Uneasy Encounters: Youth, Social (Dis)comfort and the Autistic Self

# Abstract

Notions of autistic ‘faultiness’ shape depictions of the association between autism and uneasy social relationships. That framing has been the focus of critique by autistic activists and scholars who, exploring autistic people’s sociality, reframe issues of social difficulty in terms of inequality and discomfort. Located within this set of debates, the article analyses data from a UK based study of mental health narratives derived from semi-structured interviews with 19 autistic young adults aged 23 to 24. The NIHR funded the study, and a UK National Health Service Research Ethics Committee gave ethical approval. Sociality and social difficulties, feelings of discomfort, and perceptions of the autistic self as ‘faulty’ were themes of the study. Exploring the nexus of inequality, non-autistic social power, fears about social performance and (dis)comfort that underpinned the accounts, the article explores the conclusions the young adults reached about social difficulty. Critically examining notions of improvability, the article contributes to debates about sociality, social difficulty and comfort by questioning the assumption that social dysfunction is due to autistic ‘fault’. The article concludes with a discussion of inequality in autistic and non-autistic encounters, and of the social dynamics that deny autistic people social comfort.

**Keywords: UK; autism; comfort; improvability; mental health; sociality; social difficulties; young adults**

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## **Introduction**

## Autistic Faultiness

These are core aspects of what has been described as autistic "aloneness," "withdrawal," and "disconnectedness," autistic people "living in their own worlds," being "trapped" inside "shells" or behind "invisible walls," and many similar terms used by neurotypical (NT) people to describe their perception that autistic people are unable to be "together" with other people. (Sinclair, 2010)

Scientific and popular accounts portray autism as a condition that impairs the capacity for social bonding. Diagnostic histories, for example, report stories of parents seeking support for socially ‘odd’ children (Waltz, 2014), and the ‘discovery’ of a disorder characterised by deficits in social functioning (Feinstein, 2010; Verhoeff, 2013). Clinical models of autistic cognition, embodiment and interaction interpret social ‘dysfunction’ as a fault of autistic individuals (Kohls et al., 2012). Theory of Mind, a prominent cognitive model, proposes that autistic people are ‘blind’ to the mental states of others (Baron-Cohen, 1995). An inability to ‘mind read’, it is argued, inhibits social competence, leading to one-sided social encounters, the ‘inability to join a social group’, and aloneness (Baron-Cohen, 1995, p. 63). Neurogenetic models describe a deeply impaired sociality caused by a ‘faulty’ social brain (Donaldson and Young, 2008; Wickelgren, 2005). Cutting across such accounts is an additional understanding of autism as a ‘disturbance of affect or emotion’ (Jones et al., 2001, p. 393). An impoverished emotional capacity is said to leave autistic people ‘unconcerned with the beings and doings of others’ (Davidson and Smith, 2009, p. 899), and deprived of the ability to form ‘rich, rewarding, and meaningful relationships’ (Davidson and Smith, 2009, p. 899).

Spatial metaphors reinforce the association between autism and aloneness (Broderick and Ne’eman, 2008). Clinical portrayals of autism as a foreign or enclosed space (Hewetson, 2002; Sarrett, 2011), or of autistic people as part of an alien ‘neurological class’ (Duffy and Dorner, 2011, p. 211), suggest a distance from the normal or ordinary. Such metaphors operate as part of a ‘visual rhetoric’ (Garland-Thomson, 2001) that finds expression in cultural depictions of ‘autistic presence’ (Murray, 2010). Representations of autistic people as ‘socially incapable and isolated’ (Davidson and Henderson, 2010, p. 156) echo suggestions of ‘a vast and unbridgeable gulf’ (Duffy and Dorner, 2011, p. 209) between the ‘perfectly normal’ (Frith, 2003, p. 174) and the ‘deep strangeness’ (Duffy and Dorner, 2011, p. 209) of autism. A ‘spatial relation’ (Garland-Thomson, 2001, p. 340) is staged between ‘normal’ people and ‘faulty’ autistic people who lack social ability and connections. For Duffy and Dorner (2011), pathos taints this portrayal. The tragedy of autism is that the ‘sufferer’ is destined to be alone, forever in a world of their own (Biklen, 2005; Davidson, 2007).

## Social Connectedness

Theories weren’t relevant to me. What mattered to me was how my difficulties crippled and tied the me up inside. (Williams, 1994*,* p. 8)

You DO fill my cup, and it's delicious but will go to my head if I drink too many glasses. (Boue, 2016)

Clinical and popular texts construct autism as a condition that ‘precludes meaningful social behaviour’ (Grinker, 2010, p. 172). Recently, a budding autistic movement, constructing knowledge outside dominant scientific and cultural spaces (Solomon, 2008), has made such representations the site of a ‘battle for truth’ (Broderick and Ne’eman, 2008, p. 460). From autistic autobiographies like Grandin’s *Emergence* and Williams’s *Nobody Nowhere* and *Somebody Somewhere,* to autistic activists’ online debates about neurodiversity (Baggs, 2007; Walker, 2014), suggestions of a deep social interest challenge images of autistic aloneness. Such accounts do not depict autism as an absolute barrier to interaction, but as a series of traits that colour social encounter (Boue, 2016, 2017; Hacking, 2009). Heightened sensory acuity, language issues, and misreading of behaviour, for example, alongside inequality and prejudice, influence social interactions; depictions of autism as a positive difference provide a sense of what autistic people contribute socially (Grandin and Panek, 2013; McGuire and Michalko, 2011). These ‘inside’ views of autism (Grandin, 1992; Sinclair, 1992) depict social encounters as meaningfully complex. The truth, it is argued, is not that autistic people lack ‘a thick emotional life’ (Hacking, 2009, p. 1471), or that autistic people cannot be ‘together’ with others (Sinclair, 2010), but rather that autistic sociality is different, and often difficult.

This movement has influenced research. For example, expectations that autistic people should shape research (Milton and Bracher, 2013), research led by autistic people (Milton, 2014), and an emerging scholarship that extends ideas of neurodiversity and ‘neurotypical normativity’ into social analysis (Bergenmar et al., 2015; Runswick-Cole, 2014) all signal how knowledge production is adapting. Autistic people’s concerns have also led to a critique of person-first language (Kenny et al., 2015; Sinclair, 2013). Many research outputs (including this one) acknowledge a preference for the phrase ‘autistic person’ as a recognition of the importance of autism to the person. Shifts in the depiction of autistic people as social actors accompany these changes. Anthropological work, for example, has detailed the complexities of the social and cultural life of autistic individuals (Ochs et al., 2004; Ochs and Solomon, 2010). Milton [(2012)](https://paperpile.com/c/cONm2B/ZuK9/?locator=885&noauthor=1) critically reframes the language of social difficulties in terms of interactions between people with different capabilities, outlooks and habits. Social ‘difficulty’, from Milton’s [(2012, p. 885)](https://paperpile.com/c/cONm2B/ZuK9/?locator=885&noauthor=1) perspective, is not ‘a singular problem located in any one person. Rather it is based in the interaction between two differently disposed social actors.’ Acknowledging the contribution of autistic people to social encounters, and the role of autism and other people in shaping difficult encounters, is significant. Depicting autism as complexly implicated in the unfolding of social relationships disturbs the use of autism as a ‘prosthetic device’ through which ‘normal’ sociality is explored (Hollin, 2014; Murray, 2008).

## Sticky Encounters

Spatial metaphors invoke notions of autistic ‘separateness’ [(Broderick and Ne’eman, 2008)](https://paperpile.com/c/cONm2B/Yljt%2Bpxct). In contrast, discussions of connectedness and an emphasis on relational difficulties invite metaphors that capture the experience of autistic and non-autistic encounters. Research shows that, for autistic people, feelings of alienation, insecurity and a sense of not belonging permeate such encounters (Jones et al., 2001). Negative feelings guide strategies to ease discomfort (Ryan and Räisänen, 2008). In contrast, research on autistic friendships show that, when respected and accommodated, autistic people feel more comfortable, and better about themselves. The opportunity to formulate friendship norms outside dominant expectations enhances social comfort (Bertilsdotter Rosqvist et al., 2015; Sinclair, 2010).

Metaphorically speaking, tensions in autistic and non-autistic interactions mirror what Scully (2010, p. 27) describes as the ‘stickiness’ of disabled and non-disabled encounters, which she says are often ‘charged with any combination of responses, including awkwardness, fear, impatience, resentment, disgust, embarrassment, fascination, and confusion’. For Scully (2010, p. 27), stickiness results from the way that:

...in encounters between disabled and nondisabled people, the tacit rules of engagement that govern “ordinary” social life – rules about how to speak, proper comportment, which topics of conversation or requests are taboo, and so on – may well be broken. Disabled people can speak or move differently from the norm, may look odd, and may need to introduce topics, such as details of their needs for assistance, that are conventionally restricted to a more intimate circle.

Scully thus highlights the power inequalities that shape disabled and non-disabled encounters. Whilst she invokes the materiality of impairment, she does not see impairment as the source of social difficulties; instead, she sees them as a property of ‘asymmetrical’ encounters [(Scully, 2010, p. 35)](https://paperpile.com/c/cONm2B/wmK1/?locator=35). The negative emotions such encounters elicit are things disabled people usually anticipate and frequently labour to avoid. Ultimately, Scully (2010, p. 32) argues, ‘a play of concealment and disclosure… threads through all social life’. People seek to manage encounters in order to guarantee the comfort they require to feel secure.

The sticky metaphor is useful for reinterpreting social ‘dysfunction’ (Kohls et al., 2012) as a property of unequal autistic and non-autistic encounters (Ryan and Räisänen, 2008; Walker, 2014). For instance, a sticky quality underpins Milton’s (2014, p. 6) double empathy problem which says autistic and non-autistic people can ‘struggle to understand and relate to one another’. Scully’s metaphor also illuminates autistic people’s efforts to avoid the discomfort of a stigmatized difference (McLaughlin, 2017). Notions of self-improvement, for example, commonly inform discussions of autistic people’s social capacities, and autistic children and young adults are taught with great frequency to be more ‘normal’ to avoid disrupting social norms (Bertilsdotter Rosqvist, 2012). Responsibility to self-manage is encouraged by professionals attending to the ‘individual problem’ of autism (Brownlow, 2010, p. 15).

This article analyses experiences and the management of negative responses in autistic and non-autistic encounters. Using Scully’s metaphor to acknowledge sociality, non-autistic social power, and the relationality of social ‘dysfunction’, it explores autistic young adults’ accounts of social relationship and representations of themselves as ‘faulty’. The article shows how the young adults responded to social difficulty by seeking self-improvement. The analysis follows an account of the study from which the data comes. The article concludes with a discussion of (dis)comfort and inequality in autistic and non-autistic encounters.

# Methods

The data derive from a qualitative study of autistic young adults’ mental health narratives. That study was one strand of an NIHR funded programme of research seeking to support early recognition and intervention related to mental health difficulties among autistic people (NIHR programme grant “Improving outcomes for people with autism spectrum disorders by reducing mental health problems”, RP-PG-1211-20016). Accounts of the emergence of mental health issues over time were analysed to support the goal of improved mental health outcomes. The programme employed two advisory panels: one group of autistic adults, and one group of parents of autistic children. Ethical approval was obtained from an NHS Research Ethics Committee (Ref: 14/EM/1282). Material prepared by the full research team describe the research programme and set out the broader qualitative data (project title: “The Making Sense? study”, PI: Professor Bryony Beresford). This article is authored by one researcher, who was the main interviewer, as a way to ‘zoom in’ (Wolcott, 2009, p. 103) on sociality as part of how autistic youth talk. This is valuable. Whilst not seeking to explore social connectedness, relationships nonetheless appear throughout the data. By focusing on sociality, the article contributes to the study’s aims by locating emotional experience in the context of social encounters.

## The Sample

The qualitative study aimed to recruit 20 young adults with a diagnosis of autism or Asperger’s syndrome from a cohort of families based in the South of East England. The wider clinical programme required the cohort’s use. The organizers had worked with the families over many years, building longitudinal data (including from completed mental health questionnaires) on the cohort (Baird et al., 2006). Consent to contact the families had been gained during an earlier wave of research. Using an anonymised list, the research team identified young adults with experiences of anxiety, depression, and/or OCD, who did not have a learning disability, and who communicated using spoken language. The aim was to hear their stories. Initial approaches were made by the cohort administrator who explained the study and sought consent to share their details with the research team. Those who agreed received information about the study and a return slip if they did not wish to take part. Approaches to 36 families yielded 19 young participants. A telephone call provided an opportunity to talk about the study and to check the young adults still wanted to take part. All confirmed that they were happy. Interviews took place in family homes or at a London university linked to the research programme. Each interview lasted about one and a half hours, with informed consent gained first.

The cohort had limitations. Of the 19 young adults, just two are women. This may be due to an under-diagnosis of autism in girls when the cohort (which includes few young women) was established (Baird et al., 2011). The cohort is also largely white British. The sample is thus comprised mainly of white autistic young men aged 23 or 24 (due to their age when the cohort was created). For this reason, the article does not detail variations in age, gender or ethnicity. It does not address girls’ ability to ‘fit in’ with peers (Tierney et al., 2016), or how different cultural practices shape autism (Grinker, 2008, 2010). The research team did seek details on the young adults’ life situation. Reports of parent employment indicated a range of socio-economic backgrounds. Several young adults’ parents worked full-time in high paid professions, whilst the parents of others did not work, or worked in lower paid jobs, often part time. Regarding education, all attended mainstream schools, although some had spent time in special education. Half went onto post-secondary education. Half were job seeking, whilst half who had jobs spoke of concerns with underemployment or unsatisfactory work, indicating difficulties in entering the labour market (Howlin, 2000; Taylor and Seltzer, 2011). A third notable dimension of the sample, possibly a result of the recruitment method which did not make use of autistic networks, was the young adults’ limited contact with autistic social worlds (on- or offline). None belonged to an autistic social group and most said that this was not something they had considered. Instead, membership of autistic networks was something their parents had responsibility for (although most had ceased engaging). Such networks were a source of information, rather than community or identity (Bagatell, 2010).

## The Interview Encounter: Eliciting Stories of ‘Sticky’ Encounters

Relationships with non-autistic people dominated the participants’ stories. Parents, siblings and other family were the main form of connection. Others mentioned non-autistic school peers, girlfriends, and university friends (as they cast universities as spaces of diversity and tolerance). Mentors and support workers appeared at times, as did colleagues (but rarely as ‘friends’). The stories analysed thus relate to ‘dysfunction’ as a dynamic of autistic and non-autistic encounters. Stories not heard relate to how autistic social worlds enable creativity in forming social connections outside dominant norms (Bertilsdotter Rosqvist et al., 2015; Sinclair, 2010) and identity outside a language of social deficit (Bagatell, 2007). The article thus presents the young adults’ tendency to describe social difficulties related to their interactions with non-autistic others, and deficit as a property of their personhood.

The stories are attributable to the young adults’ social worlds, including things many were experiencing as they got older or recalled in relation to past relationships. The stories of ‘sticky’ encounters are also attributable to the way the study emphasised ‘troubling’ issues. For instance, each interview started with a discussion of ‘problems’ related to mental health and autism. Cards carrying words describing various difficulties linked to autism (such as ‘communication problems’, ‘introverted’, ‘fixed, rigid thinking’) and mental health (‘stress’, ‘anxiety’, ‘depression’) structured the discussion. The two advisory panels (including autistic adults) helped produce the cards by providing words they associated with autism and mental health, although the non-autistic research team narrowed these down to focus on a smaller number of core issues. Participants could use them to select and talk about issues relevant to their experiences. In this respect, the research set the tone of the stories.

The absence of an autistic researcher may also have reinforced that emphasis. The interview setting was not a space in which shared autistic understandings could inspire different knowledge about, or contest dominant narratives of, social connectedness (Bertilsdotter Rosqvist et al., 2013; Brownlow et al., 2015). The emphasis was also on the spoken word, perhaps inhibiting expansive expressions of emotion that autistic space may allow (Sinclair, 2010). However, there was no requirement for the young adults to talk about specific issues, and the interview structure allowed for lengthy discussion about what did or did not matter.

Analysis

The question driving the analysis was how the young adults understood and managed issues related to mental health. Data were analysed thematically (Miles et al., 2013), and a thematic framework developed during a process of immersion in the data (reading and re-reading transcripts) and discussions within the research team. The team’s primary researcher (this paper’s author) led much of this work. The programme’s two advisory panels looked over and fed back on the thematic framework. Themes identified related to experiences, understandings, and responses to mental health issues, social matters, and reflections on service provision and need. Each theme and sub-theme received a unique code. The interview transcripts were marked up using the codes to highlight analytically relevant data (Rapley, 2016). Word documents, containing headings corresponding to the identified themes, helped store and organize the data (extracted as verbatim text). ID codes provided links back to the source transcripts. Once data extraction was complete, detailed analytical notes were made that fed into the writing process through which data were further analysed (Wolcott, 2009). To ensure the data had been fully analysed and comprehensively reported, the writings were continually refined over several redrafts.

# Results

## Social Discomfort

One major theme that emerged during the interviews, and which related to the topic of sociality, was the idea of ‘awkwardness’, a word (not carried on any card) frequently used by the young adults to describe their experience of autistic and non-autistic encounters. The following quote (pseudonyms are used) illustrates a typical exchange:

Megan: *…it depends what mood I’m in and sometimes, unless it’s people that I know and then I don’t mind, but if it’s not then I’d rather not do it. Like there was like a, there was a big family get together, like second cousins and second relatives, and I didn’t go…*

Interviewer: *That might, yeah.*

Megan: *…I didn’t go, I thought no (laughter) I’m not doing that one...*

Interviewer: *Might be a bit much.*

Megan: *...I’m not making conversation with people I don’t know. (laughs) So that one.*

Interviewer: *Why would, why would, why those?*

Megan: *I don’t know, I…*

Interviewer: *Does that make feel particularly…?*

Megan: *…I feel awkward in these situations, I don’t like it I really don’t, I don’t like it.* (Megan, F)

For the young adults, awkwardness was ‘normal’. Conveyed in terms of their personhood, awkward was also, for many, something they could be (either all the time or sometimes):

*I feel like I’m, I am a bit socially awkward sometimes.* (Kyle, M)

At times, the young adults presented themselves as ‘faulty interactants’ (Goffman, 1967; Ryan and Räisänen, 2008) who contributed to the awkwardness of social encounters. For example, some young adults demonstrated this in accounts of themselves as lacking social or communicative skills, such as an ability to grasp the thoughts and feelings of another:

James: *social communication… cos it sorts of links to that one, it’s sort of social skills I’ve selected… kind of always think you’re not sure what people think. (laughs) … Perhaps not to being able to tell… and also perhaps sometimes struggling to understand other people’s… emotions sometimes.*

Interviewer: *Right. I mean we have this card here; missing cues and clues?*

James: *Oh, I didn’t see (laughs) yeah, that one… and sometimes you don’t quite understand the magnitude perhaps of the situations, you’re a bit awkward towards someone so you don’t quite know… what to say or what to do.* (James, M)

Interviewees talked about making their best efforts to be social, but also feeling that despite those efforts, things could go wrong. The attribution of feelings of awkwardness or anxiety to autism depended on an understanding of those feelings as intrinsic to autism, or to a view of autism as affecting social skills and leading to awkwardness. Persistent experiences of ‘sticky’ social encounters in the young adult’s lives seemed to indicate this link:

*I thought as I was growing older that that had stopped, I thought I had gained more understanding on how other people thought, but recently, by observing my social reaction with others, I think it’s actually still a bit. (laughs) … Maybe it’s changed a bit but I would say I definitely have a different way of thinking; it’s always kind of like you’re on a bit of a different wavelength… but I would say it varies with the individual… the circumstance and topic, so there’s sort of variables.* (Will, M)

There was a suggestion at times that the social dysfunction many of the young adults talked about had contributed to them experiencing a range of challenging emotions. For example, people talked about feeling embarrassed or awkward when social encounters broke down. Sometimes people spoke about feeling nervous at the prospect of that happening. Thus, the feeling could relate to anticipated awkward encounters. In other instances, the young adults talked about lacking confidence in new social situations:

Andrew: *I think a lot of my social anxiety happened probably as a result of secondary school where it, socially it wasn’t great, to be honest it was actually quite awful, so I, I’m not sure, necessarily sure of the right way to go about things…*

Interviewer: *Sure.*

Andrew: *…socially when I meet people outside of my normal day, well outside of like close family and friends, family and friends and that.*

Interviewer: *Sure. So once you’re getting away from these people you’re familiar with?*

Andrew: *Yeah, it, it plays on my mind ‘cos I don’t know how to approach it, but not knowing how to approach it is just, you know, leads onto that, those two as well; I’m not sure how to .. cope with them, therefore I end up just withdrawing myself ‘cos I don’t want to…*

*Interviewer: You don’t want to, yeah, deal, well get, put yourself into that horrible situation?*

Andrew: *Put myself in a horrible stressful situation, so go out and almost fearing the worst, well pretty much nearly fearing the worst in those situations.* (Andrew, M)

Andrew reflections mirrored an important element of the young adults’ accounts. Bound up in reflections on past relationships, often experiences of school-based bullying, there was an anticipation of unease and difficulty. On these grounds, important distinctions were made between familiar, established relationships, which appeared to represent ‘comfort’ (Sinclair, 2010), and unmade social connections, which presented, for some, a source of anxiety.

## Explaining ‘Sticky’ Encounters

### Being ‘faulty’

The young adults described feeling uneasy which they attributed to social dysfunction. The young adults also sought to explain such occurrences. One common claim was that autism directly contributed to awkward encounters. For example, some described autism as leading to communication problems. These undermined success in social encounters:

*…the frustration of not being able to communicate… obviously this one is directly autistic; that, there’s no way I can get around that one… I would have been able to speak by the time I was twelve if I didn’t have autism (laughs).* (Daniel, M)

*...communication problems… that goes without saying about how that happens with autistic people… the wires between the mouth and the brain, or sometimes the brain sends messages too quickly… they go like a traffic jam and you end up not knowing which ones to send out first.* (Aiden, M)

An additional factor identified and attributed to autism was anxiety. For example, Samuel believed that anxiety, rooted in self-doubt, affected his ability to talk:

*...sometimes when I’m talking to someone the anxiety overrides the actual element of communication. Like I might be worrying… did I say the wrong thing a couple of sentences ago and that’ll play on my mind and I wouldn’t… really hear what they’re saying, or this, that or the other… the anxiety… it decreases your performance… you can’t do well if you’re anxious, full stop… the inherent communication problem still lingers but, you know, a good fifty percent of it will be gone.* (Samuel, M)

To the young adults, it seemed clear that autism underpinned social difficulties. Autism could affect ‘performance’, success in which can be bound up in social standing and esteem (Goffman, 1967). Associated with this was the understanding of autism as a fixed condition. No matter how subtly expressed, many felt autism played a role in a range of experiences:

*...sometimes I feel when I talk about my Asperger Syndrome… some people would say I look and act fairly normal, they just see what’s on the surface, they don’t see what’s underneath, they can’t see how I’m wired, no, nobody can.* (Will, M)

Such accounts reflected a view of social dysfunction as being the product of innate autistic deficits, or autistic ‘faultiness’, something they felt they had to manage (Bagatell, 2007)

### The response of (non-autistic) others

Understandings of ‘faultiness’ informed the young adults’ accounts of social difficulties. However, there was also a commonly articulated belief that other people contributed to ‘sticky’ social encounters. For example, Dylan described his view that communication problems were not always a ‘problem’ that could be traced back to him:

*…communication seems to always be a problem… I mean sometimes I probably don’t really express it properly but I think other times as well I think it must, just could be everybody else just not choosing not to really understand really.* (Dylan, M)

*I can’t really express myself… I mean I do feel like I do but everyone else doesn’t seem to… it’s everyone else again… They hear it but, it’s like… they don’t want to hear it… or they don’t get it, even though I try and explain it they don’t get it.* (Dylan, M)

Dylan felt that other people must contribute to social dysfunction insofar as they failed to make the effort. His focus was on how others do not listen, a concern that deepened his feelings of worry. Others described these breakdowns in terms of two people failing to make sense of each other. Will, for example, talked about his relationship with his girlfriend:

Will: *Communication problems I would say very much overlaps with different way of thinking, ‘cos I feel I communicate myself quite clearly and yet I’m always surprised to see how people have misunderstood me, yeah. (laughs)*

Interviewer: *So, is that one way in which that becomes quite apparent to you?*

Will: *Yes, yeah, yeah. Yeah, like I was saying from the social interactions where they’ve misunderstood when I’ve, I’ve felt I’ve communicated to my best efforts, yeah… again sort of overlapping with different way of thinking… I would say there is still sometimes when I’ve not understood them properly… like I’m in a relationship at the moment and I’ve noticed that occasionally … I do something to upset my girlfriend, and I’ve not done it on purpose.* (Will, M)

Misunderstanding was a common element of this framing of social dysfunction. Several described misunderstanding as a property of a relation between an autistic communicator and a non-autistic listener. James, for example, spoke of non-autistic misunderstanding:

*I can immediately go with sort of the communication problems and sort of… sometimes you have difficulty knowing how to get a point across from me to someone else… other people, it’s just sometimes difficult for someone who doesn’t have autism to sort of understand.* (James, M)

For James, this unequal relation was also one in which he could be made to feel ‘weird’. A perception of himself as ‘faulty’ seemed to emerge in encounters with non-autistic people, who had the power to make him feel that way based on his own personality and habits:

*I’m guessing sort of… a weird sort of, but I’d think that’s sort of somebody else, but yourself you’re thinking weird cos you do things differently and, and, and you do notice that you’re sometimes a bit different how you work and it can make you feel a bit weird at times, so. But that’s other people sort of treat you differently if they know you’ve got autism, which again makes you feel weird.* (James, M)

Reframing social dysfunction as non-autistic misunderstanding and judgement revealed the young adults’ critical knowledge. They talked about social difficulty as involving two people, providing an expansive relational understanding of the link between social dysfunction and autism, and of non-autistic social power. Whilst maintaining a focus on the difference autism makes, they conveyed a belief that some ‘problems’ were not internal to autism.

## The Improvable Autistic Self

In addition to talking about feelings of social unease and explaining social difficulties, the young adults also talked about how they managed those issues. These accounts indicated the predominance of notions of autistic faultiness, evidenced in the use of practices of self-improvement (Brownlow, 2010). This work usually started with a perception of the autistic person as needing to ‘improve’. For example, Richard talked about wanting to avoid others seeing him as ‘weird’ after starting at a new college:

*I went to, to college and the first thing in my mind was I don’t want to act weird, that was the first thing, and I was sort of self-judging myself thinking… I don’t wanna sound weird, I don’t wanna look weird, am I dressing correctly, you know, all that sort of stuff, and it just came down to a self, self-analysis where I kept on picking on the slightest little things wrong with me.* (Richard, M)

More specifically, the young adults described feeling that their social functioning was intrinsically ‘faulty’. They took it on themselves to ‘get better socially’:

*…for me the depression was just… feeling like I was struggling to get better socially and feeling like I was getting nowhere… trying to become more socially competent and feeling like I’m making an arse out of myself.* (Matthew, M)

*I spend every second of my life managing… well social awkwardness, I spend every second of my life fixing that one (laughs). I like to think that every single day I learn something about that one. So yeah, that one I’m fixing… I just educate myself… I used to have to do it consciously, these days I do it subconsciously, I don’t think that’s the same thing as just picking it up naturally… I’ve had practice and practice is making perfect; so maybe that one is actually fixing it now.* (Daniel, M)

The language of self-improvement used by many participants informed self-management practices targeted at enhancing social and communication skills. This included reading books on social interaction and communication and observing themselves and others in instances when things did or did not work. Some did this from a place of comfort, such as accessing tricky situations with a sibling, parent or friend. Although staying close to those networks provided respite from the challenges that came with pushing themselves:

Andrew: *there was a time a few years back.. I tried to meet some new people but ... it (sighs) it didn’t end nasty but it was like really, really awkward, and before I went out I was, I wasn’t, it, the anxiety or a bit of the thoughts or, a bit, just…*

Interviewer: *Sure.*

Andrew: *…caused a few physical symptoms like feeling sick and, you know, upset tummy and all that.*

Interviewer: *Mm hmm, OK. So you tried, is that what…?*

Andrew: *Yeah; and then I did go and do it but... it, I was sort of overwhelmed at the, when I was there I didn’t know what to say, didn’t know how to necessarily go about it*… *I just haven’t really done it since, you know… I’ve just been like staying with my family and the cricket guys who play cricket; and I know them quite well* (Andrew, M)

The young adults often sought to adapt to the social worlds around them, rather than seeking to adapt the social world, require an adaptation on the part of others, or seek out alternative spaces they could be comfortable without worry (Bertilsdotter Rosqvist, 2012).

The young adults accounts suggested an ‘engineering’ of a better self (Nadesan, 2005), one less prone to experiencing ‘sticky’ social encounters. Consequently, they targeted their efforts at themselves, although, in part, many thought they were fundamentally ‘unfixable’:

*I would say communication problems is unfixable, fundamental, at a fundamental level it’s unfixable.* (Daniel, M)

‘Improvability’ was an aspiration, even as many felt it was not realizable in practice. They worked on themselves to make their encounters with others less awkward, sometimes motivated by a view of themselves as needing ‘fixed’. The young adults, in these moments, less often reflected on the role of others. Although some did talk about judgements made by others as needing to improve. For instance, Andrew thought that feeling less uneasy would require other people making effort to be less judgemental and more understanding:

*…probably get, ways to improve, probably other people giving more time to understand autistic people better. Doing that it’d probably increase the confidence to be more social, as such, with others. ‘Cos otherwise if there’s just always like misunderstandings, people just like myself, they’re not… not going to get any more confident if they just keep getting rejected, socially rejected, as such.* (Andrew, M)

This focus on the judgement and understanding of others echoed the idea that non-autistic people contribute to social dysfunction. However, that understanding featured less prominently in the ‘improvement’ work undertaken. That work instead resembled a form of ‘hidden labour’ [(Scully, 2010)](https://paperpile.com/c/cONm2B/wmK1) undertaken to reduce uneasy social interactions and to undo any potential for feelings of failure or negative judgements and misunderstanding to occur.

# Conclusion

In an NT world we’re playing poker. (Boue, 2017)

Outside of preferred family environments or established friendships, feelings of discomfort seemed to suffuse or have the potential to disrupt the young adults’ everyday social encounters. The specific contexts of (mainly non-autistic) family or friendship provided the young adults with the security, comfort and familiarity that has been identified as important in other studies of autistic sociality (Bertilsdotter Rosqvist et al., 2015; Ryan and Räisänen, 2008; Sinclair, 2010). In those contexts, comfort derived from a sociality to which they and others contributed. Feeling connected flowed from being with those who represented love, home, care and recognition, which was of great value for the young people. There was also little indication of a depleted desire for sociality (Rochat, 2009, p. 309) or lack of concern with others (Davidson and Smith, 2009, p. 899). Yet, outside those contexts, discomfort was ‘normal’, and there was an ambivalence about the requirement to be social. For example, antipathy about being with others derived from memories of feeling out of place, bullied or ostracised at school. They were also accustomed to sticky encounters, meaning situations they could not get to work, and in which they felt judged for their presence. The anticipated unease of unfamiliar social settings was another source of discomfort – the young people often felt they could be overwhelmed with the demands of unfamiliar social occasions, so sought to minimise their exposure. Finally, feeling that social difficulty was attributable to their behaviour or capacities shaped the young adults view of themselves as ‘faulty’. Presenting themselves as ‘fixable’, the young people invested a great deal of time and effort in improving themselves so that they may better ‘fit’ a non-autistic world (Brownlow, 2010).

Viewing themselves as ‘faulty’ but fixable interactants (Ryan and Räisänen, 2008), the young adults accounts did not much depart from dominant depictions of autistic people as at fault and requiring repair. The young people often said that they should get better, improve their skills, and be less anxious. This view is widely reinforced. The message autistic people often receive is that they should change to fit ‘normal’ society. For example, Brownlow (2010, p. 17) argues that popular treatments focused on teaching socially acceptable behaviour tend to locate autistic traits ‘within the domain of abnormality’. For Brownlow (2010, p. 17), the identification of a person as ‘not normal’ legitimises a therapeutic approach that seeks to change the autistic individual to make them ‘more closely resemble the behaviour of those deemed NT [neurologically typical]’. This logic underpinned the young adults’ accounts. They frequently returned to how what they were doing was problematic or to how they should improve. The desire for a ‘fix’ mirrored the therapeutic assumption that autism is a ‘faulty’ state that should be normalized (Brownlow, 2010, p. 17). It often seemed that the additional work this required was itself a weight, a source of stress and worry. The self-surveillance described by the young adults appeared to indicate an underlying lack of ease.

Less often discussed, but which greater exploration of the young adults critical knowledge may have revealed, were understandings of the nexus of inequality, non-autistic social power, fears about social performance and anxiety. For many of the young adults, feelings associated with the dynamics of social encounter could trouble them. More than anything directly related to autism, fears of failure and judgement (sustained by negative treatment) fed into concerns with being social – which they believed (in the context of their aging) they should be. Denial of comfort was political. The young adults acknowledged that non-autistic people could deny comfort through their responses, which led to feelings that they were not recognised, attended to, or valued (Rochat, 2009). A lack of ‘deference’, indicated in a lack of effort (Goffman, 1967), added to the weight of social dysfunction that dented confidence. The response was often to want to change the (‘faulty’) autistic self (Brownlow, 2010), not the dynamics of encounter. Indeed, this critical work underway in autistic communities (Bertilsdotter Rosqvist et al., 2015; Sinclair, 2010), and carried out by families (McLaughlin et al., 2008), may be less well developed among young adults outside of, or moving away from, such support networks. One immediate response could be to think more about how to convey the value of autistic difference, rather than emphasise treatments for the ‘problems’ of autistic ‘deficit’ (which may not be ‘problematic’) (Brownlow, 2010). Finding ways in which non-autistic people may learn about autistic people’s need for recognition, comfort and care, which unequal autistic and non-autistic encounters can deny, may be another consideration.

# References

Baird, G., Douglas H.R., Murphy M.S., 2011. Recognising and diagnosing autism in children and young people: summary of NICE guidance. BMJ. 343: d6360.

Baird, G., Simonoff E., Pickles A., Chandler, S., Loucas, T., Meldrum, D., Charman, T., 2006. Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). The Lancet. 368, 210–215.

Bagatell, N., 2007 Orchestrating voices: autism, identity and the power of discourse. Disabil. Soc. 22,413-426.

Bagatell, N., 2010. From cure to community: transforming notions of autism. ETHOS 38, 33-55.

Baggs, A., 2007, January 14. In my language. Retrieved from https://www.youtube.com/watch?v=JnylM1hI2jc.

Baron-Cohen, S., 1995. Mindblindness: An Essay on Autism and Theory of Mind. Bradford Books, London.

Bergenmar, J., Bertilsdotter Rosqvist, H.B., Lönngren, A., 2015. Autism and the question of the human. Lit. Med. 33, 202-221.

Bertilsdotter Rosqvist, H., 2012. Practice, practice: notions of training and normality among adults with Asperger Syndrome. Disabil. Stud. Q. 32.

Bertilsdotter Rosqvist, H., Brownlow, C., O'Dell, L., 2013. Mapping the social
geographies of autism - online and off-line narratives of neuro-shared and separate spaces. Disabil. Soc. 28, 367-379.

Bertilsdotter Rosqvist, H., Brownlow, C., O'Dell, L., 2015. "What's the point of having friends?" Reformulating notions of the meaning of friends and friendship among autistic people. Disabil. Stud. Q. 35.

Biklen, D., 2005. Autism and the Myth of the Person Alone. New York University Press, New York.

Boue, S., 2016. You are my champagne: the social life of an autistic woman. The Other Side. Retrieved from https://soniaboue.wordpress.com/2016/08/07/you-are-my-champagne-the-social-life-of-an-autistic-woman/

Boue, S., 2017. [Autistic resilience: talking up competence.](https://soniaboue.wordpress.com/2017/02/25/autistic-resilience-talking-up-competence/) The Other Side. Retrieved from https://soniaboue.wordpress.com/2017/02/25/autistic-resilience-talking-up-competence/

[Broderick, A.A., Ne’eman, A., 2008. Autism as metaphor: narrative and counter-narrative. International Journal of Inclusive Education 12, 459–476.](http://paperpile.com/b/cONm2B/Yljt)

Brownlow, C., 2010. Presenting the self: negotiating a label of autism, J. Intellect. Dev. Disabil. 35, 14-21.

Brownlow, C., O'Dell, L., Bertilsdotter Rosqvist, H., 2015. Neurodiverse spaces: exploring the potential for social networking among people with autism, deconstructing dominant ideas of ‘friendship’. Scand. J. Disabil. Res. 17, 188-193.

Davidson, J., 2007. ‘In a world of her own…’: re-presenting alienation and emotion in the lives and writings of women with autism. Gend. Place. Cult. 14, 659-677.

Davidson, J., Henderson, V.L., 2010. ‘Coming out’ on the spectrum: autism, identity and disclosure. Soc Cult Geogr. 11, 155-170.

Davidson, J., Smith, M., 2009. Autistic autobiographies and more-than-human emotional geographies. Environ. Plan D. 27, 898-916

Donaldson, Z.R., Young, L.J., 2008. Oxytocin, vasopressin, and the neurogenetics of sociality. Science 322, 900-904.

Duffy, J., Dorner, R., 2011. The pathos of “mindblindness”: autism, science, and sadness in “Theory of Mind” narratives. Journal of Literary & Cultural Disability Studies 5, 201-216.

Feinstein, A., 2010. A History of Autism: Conversations with the Pioneers. Wiley-Blackwell, Chichester.

Frith, U., 2003. Autism: Explaining the Enigma. Blackwell, Oxford.

Garland-Thomson, R. 2001. Seeing the disabled: visual rhetorics of disability in popular photography, in: Longmore P.K., Umansky L. (Eds.), The New Disability History: American Perspectives. New York University Press, New York, pp. 336–374

Goffman, E., 1967. Interaction Ritual: Essays of Face to Face Behaviour. Pantheon Books, New York.

Grandin, T., 1986. Emergence: Labelled Autistic. Arena Press, Novato, CA.

Grandin, T., 1992. An inside view of autism, in: Schopler, E., Mesibov, G.B. (Eds.), High-Functioning Individuals with Autism. Springer, New York, pp. 105-126.

Grandin, T., Panek, R., 2013. The Autistic Brain: Thinking Across the Spectrum. Houghton Mifflin Harcourt, New York.

Grinker, R.R., 2008. Unstrange Minds: Remapping the World of Autism. Basic Books, New York.

Grinker, R.R., 2010. Commentary: on being autistic, and social. Ethos 38, 172-178.

Hacking, I., 2009. Autistic autobiography. Phil. Trans. R. Soc. B. 364, 1467–1473

Hewetson, A., 2002. The Stolen Child: Aspects of Autism and Asperger Syndrome. Bergin & Garvey, Westport, CT.

Hollin, G., 2014. Autism, sociality, and human nature. Somatosphere.Retrieved fromhttp://somatosphere.net/2014/06/autism-sociality-and-human-nature.html

Howlin, P., 2000. Outcome in adult life for more able individuals with Autism or Asperger Syndrome. Autism 4, 63-83.

Jones, R.S. P., Zahl, A., Huws, J.C., 2001. First-hand accounts of emotional experiences in autism: a qualitative analysis. Disabil. Soc. 16, 393-401

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., Pellicano, E., 2015. Which terms should be used to describe autism? Perspectives from the UK autism community. Autism 20, 442–462.

Kohls, G., Chevallier, C., Troiani, V., Schultz, R.T., 2012. Social ‘wanting’ dysfunction in autism: neurobiological underpinnings and treatment implications. J. Neurodev. Disord. 4. Doi:10.1186/1866-1955-4-10

[McGuire, A.E., Michalko, R., 2011. Minds Between Us: Autism, mindblindness and the uncertainty of communication. Educational Philosophy and Theory 43, 162–177.](http://paperpile.com/b/cONm2B/Desm)

McLaughlin, J. 2017. The medical reshaping of disabled bodies as a response to stigma and a route to normality. Med. Humanit. Doi: 10.1136/medhum-2016-011065

McLaughlin, J., Goodley, D., Clavering, E. Fisher, P. 2008. Families Raising Disabled Children: Enabling Care and Social Justice. Palgrave Macmillan, Basingstoke.

[Miles, M.B., Huberman, A.M., Saldana, J., 2013. Qualitative Data Analysis: A Methods Sourcebook. SAGE, London.](http://paperpile.com/b/cONm2B/UowCD)

[Milton, D.E., 2012. On the ontological status of autism: the “double empathy problem.” Disabil. Soc. 27, 883–887.](http://paperpile.com/b/cONm2B/ZuK9)

[Milton, D.E., 2014. Autistic expertise: a critical reflection on the production of knowledge in autism studies. Autism 18, 794–802.](http://paperpile.com/b/cONm2B/pxct)

Milton, D.E., Bracher, M., 2013. Autistics speak but are they heard? Medical Sociology Online 7, 61–69.

Murray, S., 2008. Representing Autism: Culture, Narrative, Fascination. Liverpool University Press, Liverpool.

Murray, S., 2010. Autism functions/the function of autism. Disabil. Stud. Q. 30

Nadesan, M.H., 2005. Constructing Autism: Unravelling the “Truth” and Understanding the Social. Routledge, Abingdon.

Ochs, E., Kremer-Sadlik, T., Sirota, K.G., Solomon, O., 2004. Autism and the social world: an anthropological perspective. Discourse Stud. 6, 147 – 183.

Ochs, E., Solomon, O., 2010. Autistic sociality. Ethos 38, 69-92.

Rapley, T., 2016. Some pragmatics of data analysis, in: Silverman, D. (Ed.), Qualitative Research. Sage, London, pp: 331–346.

Rochat, P., 2009. Commentary: mutual recognition as a foundation of sociality and social comfort, in: Striano, T., Reid, V. (Eds.), Social Cognition: Development, Neuroscience and Autism. Wiley-Blackwell, Oxford: 303-317.

Runswick-Cole, K., 2014. “Us” and “them”: the limits and possibilities of a “politics of neurodiversity” in neoliberal times. Disabil. Soc. 29, 1117–1129.

Ryan, S., Räisänen, U., 2008. “It's like you are just a spectator in this thing” Experiencing social life the “aspie” way. Emot. Space Soc. 1, 135-143.

Sarrett, J.C., 2011. Trapped children: popular images of children with autism in the 1960s and 2000s. J Med Humanit. 32, 141-153.

Scully, J.L., 2010. Hidden labor: disabled/Nondisabled encounters, agency, and autonomy. Int. J. Fem. Approaches Bioeth. 3, 25–42.

Sinclair, J., 1992. Bridging the gaps: an inside-out view of autism (or, do you know what I don’t know?), in: Schopler, E., Mesibov, G.B. (Eds.), High-Functioning Individuals with Autism. Springer, New York, pp. 294-302.

Sinclair, J., 2010. Cultural commentary: being autistic together. Disabil Stud Q. 30.

Sinclair, J., 2013. Why I dislike “person first” language. Autonomy. Retrieved from http://www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/22

Solomon, A., 2008, May. The autism rights movement. New York Magazine. Retrieved from http://nymag.com/news/features/47225/

Taylor, J.L., Seltzer, M.M., 2011. Employment and post-secondary educational activities for young adults with Autism Spectrum Disorders during the transition to adulthood. J. Autism Dev. Disord. 41, 566-574.

Tierney, S., Burns, J., Kilbey, E., 2016. Looking behind the mask: social coping strategies of girls on the autistic spectrum. Res. Autism Spect. Dis. 23, 73-83.

Verhoeff, B., 2013. Autism in flux: a history of the concept from Leo Kanner to DSM-5. Hist. Psychiatry 24, 442-458

Walker, N. 2014. Neurodiversity: some basic terms & definitions. Neurocosmopolitanism. Retrieved from http://neurocosmopolitanism.com/neurodiversity-some-basic-terms-definitions/

[Waltz, M., 2014. Autism: A Social and Medical History. Palgrave Macmillan, Basingstoke.](http://paperpile.com/b/cONm2B/7si9)

Wickelgren, I., 2005. Autistic brains out of sync? Science 308, 1856-1858.

Williams, D., 1992. Nobody Nowhere: The Extraordinary Autobiography of an Autistic. Times Books, New York.

Williams, D., 1994. Somebody Somewhere: Breaking Free from the World of Autism. Times Books, New York.

Wolcott, H., 2009. Writing Up Qualitative Research, third ed. SAGE, Thousand Oaks, CA.

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