 'virtual closeness'.

Related very much to the above point is that of the vicarious enjoyment felt by people with learning disabilities when perusing the posts of their online contacts. Several people made comments expressing pleasure at following the activities described and photographed, and there were indications of a sense of pride at the achievements of their peers and family ('My sister's sending [posting] pictures from Canada!'). Little research appears to have been undertaken on vicarious experiences and learning disabilities although it is mentioned in an educational context, in terms of 'vicarious reinforcement' (Westwood, 2013). Work undertaken on emotional responses tends to be in the area of behavioural therapy (e.g., Vereenooghe et al, 2015). Pestana (2015), however, in an admittedly very small-scale qualitative study of the self-concept of adults with mild learning disabilities, found that his interviewee participants reported being strongly supportive of family and friends.

4.2.4. The projection of self

In addition to the imbibing and enjoyment (or otherwise!) of the posts of others, the active behaviour of the cohort needs to be explored. There is a huge body of literature around how people generally portray themselves in online communities. Research shows that in general, 'individuals employ impression management and self-presentation strategies to present themselves in positive ways' (Kim, 2018, p. 770). Evidence accrued for the present study suggested that, by contrast, people with learning disabilities make little effort on Facebook to present a particular 'self' (and, unlike in Shpigelman and Gill's (2014) study, did not mention the anonymity afforded by Facebook making them feel 'normal'. Neither did they in any way attempt to exaggerate achievements or prowess. Posts (where these were shown to the researcher) tended to be photos of one's pets, various personal hobbies or interests (including crochet or oil tankers) or cultural icons such as football or pop stars. One supporter opined, unknowingly reflecting the content of the (15) profile timelines shown to the researcher in the course of the project, that the cohort did not feel the need to self-project the way others might—in, for example, writing constant status updates and seeking appropriate responses, such as sympathy or admiration. Another observed, with regard to online identities, 'wanting to be somebody else doesn't happen so much with people with LD' [supporting this view, Seale (2001), found that personal web pages of people with Down Syndrome were very open in mentioning the condition, albeit there was substantial evidence of third-party content writing]. This makes it difficult to teach people that it is common online to use an alias or that some people are not who they purport to be. Indeed, this led to the problem of being tricked by those posing as potential friends or (in two cases) sexual partners, as outlined below.

4.2.5. Factors relating to non-use

There are, of course, several reasons for not adopting a Facebook page, regardless of any disability or other particular circumstance. These have been documented as having fewer peers using the platform (Ljepava, Orr, Locke & Ross, 2013), privacy concerns (Rymarczuk, 2016) and disenchantment with the format (Rymarczuk & Derksen, 2014). Personality traits (notwithstanding those that impact on the above reasons) have also been explored as predictors of non-use. These include less willing to 'self-disclose', being less introverted (Ljepava et al., 2013) and less shy than users (Orr et al., 2009; Ross, Orr, Sisic & Arseneault,, 2009).

For the study cohort, one factor was a lack of knowledge about the platform and about social media in general. Two main reasons appear to be in play. First, as alluded to above, supporters of those considered more vulnerable expressed concerns about them using the media and were, therefore, disinclined to expose them to it. Their peers too, being likewise ignorant, were not in a position to explain or demonstrate. Second, some participants did not have (or, apparently, have access to) Internet-enabled devices and/or were not immersed in the technology.

There were also several cases where Facebook was known, but prohibited, either by support worker, parents or, in institutional settings, by being blocked and therefore inaccessible. Interestingly, the participants affected tended very much to agree with this decision—speaking themselves about the potential dangers. Although this may have been partly an example of the trust invested in supporters, many examples were given of the negative experiences suffered that have caused people to deactivate their Facebook accounts. These have included several examples of ridicule and abuse, and in one case, a woman (or supposed woman) faking sexual interest in one of the people supported, and then continuously asking for money. Reasons cited above with regard to a lack of active participation—fear of ridicule or low self-efficacy, for example—pertain to non-use also, of course.

On a more positive note, non-using study interviewees said they simply did not need a Facebook (or online) presence, in some cases because they had 'real friends', or they did not have time. One of the supporters said that at the charity where he worked that offered supported, opined in an email to the researcher that: 'if they lived in more socially isolated situations and this were a means to communicate with others in a 'safe' virtual community this would be time well spent. But … they have full and active lives in a community of real people and a lot of outgoing social activity already'. One could argue here that for some participants, Facebook did not offer any 'need gratification' (Kim & Kim, 2019).

5. Discussion

The results of this study, as documented above, show that although many positive aspects of using Facebook are enjoyed by people with learning disabilities, a lot of concern was also expressed, both by themselves and by their supporters. Having explored factors that influence the use (and non-use) of Facebook, this section will examine how opportunities for safe and enjoyable exploitation of the platform can be best facilitated. Clearly, supporters play a major role in this context. However, it is important to note that in the UK, the Mental Capacity Act (DoH, 2005) obliges people in a supporting role to make an assumption 'that everyone from the age of 16 [has] mental capacity', and that 'all practicable steps' must be taken to help them make *their own* choices,' [emphasis added]. The aspiration is, of course, to promote independence and autonomy. There were cases of clandestine monitoring (in one case, to the point of deleting friend requests—an action possible by having access to the user's password, having set up the account) which arguably do not meet these requirements. It is important to emphasise, however, that such behaviour was always undertaken for the best of motives, and felt to be the right course to safeguard people supported from exploitation, online bullying or other hurtful experiences.

Many supporters mentioned helping in a manner which reflected more a policy of trying to facilitate individual choice, albeit also being mindful of the potential negative outcomes. As one supporter interviewee put it 'Great support can help people use social media. It is a question of getting the balance right between support and encouraging and opening possibilities for independence'. A way of describing this would be as 'facilitated, guided autonomy'. Examples offered included helping to write posts, navigating the privacy and other settings, and giving general advice. In one case, an informal agreement was in place between a support worker and the people they supported, to jointly evaluate 'friend' requests (arising out of an earlier case of online abuse). People supported expressed an appreciation of what they appeared to regard as caring behaviour.

A different level of support was articulated by one organisation which had taken the attitude, as expressed by a supporter interviewee, that 'if you can't beat them, join them!'. It has set up various (closed) Facebook groups of its own. This came about because its self-advocacy 'Council' wanted to be part of 'something about campaigning for change … with themes around social care cuts, health inequalities, etc.' They wanted an online channel, as a way of continuing a discussion between meetings. Facebook was chosen as a pre-existing platform, operated very much within a 'facilitated, guided autonomy' ethos—as demonstrated by the fact that posts can contain 'It's my birthday', despite the main aim being to highlight the political campaigning of the group. As posts are

moderated, however, abusive or hurtful posts are deleted, and supporters help write some of the posts, in Council meetings, for example.

It is worth noting, to conclude this discussion that having a 'learning disability' does not signify an inability to learn. One supporter interviewee remarked that he and his staff always aimed to enable or facilitate learning, and support would gradually diminish as the learner became more accomplished and thence more autonomous. This is exactly the aim of the 'facilitated guided autonomy' approach.

6. Conclusion

The research described in this paper shows that, while Facebook can be a powerful tool for enjoyment, social engagement and self-expression, many PWLD are reluctant to contribute themselves, for fear of ridicule; and others declined to use the platform at all (albeit in some cases simply because they already led full lives). Supporters saw positive social opportunities but were concerned about safety. A complex picture emerged of a delicate interplay between facilitating engagement while protecting against harm. This paper argues that constructive engagement by supporters offering a facilitated, guided autonomy for those they support would help the latter very much in enjoying all the fun and enjoyment afforded by this form of online connectivity. The term 'Facebook assistants' conferred on the supporters might even be used to emphasise their subservient role they should adopt in these endeavors.

7. Acknowledgements

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