

# Edinburgh Research Explorer

# Using social media to be 'social'

## Citation for published version:

Gillespie-Smith, K, Hendry, G, Anduuru, N, Laird, T & Ballantyne, C 2021, 'Using social media to be 'social': Perceptions of social media benefits and risk by autistic young people, and parents', Research in Developmental Disabilities, vol. 118, 104081. https://doi.org/10.1016/j.ridd.2021.104081

#### **Digital Object Identifier (DOI):**

10.1016/j.ridd.2021.104081

#### Link:

Link to publication record in Edinburgh Research Explorer

#### **Document Version:**

Peer reviewed version

#### Published In:

Research in Developmental Disabilities

#### **General rights**

Copyright for the publications made accessible via the Edinburgh Research Explorer is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy
The University of Edinburgh has made every reasonable effort to ensure that Edinburgh Research Explorer content complies with UK legislation. If you believe that the public display of this file breaches copyright please contact openaccess@ed.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.



Using social media to be 'social': Perceptions of social media benefits and risk by autistic young people, and parents.

Karri Gillespie-Smith\*<sup>1</sup>, Gillian Hendry<sup>2</sup>, Nicole Anduuru<sup>2</sup>, Tracey Laird<sup>2</sup>, & Carrie Ballantyne<sup>2</sup>

- 1. Department of Clinical Psychology, School of Health in Social Science, University of Edinburgh, Edinburgh, UK.
- 2. Division of Psychology, School of Education and Social Sciences, University of West of Scotland, Paisley, UK.

\*The corresponding author is Dr Karri Gillespie-Smith, Department of Clinical Psychology, School of Health in Social Science, University of Edinburgh, Edinburgh, UK. Email: <a href="mailto:Karri.Gillespie-Smith@ed.ac.uk">Karri.Gillespie-Smith@ed.ac.uk</a>. Telephone: (0)131 651 3932.

Accepted to Research in Developmental Disabilities – 28th August 2021

Title: Using social media to be 'social': Perceptions of social media benefits and risk by autistic young people, and parents.

#### Abstract

Autistic individuals are known to struggle with aspects of social interaction. Past research has shown that social media use can help to facilitate social functioning, however, the perceptions of risks and benefits when engaging on social media platforms remains unclear. The current study aimed to explore perceptions of social media participation in terms of online risk and online relationships in both autistic young people and parents. Eight autistic young people and six parents of autistic young people took part in semi-structured interviews, with the resultant data being transcribed and analysed using Braun & Clarke's (2006) inductive thematic analysis. Two themes were identified in relation to the impact social media has on autistic young people's relationships (Socialisation; Communication) and two themes were identified in relation to the perceived barriers and risks to engaging online (Abusive interactions; Talking to strangers). These findings show that social interaction is of particular value to young autistic people, in terms of affording them easier social interactions than there would be in 'real life'. The findings also show that the autistic young people were aware of risks online, and considered ways in which they try to manage this risk. Future research is needed to understand if similar interactions and risk take place across all platforms and whether online communication is successful between matched or mixed autistic and nonautistic groups.

## **Keywords:**

autism, young people, parents, social media, relationships, risk, communication

## What this paper adds

This paper adds to existing autism and online technologies literature since it is the first study to investigate perceptions of benefits and risks associated with social media use in autistic young people, and parents of autistic children. The current study showed that online social interactions were particularly valuable to autistic young people since it allowed them to interact more easily with others by removing some of the perceived social barriers. The findings also indicated that there are risks to such online engagement that the autistic young people may encounter, however rather than showing social naivety online, the autistic young people in the current study indicated awareness of such risks. They were able to reflect on the need to employ strategies when interacting online to ensure their safety. This research shows that social interaction that takes place over social media is valuable to autistic young people, however, more research is required to investigate whether there are similar benefits across all online platforms and when interacting with different types of groups (i.e. autistic and non-autistic).

#### 1. Introduction

Autism is a neurodevelopmental condition which comprises of a range of repetitive and restricted interests as well as core impairments in social interaction and communication (American Psychiatric Association - APA, 2013). Autism is heterogeneous with socio-communicative differences occurring along a continuum (Landa & Goldberg, 2005), further interacting with complex cognitive profiles (Rice et al., 2012). Many autistic individuals are reported to show difficulties interpreting social situations (Smith et al., 2010) and may miss or inappropriately respond to communicative cues (Rump et al., 2009). Recently, however, research suggests that such communication difficulties are the result of a mismatch in neurotypes as opposed to autistic-specific issues with communicating (e.g. Milton, 2020; Crompton et al., 2020a) and are less intimated by negative first impressions when communicating with another autistic person (DeBrabander et al., 2019). This highlights that there are no communication issues when autistic people are interacting with each other and that instead, misunderstandings arise when autistic people are communicating with neurotypical people (Crompton et al., 2020b).

Regardless of reported social difficulties, research has shown that autistic young people recognise the value of peer relationships and strive to create and maintain common bonds with others (Azad et al., 2017; Jaswal & Akhtar, 2019). Despite this motivation to make lasting connections and friendships, evidence suggests that autistic groups lack close friendships (Eaves & Ho, 2008; Whitehouse et al., 2009), making them suffer higher rates of social isolation (Orsmond et al., 2004; Orsmond et al., 2013) and social vulnerability (Hebron & Humphrey, 2014; Howlin et al., 2004). Autistic individuals have fewer friends compared to their typically developing (TD) peers (Petrina et al., 2014), generally last for a shorter period of time, and are often with other children with disabilities rather than TD children (Bauminger & Shulman, 2003; Locke et al., 2010). The lack of social connections and

heightened social vulnerability can have real implications on mental health and wellbeing (Cage et al., 2018), and so friendship creation and maintenance is an important area for research in autism; particularly the impact of social media on friendships and relationships.

Online social media platforms offer autistic individuals an alternative method of engaging in social interaction, and may be appealing due to the diminished levels of social demands (Lough et al., 2015) whilst at the same time drawing on strengths and interests in screen-based technology (Mazurek, 2013). Research has shown that groups with developmental disabilities spend greater amounts of time online compared to their typical counterparts (Kagohar et al., 2013; Mazurek & Wenstrup, 2013) and rely more on online communication for social interactions and relationships (Heasman & Gillespie, 2019; Stiller et al., 2019; Ward et al., 2018).

However, although there are great benefits for autistic young people to engage with others online, there are also risks that accompany this. Many children still struggle to identify risks or distinguish what behaviours and norms should apply offline and online (Livingstone et al., 2019). This issue may be greater in autistic groups where real life social vulnerability may extend to online platforms and situations (Lough et al., 2015), increasing the risk of online bullying, peer pressure and exposure to images displaying violent and sexual content (Livingstone et al., 2014). It has also been reported that older autistic children spend a large amount of time using the internet (Brewster & Coleyshaw, 2010; MacMullin et al., 2016) suggesting that their exposure to online risk may be higher compared to their typically developing peers. In line with this, evidence suggests that autistic people may be more susceptible to cyberbullying and online exploitation (Levine, 2013), however, to date there has been no research carried out to examine whether autistic young people do encounter more risks or are more vulnerable online compared to their typical counterparts. Given the

reported high levels of time spent online by this group (Brewster & Coleyshaw, 2010; MacMullin et al., 2016) this is an important question that needs to be addressed.

The increased risk of internet use could be an additional stressor for parents of autistic children who may feel concerned over their child using social media platforms to engage with others. Parents of typically developing children and young people often report that they are concerned about online risks (Facer et al., 2003; Livingstone, 2002; Livingstone 2006). To date, however, there has been no research focused on whether there are similar concerns in parents who have autistic children. This is a considerable knowledge gap within the literature, given that autistic young people are reported to show high levels of vulnerability in real-life encounters (Lough et al., 2015). It is therefore imperative to explore actual autistic experiences and parental perceptions of online risk and benefits for young autistic people. The current study aims to examine perceptions and experiences of online interactions and online risk in autistic young people and parents of autistic young people.

#### 2. Methods

#### 2.1 Procedure

The data for this paper is taken from two separate projects exploring the role of online social networking sites for establishing and maintaining relationships amongst autistic young people, while also navigating online risk. The first project (A) focused on the experiences of autistic individuals themselves and the second (B) on parental understandings of autistic young people's online interactions. Both studies come from the same institution, and following ethical approval by the University Research Ethics Committee, the researchers contacted parent and autistic youth organisations to recruit participants. Organisations advertised the study via their mailing lists and social media accounts, and interested participants contacted the researchers to arrange mutually convenient face-to-face or

telephone/ online interviews, on a one-to-one basis. Face to face interviews were conducted at the home institution, where both the participant and researcher had complete privacy to engage in the interview. Consent was obtained before interviews were carried out. Data was collected between February 2019 and July 2019, and the interview schedules can be found in Appendix A.

As shown in Table 1 below, semi-structured interviews were conducted with eight autistic young people (six of whom were interviewed twice, to obtain further information and clarify details) between the ages of 16 and 19 years, and six parents of autistic young people between the ages of 7 and 14 years. The ages of parent participants were not obtained, as it was not relevant to the study, and it should be noted the parent participants were unrelated to the autistic participants who took part as these were separate projects (A and B). Semi-structured interviews have the advantage of allowing the researcher to address pertinent issues, but maintaining flexibility to permit subsequent topics or points of interest to be discussed; focusing on a core topic to provide a general structure, but allowing for discovery as the conversation unfolds (Magaldi & Berler, 2020).

Interviews lasted between 4 minutes 23 seconds and 21 minutes 45 seconds, totalling 188 minutes 13 seconds, and averaging 13 minutes 26 seconds. Participants were verbally debriefed at the end of the interview and also provided with a debrief form with further contact details and support services.

## [Insert Table 1 here]

## 2.2 Data analysis

Braun & Clarke's (2006, pp.87) inductive approach to thematic analysis was applied to both data sets, consisting of the following six stepwise stages: 1. Becoming familiar with the data; 2. Generating initial codes; 3. Searching for themes; 4. Reviewing themes; 5. Defining and

naming themes; 6. Producing the report. This approach has been used to analyse data from similar populations previously (e.g. Crompton et al., 2020a; 2020b; Healy et al., 2013; Ludlow et al., 2012; Muggleton et al., 2019; Robertson et al., 2018), and is considered "creative, reflexive and subjective, with researcher subjectivity understood as a resource rather than a potential threat to knowledge production" (Braun & Clarke, 2019, p. 591). The analyses were initially guided by the aims of exploring (1) the role of online social networking sites and gaming forums in establishing and maintaining relationships amongst adolescents and young adults with ASD, and (2) parental understandings of their autistic children's online relationships and online safety.

The approach was inductive in that there was no pre-determined theory cited to underpin the data or the analysis process: indeed, data collection focused on autistic young peoples' interactions with social media generally, and themes were identified naturalistically through the analytical process. Identified themes can be found in Appendix B.

Through the process of analysis, it became clear that the two separate studies reported a similar focus on risks and benefits when engaging on social media platforms. By combining the autistic adolescent lived experience with parental perception, distinct but equally important perspectives are considered. As such, a subsequent thematic analysis (Braun & Clarke, 2006) was conducted on both data sets, focusing on the impact of social media on young people's relationships, and barriers and risks to engaging online, resulting in the generation of eleven initial themes (see Appendix 2 for these). These themes were reviewed and refined by the research team, resulting in the following four final themes (see Table 2 below), which will now be examined using excerpts from the data. For reference, 'A (number)' refers to an autistic young person, and 'P (number)' refers to a parent (as detailed in table 1 above).

## [Insert Table 2 here]

#### 3. Results

The analysis identified the following themes in relation to the two research aims, demonstrated below with example quotations.

## The impact of social media on relationships:

#### 3.1 Socialisation

To begin, the current data identified that social media was used as a way for autistic young people to socialise, despite the difficulties they might have in doing so:

- A(1) "I use it to socialise"
- P(1) "it means he gets to socialise with other people because if he wasn't on it he wouldn't get to socialise at all"
- P(3) (child uses social media for) "socialising and chatting to people"

The data therefore provided evidence that autistic young people used social media in the same way everyone else did, which is of interest given that a number of the platforms used by participants – or reported by parents – were for gaming rather than social media or social interaction specifically. P1 above in particular made reference to the fact that if her child did not socialise online, he would not socialise at all, highlighting the important role that social media played in these individuals' lives. Such socialisation can be further unpacked in terms of functions; the first being for friendship maintenance, as detailed by the following:

- A(2) "you can go on Facebook and just see what your friends are up to"
- P(4) "it's useful for keeping in touch"
- P(3) "he chats to his friends"

From the above, we saw that both autistic individuals and parents valued social media for maintaining contact with pre-established connections such as friends and family through the likes of chatting and visiting social media profiles such as Facebook. In addition, social media is used for friendship building, as detailed by the following:

- A(3) "it's sometimes good to talk to other people you don't know, to meet new people"
- A(7) "the thing is on social media, you don't know them all but you get to know them"
- A(4) (functions of social networking) "they are for making new friends"

Participants here talked about using social media as a way to establish new connections, by making new friends and getting to know people. Additionally, they also highlighted one of the inherent advantages of using social media in this way:

- A(1) "I can speak to more people online... compared to face to face"
- A(7) "helps you build a friendship with other people around the world"
- A(2) "I would say like if you really just wanting to talk to people and they're in a different country... I'm friends with different people from all over"

While individuals with autism can struggle to make new friendships, the evidence from the current data set suggests that, for these participants, having the opportunity to engage with others from around the world opens up a number of new opportunities for them in terms of developing friendships and making new connections. Whether autistic young people use social media to create new or maintain existing friendships, this demonstrates the positive impact of social media on their relationships.

3.2 Communication

We have seen from the above theme that social media provides a platform for socialisation,

but have not yet explored specifically how this socialisation is facilitated. Participants talked

about the value of developing communication skills, as detailed below:

P(1) (social media helps with) "communication skills so he can express himself as

he's not having to focus on looking at someone; he's able to talk away as he finds

normal conversations very distracting"

P(1) acknowledged some of the typical challenges autistic individuals have when

communicating face to face, highlighting that being behind a screen removes these and so

makes it easier: instead of having to deal with the "distracting" elements of interaction, her

child can focus on expressing himself correctly. Given that we know that autistic individuals

can struggle with face-to-face interaction, it is intuitive to assume, then, that online

interactions have a number of benefits over offline face-to-face interactions. Indeed, when

considering their online versus face-to-face communications, participants made reference to

which were better and easier:

A(3) "they're better online"

A(7) "I still find it easier online"

In addition, participants offered more substantial explanations as to why they preferred online

communication:

A(2) "I think some people, if they're that shy and scared, and too much anxiety and

all that. It's probably more best for them to do it behind a screen"

A(3) "maybe you would talk about things you wouldn't talk face to face"

11

A(7) "when you're talking to them like on a media thing you can actually speak to them more... instead of being scared what to say"

Here, participants referenced the various feelings that can accompany face to face interactions: anxiety, discomfort and fear. A2 identified that, although these feelings may not be removed, experiencing them behind a screen offers some form of shield that makes interaction more bearable and less intimidating. A3 detailed how, in the same way, the protection of the screen offers the opportunity to talk about things that may be more difficult to discuss in person, while A7, like P1 earlier, highlighted how, by removing the intensity of in-person interaction, the focus can remain on the topic of discussion. Participants also mentioned specific difficulties faced by individuals with autism such as eye contact, and how online communication therefore negates this:

A(7) "when you're talking to them you don't feel scared to... 'cause they're not actually looking at you in the eye... you're just relaxed with them... not quite as personal"

P(3) "I think because they're not having to use social cues or eye contact etc. it's better for him"

Evidence from the current data set, therefore, suggested that social media seems to offer these young people a specific and safe avenue of socialisation and communication, demonstrating a positive impact on their relationship. The analysis, however, also identified barriers and risks of engaging online as a young autistic person, which will be explored next.

## **Online barriers and risks:**

3.3 Abusive interactions

We know that bullying victimisation is more prevalent among autistic adolescents than in the general population and we also know that because of reported social skills deficits, the internet can provide an easier means of interaction for autistic individuals, as discussed in the above themes. However, increased online engagement heightens the possibility of autistic young people being involved with abusive interactions, detailed in three different ways in the current data. Firstly, participants discussed the types of abusive interactions they were aware of or had experienced:

- A(6) "there's some abuse online"
- A(8) "I've got people that comment hate stuff"
- A(2) "there'll be people that will be judgemental to you no matter what you are doing"
- A(2) "I do get a lot of criticism"

Here, we saw participants talk about "abuse", "hate stuff", "judgemental" comments and "criticism", demonstrating the variety of forms that abusive interactions may take. These were not identified as being linked to autism specifically, and so it could be argued that they are the same type of abusive interactions that anyone may face, which in turn goes some way to 'normalise' them. For some participants, such interactions were more resolutely interpreted as examples of bullying:

- A(5) (a risk is) "cyberbullying"
- P(1) "there are always risks of online bullying"

This highlighted the severity with which such interactions are considered and demonstrated a clear risk of engaging online; that these young people may face being bullied. In addition, participants detailed the impact that such abusive interactions can have:

P(1) "sometimes he comes through and says he has had to throw someone off for being rude or block someone – this made him upset and he was shouting and screaming"

P(2) "I also think there are people who think they can say things because they're online: they couldn't say to your face that could cause a bit of emotional disturbance"

A(8) "it can be (stressful). A while back, young people had been saying stuff to me"

A(2) "people can just go on you and just really upset you"

Here, we saw mention of the distress that results from such abusive interactions, in terms of causing upset, emotional disturbance and stress. This provides further evidence that these autistic young people – and parents –recognise the potential consequences of their online interactions, further highlighting that one barrier to engaging online is the risk of encountering abuse of some nature.

## 3.4 Talking to strangers

A second barrier/ risk to engaging online is talking to strangers, as demonstrated by the following:

A(3) "there can be bad experiences online, especially if you're talking to somebody who you don't know"

A(6) "with strangers... I tend to avoid them... if I don't know you, then, no thanks"

P(6) (one thing causing concern is) "in case she... talks to people she

doesn't know"

Participants discussed the importance of knowing who is on the other side of the screen, and avoiding interacting with individuals who are unknown. In the interviews, participants were specifically asked whether or not they knew the people they interacted with online, and all eight autistic participants responded that they did, though did not classify specifically what this meant. Some were quite clear about the criteria that had to be met in order to consider 'knowing' an individual: for instance, having met them in real life, e.g.:

- A(6) "everyone I have online I have met at more points in my life"
- A(7) (how many online friends they know in real life) "most of them I know"

On the other hand, others did not make this as clear and rather focused on the extent to which they felt they knew a person without having physically met them:

- A(2) "I don't let anyone else get my Facebook who I don't properly know yet"
- A(3) "I don't really add anyone I don't know"

It would therefore appear that these participants self-policed the connections they made online, which seemed to stem from concern about interacting with people who may lie about themselves; primarily regarding their identity. Consider the following:

- A(3) (a risk is) "someone pretending to be someone... because behind the screen it could be anybody"
- A(7) "you never know there could be-someone could be pretending to be a certain age when they're not...like they're way older than you. Then they try and ask you to meet them or something like that"
- P(4) "of course there are risks, they could be anybody posing as a child. I try to monitor to make sure she's only talking to people she knows"

P(5) "I am worried with chat possibly if she chats to someone she thinks is a child and it's a grown man"

Both the autistic young people and parents demonstrated the importance of trust, though there is an interesting parallel raised here when we consider that the same participants who were very exacting about who they engaged with online also suggested that social media was an avenue to explore new relationships. The autistic young people in the current study seemed to put a lot of significance on 'knowing' their connections, which contradicts the earliest focus on using social media for socialisation and making new friends, but could perhaps be explained in terms of considering how online relationships/ friendships are built: that 'knowing' an online acquaintance follows a period in which friendships are explored and built.

The parents in the current study also highlighted the worry/ fear they have regarding who their children are speaking to online, in addition to the efforts they go to to try and keep their children safe. It is therefore suggested that although talking to strangers can be considered a risk of socialising online, the participants in this study appear to be very aware of it and protect themselves from any potential harm by only interacting with people they get to 'know', however this is constituted.

#### 4. Discussion

The current findings demonstrated two key points. Firstly, online social interaction is of particular value to young people with autism, given that they can interact without facing the usual social difficulties. Both parents and young people showed an awareness of social media being used as a platform for socialisation and connecting with others; facilitating the formation and maintenance of friendships which is in line with previous research showing

that friendship is related to online social media use in autistic groups (Brownlow et al., 2015; Subrahmanyam & Greenfield, 2008; Heasman & Gillespie, 2019; Van Schalkwyk et al., 2017; Wang & Edwards, 2016). While we are not arguing that online friendship development is specific to these participants – or indeed within the autistic population – it is evident that online socialisation provides particular benefits for autistic individuals; for instance, that they can concentrate on the interaction as opposed to more 'social' aspects that they may struggle with such as reading body language (e.g. Müller et al., 2008), tone of voice (Rutherford & Baron-Cohen, 2002), co-ordinating eye gaze (Canigueral & Hamilton, 2019), attending faces (Riby Doherty-Sneddon & Whittle, 2012; Sasson & Touchstone, 2014) and understanding facial communicative cues (Loth, Garrido, Ahmad, Watson, Duff & Duchaine, 2018).

The focus on communication indicated that both young people and parents specifically identified this as the most valued aspect of social interaction. Barker (2009) identified that, in neurotypical adolescents, communication with peer group members was the most important motivation for social media usage, and the autistic individuals in the current study showed that they are no different. Online spaces can be a helpful way for autistic people to communicate (Rosqvist et al., 2013; Stiller et al. 2019; Ward et al., 2018), and in the current study, participants expressed their preference for online interaction, in comparison to face-to-face interaction. Vallor (2012) suggests that online friendships can be strengthened through reciprocity, empathy, self-knowledge and sharing life, but warns that such interactions should be used to supplement – rather than substitute – face-to-face interactions, suggesting that there are advantages of having both on- and off-line relationships, so future work may want to more closely consider how autistic young people manage both types of interactions. Additionally, it is important to examine who the online interactions are with as autistic individuals do not show the same communication difficulties when conversing with other autistic people (Crompton et al., 2020a; 2020b; Milton 2012; 2020). Future research

should explore whether online social interactions are different within matched autistic groups, matched non-autistic groups and mixed autistic and non-autistic groups. This would highlight whether the same interaction and communicative challenges reported during real-life interactions (Crompton et al., 2020a; 2020b) are similar when these interactions take place online thereby exploring whether the double empathy problem (Milton 2012; 2020) extends to online interactions.

The current study shows that promoting social interaction online is inherently beneficial. However, we also need to pay heed to the drawbacks and risks of such engagement, which leads us to the second key point of the paper. The findings also indicate that there are risks to such online engagement, but that these are not necessarily any different to the risks encountered by individuals who do not have autism. In the current study, participants highlighted risks and barriers in terms of encountering abusive interactions and talking to strangers, but the fact that they are experiencing this suggests that they are being treated in a way similar to their non-autistic peers. Although past research has suggested that autistic young people may be more naïve online than their neurotypical peers (Frith, 1989; Jaarsma et al., 2012; Sidhu et al., 2016), the current paper demonstrated that participants were acutely aware of risks and barriers, and took steps to counter them; contrary to previous research that has reported how autistic young people show a lack of caution for strangers and risk awareness (e.g. Pfeffer, 2014; Sallafranque-St-Louis & Normand, 2017). The autistic young people in the current study (similar to the parents) acknowledged the difficulty of knowing who they were actually interacting with online in terms of talking to strangers. Past research has suggested that autistic people may be particularly vulnerable to individuals misrepresenting themselves (Benford, 2010), though the current study has shown that autistic individuals have a good understanding of the importance of knowing who they were talking to. How this was determined was not, however, particularly clear in that participants would not entertain the idea of engaging with "strangers", yet later discussed the development of friendships online, which must have begun this way.

Again, we must consider here how new friendships are formed within neurodiverse frameworks and approaches, given the apparent reluctance to engage with anyone unknown to the autistic young person. To explore this, future research could examine the processes involved in which a 'stranger' becomes a 'friend', in autistic young people to gain a better understanding of how relationships are created and maintained in neurodiverse groups.

#### Limitations

There are a number of limitations in the current study that warrant consideration in terms of both methodology and findings. Firstly, there was no measure of how much time the young people spent on social media. This would have allowed the researchers to better understand whether experiences or perceptions of benefits and risk were similar across all social media platforms and were similar for children who spent varying amounts of time on each platform. This would help to elucidate whether some risks or benefits were associated with specific platforms and whether better safety precautions or support is required. Secondly, parents who were recruited and interviewed were parents of autistic *children* and not autistic young people. Different results may have been found depending on a child's age, such as different platforms being popular with different age groups. Such factors should be controlled and explored in future lines of enquiry. Additionally, the parents and young people were not recruited from the same families which would have better represented the dual perspectives (parent and child) of social media within each family unit. Future research could better measure these variables within family units and explore whether perceptions of social media are similar in autistic young people and their parents to ascertain whether conflicting or similar views of social media arise between parents and their children. The study also did not measure linguistic or cognitive abilities within the sample, which may impact on the abilities to communicate online, understanding others, awareness of risk and the ability to use different online platforms. These are all important factors that need to be considered when looking at autistic people's views and perceptions of social media since these may differ considerably across autistic groups.

In terms of the findings, we must be mindful that the results gleaned are only specific to the current participants and so are not representative of all young autistic people – and parents of children with – autism. Although qualitative research such as this can provide more in depth data than other methods can, it is limited in terms of generalising findings, its validity and its reliability (Rose & Johnson, 2020), and it is important to note that these responses may be culturally specific. One final limitation to note – and worthy of discussion in itself – is the contrasting finding that participants use social media both to make new friends but also to avoid strangers. This juxtaposition seems counterintuitive; how can new friendships be established if individuals are unwilling to engage online with strangers? As detailed earlier, one way to interpret this finding is to consider it in terms of 'knowing'; that strangers become friends once the participants felt that they knew more about them. The researchers in the current study could have investigated this to a greater extent in order to try and better understand this apparent contradiction however this may have disrupted the interview quality and the authors believe that it is the interviewer's responsibility to accept the participant's version of events.

Despite these shortcomings the current study is the first study to examine parent and autistic young peoples' experiences and perceptions of online relationships and online risk. This is the first step towards a fruitful line of enquiry exploring online peer communication, interactions and relationships. Given the current universal circumstances (i.e. COVID-19 restrictions) that have impacted face-to-face interactions, leading to longer time being spent

online, more research is needed to examine these online interactions and relationships in young people. This will allow us to better understand the intricacies of online interactions and relationships, and establish whether young people can still have supportive peer groups and meaningful relationships to protect against isolation and related poor mental health.

To conclude, the current study adds to existing literature by highlighting the perceptions of social media of both autistic young people, and parents. These included positive experiences such as opportunities to socially connect, opportunities to create and maintain friendships as well as negative experiences around negative online attention and bullying. Interestingly the autistic young people's comments indicated that they were aware of online risks and that they reflected on ways to try and police their own behaviour, such as only adding known people as friends. This suggests that the autistic participants in the current study are not as socially naïve as past research suggests and that their knowledge of online safety allows them to mitigate some risks social media poses on them.

#### References

- Allen, K.A., Ryan, T., Gray, D.L., McInerney, D.M. & Waters, L. (2014). Social media use and social connectedness in adolescents: The positives and the potential pitfalls. *The Educational and Developmental Psychologist*, 31(1), 18-31.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). American Psychiatric Publishing.
- Atherton, G., Lummis, B., Day, S. X., & Cross, L. (2019). What am I thinking? Perspective-taking from the perspective of adolescents with autism. *Autism*, 23(5), 1186-1200.
- Azad, G. F., Locke, J., Kasari, C., & Mandell, D. S. (2017). Race, disability, and grade:

  Social relationships in children with autism spectrum disorders. *Autism*, *21*(1), 92-99.
- Bauminger, N. & Shulman, C. (2003). The development and maintenance of friendship in high-functioning children with autism. *Autism*, 7(1), 81–97.
- Barker, V. (2009). Older adolescents' motivations for social network site use: The influence of gender, group identity, and collective self-esteem. *CyberPsychology & Behaviour*, 12(2), doi: 10.1089/cpb.2008.0228.
- Baron-Cohen, S., Leslie, A. M., & Frith, U. (1985). Does the autistic child have a "theory of mind". *Cognition*, 21(1), 37-46.
- Benford, P. (2008). *The use of internet-based communication by people with autism*.

  Unpublished doctoral dissertation. University of Nottingham; United Kingdom.
- Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research* in *Psychology*, 3(2), 77-101.
- Braun, V. & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative*Research in Sport, Exercise and Health, 11(4), 589-597.

- Brewster, S., & Coleyshaw, L. (2011). Participation or exclusion? Perspectives of pupils with autistic spectrum disorders on their participation in leisure activities. *British Journal of Learning Disabilities*, 39(4), 284-291.
- Brownlow, C., Rosqvist, H.B. & O'Dell, L. (2015). Exploring the potential for social networking among people with autism: challenging dominant ideas of 'friendship'. Scandinavian Journal of Disability Research, 17(2), 188-193.
- Cage, E., Di Monaco, J. & Newell, V. (2018). Experiences of autism acceptance and mental health in autistic adults. *Journal of Autism and Developmental Disorders*, 48(2), 473-484.
- Cañigueral, R., & Hamilton, A. F. D. C. (2019). The role of eye gaze during natural social interactions in typical and autistic people. *Frontiers in Psychology*, *10*, 560.
- Carter, E.W., Common, E.A., Sreckovic, M.A., Huber, H.B., Bottema-Beutel, K., Gustafson, J.R., Dykstra, J. & Hume, K. (2014). Promoting social competence and peer relationships for adolescents with autism spectrum disorders. *Remedial and Special Education*, 35(2), 91-101.
- Crompton, C.J., Hallett, S., Ropar, D., Flynn, E. & Fletcher-Watson, S. (2020a). 'I never realised everybody felt as happy as I do when I am around autistic people': A thematic analysis of autistic adults' relationships with autistic and neurotypical friends and family. *Autism*, 24(6), doi.org/10.1177/1362361320908976
- Crompton, C. J., Ropar, D., Evans-Williams, C. V., Flynn, E. G., & Fletcher-Watson, S. (2020b). Autistic peer-to-peer information transfer is highly effective. *Autism*, *24*(7), 1704-1712.
- DeBrabander, K. M., Morrison, K. E., Jones, D. R., Faso, D. J., Chmielewski, M., & Sasson, N. J. (2019). Do first impressions of autistic adults differ between autistic and nonautistic observers? *Autism in Adulthood*, *1*(4), 250–257.

- Didden, R., Scholte, R.H.J., Korzilius, H., de Moor, J.M.H., Vermeulen, A... & Lancioni, G.E. (2009). Cyberbullying among students with intellectual and developmental disability in special education settings. *Developmental Neurorehabilitation*, 12(3), 146-151.
- Eaves, L. C., & Ho, H. H. (2008). Young adult outcome of autism spectrum disorders.

  \*\*Journal of Autism and Developmental Disorders, 38, 739–747.\*

  doi:10.1007/BF02172209.
- Facer, K., Furlong, J., Furlong, R., & Sutherland, R. (2003). ScreenPlay: Children and computing in the home. London: Routledge Falmer.
- Frith, U. (1989). Autism and "theory of mind". In C. Gillberg (ed.), *Diagnosis and treatment of autism*. Springer.
- Healy, S., Msetfi, R. & Gallagher, S. (2013). 'Happy and a bit nervous': the experiences of children with autism in physical education. *British Journal of Learning Disabilities*, 41(3), 222-228.
- Heasman, B., & Gillespie, A. (2019). Neurodivergent intersubjectivity: Distinctive features of how autistic people create shared understanding. *Autism*, 23(4), 910-921.
- Hebron, J., & Humphrey, N. (2014). Exposure to bullying among students with autism spectrum conditions: A multi-informant analysis of risk and protective factors. *Autism*, *18*(6), 618-630.
- Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry*, 45, 212–229. doi:10.1111/j.1469-7610.2004.00215.x.
- Jaarsma, P., Gelhaus, P. & Welin, S. (2012). Living the categorical imperative: autistic perspectives on lying and truth-telling between Kant and care ethics. *Medicine*, *Health Care and Philosophy*, 15(3), 271-277.

- Jaswal, V. K., & Akhtar, N. (2019). Being versus appearing socially uninterested:
  Challenging assumptions about social motivation in autism. *Behavioral and Brain Sciences*, 42, E82.
- Kagohar, D. M., van der Meer, I., Ramdoss, S., O;Reilly, M.F., Lancioni, G. E., Davis, T. N.,
  Rispoli, M., Lang, R., Marschik, P.B., Sutherland, D., Green, V.A. & Sigafoos, J.
  (2013). Using iPads and iPads in teacher programs for individuals with developmental disabilities. *Research in Developmental Disabilities*, 34, 147-156.
- Kowalski, R.N. & Fedina, C. (2011). Cyber bullying in ADHD and Asperger Syndrome populations. *Research in Autism Spectrum Disorders*, *5*(3), 1201-1208.
- Kuo, M.H., Orsmond, G.I., Coster, W.J. & Cohn, E.S. (2013). Media use among adolescents with autism spectrum disorder. *Autism*, *18*(8), 914-923.
- Landa, R. J., & Goldberg, M. C. (2005). Language, social, and executive functions in high functioning autism: A continuum of performance. *Journal of Autism and Developmental Disorders*, 35(5), 557.
- Levine. T, (2013). "The pros and perils of the internet in the autism community". Autism Spectrum Quarterly: Summer 2013.
- Little, L. (2002). Middle-class mother's perceptions of peer and sibling victimization among children with Asperger's syndrome and nonverbal learning disorders. *Issues in Comprehensive Pediatric Nursing*, 25, 43–57.
- Livingstone, S. (2002). Young people and new media. London: Sage.
- Livingstone, S., & Bober, M. (2006). Regulating the internet at home: contrasting the perspectives of children and parents. *Digital generations: Children, young people, and new media*, 93-113.
- Livingstone, S., Kirwil, L., Ponte, C., & Staksrud, E. (2014). In their own words: What bothers children online?. *European Journal of Communication*, 29(3), 271-288.

- Livingstone, S., & Palmer, T. (2012). Identifying vulnerable children online and what strategies can help them. *UK Safer Internet Centre*. London, UK.
- Livingstone, S., Stoilova, M., & Nandagiri, R. (2019). Children's data and privacy online: growing up in a digital age: an evidence review. *London School of Economics and Political Science*. London, UK.
- Locke, J., Ishijima, E.H., Kasari, C. & London, N. (2010). Loneliness, friendship quality and the social networks of adolescents with high-functioning autism in an inclusive school setting. *Journal of Research in Special Educational Needs*, 10(2), 74–81. https://doi.org/10.1111/j.1471-3802.2010.01148.x
- Loth, E., Garrido, L., Ahmad, J., Watson, E., Duff, A., & Duchaine, B. (2018). Facial expression recognition as a candidate marker for autism spectrum disorder: how frequent and severe are deficits?. *Molecular autism*, *9*(1), 1-11.
- Lough, E., Flynn, E., & Riby, D. M. (2015). Mapping real-world to online vulnerability in young people with developmental disorders: Illustrations from autism and Williams syndrome. *Review Journal of Autism and Developmental Disorders*, 2(1), 1-7.
- Ludlow, A., Skelly, C. & Rohleder, P. (2012). Challenges faced by parents of children diagnosed with autism spectrum disorder. *Journal of Health Psychology, 17*(5), doi.org/10.1177/1359105311422955
- MacMullin, J. A., Lunsky, Y., & Weiss, J. A. (2016). Plugged in: Electronics use in youth and young adults with autism spectrum disorder. *Autism*, 20(1), 45-54.
- Magaldi, D. & Berler, M. (2020). Semi-structured interviews. In V. Zeigler-Hill and T.K. Shackelford (eds.), *Encyclopedia of Personality and Individual Differences* (p. 4825). Springer.
- Mazurek, M.O. (2013). Social media use among adults with autism spectrum disorders.

  Computers in Human Behaviour, 29(4), 1709-1714.

- Mazurek, M. O., & Wenstrup, C. (2013). Television, video game and social media use among children with ASD and typically developing siblings. *Journal of Autism and Developmental Disorders*, 43(6), 1258-1271.
- Milton, D. E. (2012). On the ontological status of autism: the 'double empathy problem'. *Disability & Society*, 27(6), 883-887.
- Milton, D.E. (2020) The double empathy problem. In: International Conference on 'Neurodiversity: A Paradigm Shift In Higher Education & Employment', 3-4 Dec 2020, Dublin, Ireland (online).
- Muggleton, J.T.B., MacMahon, K. & Johnston, K. (2019). Exactly the same but completely different: A thematic analysis of clinical psychologists' conceptions on autism across genders. *Research in Autism Spectrum Disorders*, 62, 65-84.
- Müller, E., Schuler, A. and Yates, G., 2008, Social challenges and supports from the perspective of individuals with Asperger syndrome and other autism spectrum disabilities. *Autism*, 12(2), 173–190. https://doi.org/10.1177/1362361307086664
- Orsmond, G. I., Krauss, M. W., & Seltzer, M. M. (2004). Peer relationships and social and recreational activities among adolescents and adults with autism. *Journal of Autism and Developmental Disorders*, *34*, 245–256. doi: doi:10.1023/B:JADD.0000029547.96610.df.
- Orsmond, G. I., Shattuck, P. T., Cooper, B. P., Sterzing, P. R., & Anderson, K. A. (2013).

  Social participation among young adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 43(11), 2710-2719.
- Petrina, N., Carter, M. & Stephenson, J. (2014). The nature of friendship in children with autism spectrum disorders: A systematic review. *Research in Autism Spectrum Disorders* 8(2), 111–126. doi.org/10.1016/j.rasd. 2013.10.016

- Pfeffer, R. (2014). Risk and protective factors for the safety of children with autism: A qualitative study of caregivers' perspectives. *Journal of Family Strengths*, 14(1), 21.
- Riby, D. M., Doherty-Sneddon, G., & Whittle, L. (2012). Face-to-face interference in typical and atypical development. *Developmental science*, *15*(2), 281-291.
- Rice, K., Moriuchi, J. M., Jones, W., & Klin, A. (2012). Parsing heterogeneity in autism spectrum disorders: visual scanning of dynamic social scenes in school-aged children. *Journal of the American Academy of Child & Adolescent Psychiatry*, 51(3), 238-248.
- Robertson, A.E., Stanfield, A.C., Watt, J., Barry, F., Day, M., Cormack, M. & Melville, C. (2018). The experience and impact of anxiety in autistic adults: A thematic analysis. *Research in Autism Spectrum Disorders*, 46, 8-18.
- Rose, J. & Johnson, C.W. (2020). Contextualizing reliability and validity in qualitative research: toward more rigorous and trustworthy qualitative social science in leisure research. *Journal of Leisure Research*, *51*(4), 432-451.
- Rosqvist, H.B., Brownlow, C. & O'Dell, L. (2013). Mapping the social geographies of autism online and off-line narratives of neuro-shared and separate spaces. *Disability & Society*, 28(3), 367-379.
- Rump, K., Giovannelli, J., Minshew, N., & Strauss, M. (2009). The development of emotion recognition in individuals with autism. *Child Development*, 80(5), 1434–1447.
- Rutherford, M., & Baron-Cohen, S. (2002). Reading the mind in the voice: A study with normal adults and adults with Asperger syndrome and high functioning autism.

  \*Journal of Autism and Developmental Disorders, 32, 189–194\*
- Sallafranque-St-Louis, F. & Normand, C.L. (2017). From solitude to solicitation: How people with intellectual disability or autism spectrum disorder use the internet.

  Cyberpsychology: Journal of Psychosocial Research on Cyberspace, 11(1), article 7.

- Sasson, N. J., & Touchstone, E. W. (2014). Visual attention to competing social and object images by preschool children with autism spectrum disorder. *Journal of autism and developmental disorders*, 44(3), 584-592.
- Sidhu, S.S., Gwynette, M.F. & Veenstra-VanderWeele, J.M. (2016). Will you friend me?

  Understanding the complex interplay between social media, online gaming, and technology in autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, 55(10), S70.
- Smith, M. J., Montagne, B., Perrett, D. I., Gill, M., & Gallagher, L. (2010). Detecting subtle facial emotion recognition deficits in high-functioning autism using dynamic stimuli of varying intensities. *Neuropsychologia*, 48, 2777–2781.
- Stiller, A., Weber, J., Strube, F., & Mößle, T. (2019). Caregiver reports of screen time use of children with autism spectrum disorder: A qualitative study. *Behavioral Sciences*, *9*(5), 56.
- Subrahmanyam, K. & Greenfield, P. (2008). Online communication and adolescent relationships. *The Future of Children*, 18(1), 119-146.
- Vallor, S. (2012). Flourishing on Facebook: virtue friendship & new social media. *Ethics and Information Technology*, 14, 185-199.
- Van Schalkwyk, G. I., Marin, C. E., Ortiz, M., Rolison, M., Qayyum, Z., McPartland, J. C., Lebowitz, E.R., Volkmar, R.F. & Silverman, W. K. (2017). Social Media Use, Friendship Quality, and the Moderating Role of Anxiety in Adolescents with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 1-9.
- Wang, V. & Edwards, S. (2016). Strangers and friends I haven't met yet: a positive approach to young people's use of social media. *Journal of Youth Studies*, 19(9), 1204-1219.
- Ward, D. M., Dill-Shackleford, K. E., & Mazurek, M. O. (2018). Social media use and

- happiness in adults with autism spectrum disorder. *Cyberpsychology, Behavior, and Social Networking, 21*(3), 205-209.
- Weiss, J.A., Cappadocia, M.C., Tint, A. & Pepler, D. (2015). Bullying victimisation, parenting stress, and anxiety among adolescents and young adults with autism spectrum disorder. *Autism Research*, 8(6), 727-737.
- Whitehouse, A. J. O., Watt, H. J., Line, E. A., & Bishop, D. V. M. (2009). Adult psychosocial outcomes of children with specific language impairment, pragmatic language impairment and autism. *International Journal of Language & Communication Disorders*, 44(4), 511–528. doi:10.1080/13682820802708098.

## **Appendix A: Interview Schedules**

Appendix A1: Interview Schedule for autistic young people (Project A)

- 1. Which social networking sites do you use?
- **2.** How do you use these sites (i.e. to socialise or for information and resources, links to follow etc)?
- **3.** How many friends do you have on your Facebook/Twitter/Instagram or other social networking site like online gaming forums?
- **4.** How many of these friends do you know in person?
- **5.** Do you find that social networking sites or online gaming forums are a good way to make friends? Or get boyfriends/girlfriends? How does online sites help you do this?
- **6.** How do you find talking to others on these forums and sites compared to face to face communication?
- 7. How would you describe the quality of your online friendships compared to your offline friendships? Are your online friendships better than your real everyday friendships? In what ways?
- **8.** Do you think there are any risks associated with you being on social media sites? What do you think these are? Have you had such experiences? How have you previously or currently deal with these?
- **9.** Do you think social networking sites could be made better for young people by providing safeguards or better/easier access?
- **10.** In what way are social networking sites or online gaming forums a positive or negative influence on your life?

## Appendix A2: Interview Schedule for parents of autistic young people (Project B)

- 1. Which social networking sites does your child use?
- **2.** Which do they use most frequently?
- **3.** How many hours a day/week do you think they use the sites for?
- **4.** How does your child use these sites (i.e. to socialise or for information and resources, links to follow, support from peers etc)?
- 5. In what way are social networking sites or online gaming forums a positive influence on your child's life?
- **6.** In what way are social networking sites or online gaming forums a negative influence on your child's life?
- 7. Which skills do you think your child needs to use these sites? (Cognitive, emotional, social skills, communication and literacy skills / IT skills)
- **8.** Does your child acquire any skills in using these sites?
- **9.** How many friends does your child have on Facebook/Twitter/Instagram or other social networking sites like online gaming forums?
- 10. How many of these friends does your child know in person (i.e. real life)?
- **11.** Does your child find that social networking sites or online gaming forum are a good way to make friends?
- **12.** How do online sites help them do this is it the anonymity or because it's online?
- 13. Are you worried about your child being online? If so why? (safety concerns)
- **14.** Do you think there are any risks about your child being on social media sites? What do you think these are? (grooming, bullying, naivety)
- **15.** How do you currently deal with these?
- **16.** How do you educate your child about the online risks? (safety protocols, restrictions)

**17.** Do you think social networking sites could be made better for children with autism by providing safeguards or better easier access?

## **Appendix B: Initial theme development**

## Barriers & risks

- Risk of bullying/ fighting/ abuse
- Generic risk/ danger
- Strangers
- Identity/lying
- Account safety
- Transient "friendships"
- Content concerns
- Interpersonal abilities
- Time and impact
- Barriers: fear
- Barriers: electronic footprint

## Impact on relationships

- Socialisation (generally)
  - o Friendship maintenance
  - Friendship building
  - Widening circles
- Communication
  - o Easier/ better face to face
  - o Easier/ better online
- Being careful
- 'Knowing' online vs. real life
- Information gathering

• Parental monitoring

**Appendix C: Theme frequency data across participants** 

Participant	Theme 1 (Socialisation)	Theme 2 (Communication)	Theme 3 (Abusive interactions)	Theme 4 (Talking to strangers)	Total
A1	3	2	0	0	5
A2	8	6	4	6	24
A3	3	6	1	5	15
A4	2	1	0	0	3
A5	2	2	3	1	8
A6	4	2	1	4	11
A7	3	6	0	2	11
A8	0	3	2	1	6
P1	2	5	2	0	9
P2	1	0	1	2	4
P3	2	1	0	1	4
P4	2	1	0	3	6
P5	0	0	0	1	1
P6	0	0	0	1	1
Total	32	35	14	27	108