Contents lists available at ScienceDirect

Social Science & Medicine

Uneasy encounters: Youth, social (dis)comfort and the autistic self

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ABSTRACT

Notions of deficit and '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.

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1. Introduction

1.1. Autism and social difficulty

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).

1.2. 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)

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) 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) 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).

1.3. Sticky encounters

Spatial metaphors invoke notions of autistic 'separateness' (Broderick and Ne'eman, 2008). 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). 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