


Perplexing Presentations: Compulsory Neuronormativity and Cognitive Marginalisation in Social Work Practice with Autistic Mothers of Autistic Children

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Abstract

In recent years, there has been growing interest in exploring the experiences of autistic adults through a lens that adopts emancipatory theorisations of autism. However, despite this changing terrain, autistic people remain a highly subjugated population. Research has begun to theorise a distinctive form of epistemic injustice they encounter in which they are denied access to epistemic resources by a society that valorises cognitively normative ways of being, knowing and existing. An under-explored aspect of this emerging literature relates to the experiences of autistic mothers who are, themselves, much more likely to have autistic children. Evidence suggests that they may be at a substantially increased risk of involuntary social work interventions. This study explores the nature of these experiences, drawing on interviews with autistic mothers as well as my own, lived experiences as an autistic mother. It finds that, through a neuro-normative lens of social work scrutiny, indicators of neuro-divergency in both mothers and children are considered perplexing and assigned malign meanings by those with hermeneutic privilege. This was particularly evident in social work responses to children's difficulties in attending school, with these difficulties located in mothers rather than in exclusionary, hostile school environments.

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Introduction

If I could encapsulate my interactions with professionals, strangers, colleagues and peers in a single word, I would choose ‘perplexing’. As an autistic woman with Attention Deficit and Hyperactivity Disorder (ADHD), it is a word that describes both the way I am perceived by others and my own feelings about the way others respond to me. As a child, I came to realise that most people I encountered just did not ‘understand’ me. My direct manner and uncompromising honesty, my passion for unusual and niche topics, my propensity for interrupting overheard conversations to correct factual errors, my difficulty in mastering basic life skills despite competence in other areas that were far beyond my years.

These traits became particularly problematic after I began compulsory education and became exposed to the practices, processes, expectations, cliques and rules that characterise a typical school experience in the UK. I was fortunate enough to have been raised by parents who valued my strengths and appreciated my quirks. However, it became clear that the world I was brought into did not see me the same way. ‘ADHD’ and ‘autistic’ were not labels I received until later on in my life, but throughout my school years and beyond, I accumulated many other labels. Precocious, arrogant, rude, odd, aggressive, selfish, lazy, obsessive, argumentative, immature, naïve, melodramatic. Over the years, I was slowly crushed by the relentlessly negative way the core of my being was framed and understood by those around me. It was clear that my cognition—how I experienced the world and made sense of my experiences—made me different from the majority of people that I met. There was a fundamental mismatch in how we understood one another. I was a ‘perplexing’ person. And I was equally perplexed by others.

I am in no doubt that the hostile social conditions I encountered from early childhood contributed significantly to the profound difficulties and recurrent crises I had throughout my teens and twenties. This resulted in involuntary social service intervention when I began having difficulties parenting my own children who were similarly perplexing. Although my life has improved significantly in recent years, I still require ongoing social work support albeit on a voluntary basis. And the effects of social work surveillance remain with me.

Neurodivergence (including ADHD and autism) is strongly heritable. Yet, the experience of navigating parenthood and schooling as a

neurodivergent parent of a neurodivergent child has received little attention. Even less attention has been paid to the way this is understood within social work, an institution with significant influence and power in the lives of families like mine.

This article is my tentative, preliminary attempt at bridging that gap.

Before I proceed, I consider it important to explain my choice to use identity-first ('autistic', 'disabled') as opposed to person-first ('person with autism', 'person with disabilities') language throughout my piece. This reflects a preference expressed by autistic activists and autistic-led organisations, including Autistic UK (A-UK) who supported me in conducting this research. It also reflects my own, personal preference as an autistic woman. I consider autism to be a value neutral, innate part of my identity and do not feel a need to separate myself from it discursively to remind others of my personhood.

Context

Autism research, social work intervention and the freedom to be 'perplexing'

Autism has long been considered a 'perplexing' condition, reflected in the vast body of bio-medical and psychological research devoted to its causes, characteristics and treatments. Every aspect of our being has been pathologised; examined, unpicked and analysed by baffled 'outsiders'. Can autistic people be taught social skills by robots (Scassellati *et al.*, 2018)? What sort of fear responses can be evoked from frightening autistic toddlers with mechanical spiders (yes, really; Macari *et al.*, 2021)? How can autistic children be taught to play appropriately with toys (Stahmer and Schreibman, 1992)?

Such research is afforded epistemic privilege. And yet, Botha (2021) exposes the cognitive dissonance at its heart; in its use of seemingly neutral and scientific language to obscure the strong, normative value judgements that underlie its designation of autism's very existence as an ontological problem.

This understanding of autism—as innately complex and problematic—is evident in broader public perceptions, too. This is perhaps best exemplified by the jigsaw puzzle piece—autism's most widely known symbol. Chosen by non-autistic people, it is a semiotic representation of the 'mystery' of autism. The negative implications of this are borne out by studies showing puzzle-piece imagery that is implicitly associated with 'oddity, incompleteness, imperfection' (Gernsbacher *et al.*, 2018).

Why is this so problematic? After all, the designation of perplexing might appear fairly benign. And yet, for those parents who come to the attention of social services as I did, whose lives are governed, regulated

and examined under a microscope, perplexing is a loaded and pejorative term. Under the lens of social work scrutiny, behaviour that deviates from established, valorised norms leaves us open to suspicion—and worse.

The term perplexing has even, explicitly, come to be associated with a specific form of child abuse. As [Gullon-Scott and Long \(2022\)](#) point out in their landmark paper, guidelines encourage social work practitioners to treat perplexing presentations as a red flag for abuse against children in the form of fabricated and induced illness (FII). The authors argue that FII guidelines have created suspicion and marginalisation of vulnerable groups, including parents of disabled children. I suggest, however, that such prejudices do not originate in these guidelines. Rather, the guidelines extend the vocabulary that is used in discourse which seeks to rationalise age-old prejudices against those who are ‘not normal’ (see [Davis, 1995](#)). They represent an example of the hermeneutic injustices that I will discuss later: in which unconventional or unusual presentations are assigned a deleterious meaning by epistemically privileged outsiders (see [Fricker, 2009](#)).

Whilst [Gullon-Scott and Long \(2022\)](#) focus on perplexing presentations in children, I argue that a hegemonic privileging of normalcy—and association of non-normalcy with risk—has significant implications for how perplexing mothers of similarly perplexing children experience social work intervention.

Social work intervention and learning disability: a brief overview

Social work outcomes/interventions for autistic mothers of autistic children have not been explicitly explored or theorised. However, turning our attention to a closely related body of work—which considers social work intervention and parents with an intellectual/developmental disability—yields valuable insights. It suggests they have difficult experiences with social workers ([Gould and Dodd, 2014](#); [Theodore *et al.*, 2018](#); [Atkin and Kroese, 2021](#)) and are at a greatly heightened risk of having children removed from their care ([Llewellyn and Hindmarsh, 2015](#); [Tøssebro *et al.*, 2017](#); [Slayter and Jensen, 2019](#)). Globally, between 30 and 50 per cent of the children born to parents with learning disabilities are not in the care of their birth parents ([Booth and Booth, 2004](#)).

Research into the attitudes of social work professionals is also telling. It suggests an aversion to oddity which is used to rationalise aggressive, involuntary interventions ([Sigurjónsdóttir and Rice, 2017](#)). The meaning assigned to non-normalcy is a central concern for the critical perspectives that frame my own paper, as I will discuss next in my introduction to the terminology and theoretical framework I have used.

Neurodiversity and cognitive marginalisation: a new paradigm

Aligning with the neurodiversity paradigm (Grinker, 2020), I adopt an affirmative view of neurological differences such as autism and ADHD. I consider them to be value-neutral variations that sit within a healthy, desirable landscape of neurological diversity or ‘neurodiversity’. To be ‘neurodivergent’, as I am, is to have a neurology that diverges from the majority. It means that there are differences in my cognition that affect how I experience the world around me; how I think, reason, sense, process, express, perceive, communicate and feel.

Grounded in social models of disability (see Oliver, 2009), the neurodiversity paradigm recognises neurodivergence to be disabling within the world that privileges normative ways of being, knowing and existing. This results in epistemic injustices, both hermeneutical and testimonial, in which our lived experiences are disregarded, discounted and devalued.

In the context of neurodivergence, this form of oppression has been theorised as ‘cognitive marginalisation’ by Legault *et al.* (2021). The authors argue that many of the supposed deficits of autism are a direct result of inequity in accessing the epistemic resources required to participate in a society designed around ‘neuro-majorities’, that is those whose cognition aligns with socio-cultural norms. This, they argue, is a circular process by which we are denied a role in the creation of the same normative knowledge which is used to subjugate and exclude us.

This has particularly troubling implications within social work practice, given that how we are judged by social workers and the knowledge that is created about us in records and reports has the power to significantly harm us.

In what follows, I apply this understanding to an analysis of seven interviews with autistic mothers of autistic children. I propose ‘compulsory neuro-normativity’ as a neologism that describes a discursive cog within the broader machinery of ‘cognitive marginalisation’. It is a term influenced by concepts of both ‘compulsory heteronormativity’ (Rich, 1981) from feminist/queer theory and ‘compulsory able-bodiedness’ (Campbell, 2009) from disability studies.

I hope, in doing so, I can draw attention to a neglected aspect of cultural competence in social work practice, that is social work practice with the neurodivergent—exploring how compulsory neuro-normativity may contribute to the cognitive marginalisation of autistic parents of divergent children.

Methods

This article draws on interviews undertaken as part of my MSc dissertation. I enlisted the support of A-UK during the planning stage of my

study. A-UK is an organisation comprised entirely of autistic people, whose work involves campaigning for autistic rights. I met with them on several occasions to discuss matters such as ethics, terminology, accessibility and aims.

Ethics approval was sought from Cardiff University and granted on 20 May 2021.

I used purposive sampling to recruit participants based on the following criteria:

1. parents with either a formal diagnosis of autism spectrum disorder or who self-identify as autistic¹ and
2. subject to social work intervention between 2014 and 2021 for reasons related to parenting.

Participants were recruited via adverts on Facebook and Twitter on my own personal channels and the media channels of A-UK. Those who wished to participate were offered an opportunity to discuss with me. Written information and consent form were provided in both standard and easy-read versions.

I did not intentionally recruit parents of disabled children. However, it transpired that of the ten mothers I interviewed, those who retained custody of their children beyond infancy—seven in total—reported that their children were autistic. In addition, all of their children had co-occurring conditions from a range that included anxiety, phobias, eating disorders, encopresis (faecal incontinence and constipation), ADHD, hypermobility syndromes and learning disability.

During interviews and analysis it became clear that the specific experience of receiving social work services as an autistic mother of autistic children was an important—and sorely neglected—consideration for social work practitioners. And so, for the purposes of this article, I have chosen to focus on those seven participants who capture this demographic.

Additionally, I have included some of my own experiences of social work intervention as an autistic mother to two disabled children as data within this study. I adopt a view that autistic people should, themselves, be seen as ‘critical autism experts’ (Gillespie-Lynch *et al.*, 2017) challenging a view in which experiences such as my own are only considered valid data when filtered through the lens of an outsider.

I chose to gather data through the use of semi-structured interviews. I suggest that interviewing has emancipatory potential as a method, representing a backlash against a traditional preference for standardised measures and ‘objectivity’ in research. It can be argued that positivistic

1 Self-diagnosis of autism is a contentious issue but there is broad agreement within the autistic community that it should be accepted as valid. This reflects a view of autism as an identity rather than a disorder. It also acknowledges race, gender and class-based disparities in accessing formal diagnosis.

approaches such as this serve to ‘deform the localised and personal knowledge of research participants’ (Gergen, 2012, p. 21), allowing researchers to dictate the terms through which truth, knowledge and meaning are expressed. Intensive, semi-structured interviewing as conceptualised by Charmaz (1991) functions, instead, as a ‘guided conversation’. It allows for the gathering of rich data that are structured according to the participant’s priorities and thought processes rather than the researcher’s.

Interviews took place virtually and participants were provided with a range of options to enhance accessibility. Data were transcribed straight after interviews. I listened to recordings several times, utilising the process as a reflexive space that involved concurrent analysis. After transcription, data were inputted onto NVivo 12 for coding, using principles drawn from constructivist grounded theory (CGT) (Charmaz, 2014). Data underwent several rounds of coding; starting with initial coding for processes and finishing with refinement of codes into theoretical categories. The process was iterative and reflexive involving ongoing movement back and forth between data, literature and developing codes and categories (Henwood and Pidgeon, 1994).

Additionally, I made use of the situational analysis (SA) (Clarke, 2005) technique of mapping. This is an approach that has been used within disability studies as a means of situating personal stories within a complex, messy and layered social context (Thomas, 2020). SA posits a ‘situation’ to be the unit of analysis. This is treated as an entity comprising discursive, political, structural, temporal, geographical, spatial and social elements. These constituent parts—and the relationships between them—are identified and visually mapped out. Maps are continually updated throughout the process of data gathering and analysis. SA’s roots are grounded in CGT, and it is argued to both expand on and complement it, a ‘sister methodology’ (Clarke and Charmaz, 2013).

Limitations

My study is subject to a number of limitations which should be borne in mind when considering its findings.

First, the intersectionality I aspired to in my analysis was tempered by the relatively homogeneous nature of my sample. Whilst there was some variation in terms of social class, nationality and age, it should be noted that my participants were, for instance, almost universally white, aside from one participant who identified as mixed-race. This reflects an unfortunate tendency for disability studies to be white-centric to the extent that it has been characterised as ‘white disability studies’ (Bell, 2006). Additionally, my sample did not contain any participants with a learning/intellectual disability, reproducing broader social hierarchies that relegate

such voices to the fringes of thought. Future development of this research would, therefore, require a more purposeful and considered strategy for recruiting non-white and learning-disabled participants.

Secondly, as a piece grounded firmly in critical constructivism which also explores my own experiences, it cannot be considered a neutral account nor do I attempt to present it as one. The analysis which follows is unashamedly political, laying no claim to objectivity.

Findings

Perplexing children and cognitive injustice

Hegemonic discourses around motherhood contend that the ‘measure of a mother is her child’ (Carpenter and Austin, 2007, p. 660) with mothers positioned as innately responsible—and ‘culpable’—for everything their child is, does and experiences. It is a narrative with ominous implications for mothers of children who experience adversity, including disabled children.

Correspondingly, there is evidence of a culture of institutional parent blame within UK child disability social services (Clements and Aiello, 2021). Considered alongside evidence of long-standing social prejudices towards both disabled mothers (Fitzmaurice, 2002) and mothers of children with ‘invisible’ disabilities (Blum, 2007), it is not hard to see how interactions with statutory services might be particularly treacherous ground for autistic mothers of autistic children.

Here, ‘Jane’ describes her social worker’s response to her son expressing a belief he was autistic:

What’s written on the paperwork is ‘we’re very concerned that he thinks he’s autistic’. As if it’s the worst thing in the world to see yourself as autistic. So my perception of social workers and the word ‘autism’ is that they actually think that it’s some really bad thing to have, and they’ve got a really negative opinion on what autism is. And I think that that’s a really negative thing for our community

Jane interpreted this as assigning a negative value judgement to autism itself, an implication that neurodivergence is something unfortunate and undesirable. Additionally, I would suggest an accusatory undertone to this encounter. In echoes of language around FII discussed by Gullon-Scott and Long (2022), there are hints that Jane is being accused of fabrication or exaggeration. There is, too, evidence of testimonial injustice (Fricker, 2009) here in which neither Jane nor her son is considered credible sources of knowledge and their testimony is discounted.

A tendency to discount or dismiss indicators of neurodivergency was evident elsewhere, too, in the form of a hermeneutical injustices as well as testimonial ones. Without a shared understanding to draw on, there was a tendency to interpret perplexing presentations using a neuro-normative lens through which autistic traits were reconfigured as ‘suspicious’, suggestive of harm or damage.

For instance, ‘Susan’s’ child, Lilly, liked to wear a onesie outside the home:

She went through a whole year of wearing nothing but a onesie. And she also developed agoraphobia quite severely. . . So to be honest, if it was a choice between wearing a onesie and being prepared to not go out. . . well. . . I’d do anything to get her out of the house

Susan did not see enforcing ‘normal’ dress as particularly necessary or helpful. However, those around her took a different view. She notes ‘we had a complaint that Lilly was looking uncared for’. This resulted in the sudden appearance of a social worker at the family home, provoking a distressed response from her daughter, Lilly:

That sent her into a panic attack. Yeah, so she did her usual ‘naked at home’, which she always was, at the time, wrapped in a blanket rocking on the bed that was unmade. Her room was a mess, because that’s how she wanted it. Rocking on the bed going ‘I’m too hot. I’m too hot’. So yeah, it was bizarre. But still, the assumption was made that this was abuse rather than an autistic child having a panic attack

As in [Sigurjónsdóttir and Rice’s \(2017\)](#) study which explored the rationalisation of neglect accusations against learning-disabled mothers, observations of Susan’s homelife were interpreted through a ‘lens of disablist frames of knowledge’ ([Sigurjónsdóttir and Rice, 2017](#), p. 30).

The scene was interpreted as indicative of abuse or neglect, based on a neuro-normative understanding of ‘bizarre’ behaviours. The social worker had failed to consider the role that they had played in Lilly’s visible distress or why an unexpected intrusion into the family home might have been particularly distressing for an autistic family. As a neuro-minority subject to involuntary, state intervention, Susan was denied access to the hermeneutic privilege afforded to the social worker. Equally, the social worker did not have access to hermeneutic resources which might have allowed them greater insight into Lilly’s behaviour. This allowed the incident to be framed in a way that further marginalised Susan, and left her subject to increased scrutiny, governance and control by powerful others.

As we will see perplexing presentations were consistently identified as problematic by social workers with explanations and solutions being proposed in accordance with neuro-normative knowledge and standards.

Neurodivergent children and the battleground of school

Attitudes towards schooling expose a fundamental discord between neuro-normative and neuro-divergent experiences, values and beliefs. There is an ingrained, received wisdom which holds that school attendance is of critical importance to children's development, well-being and future success. In the UK, harsh measures are taken against parents who fail to secure their children's attendance including criminal prosecution.

Like many other parents, I have been told that school is the 'best place' for my children, that I should get them through the school gates by 'any means necessary'. I was not listened to when I described the clear and overt 'distress' that school attendance was causing my child.

My own experiences of school were extremely difficult to the extent that I had nightmares about being forced to return for years after I left. Everything from the structure of the school day with its constant shifts between subjects and spaces to the loud, crowded, noisy environment to the arbitrary rules, uncomfortable uniforms and pressure to make eye contact and keep still, to the likelihood of being harshly bullied if your face did not fit makes it hard to imagine a more hostile and exclusionary setting for autistic children.

Difficult experiences with school were a strong theme among my participants, too, compounded by forceful social work practice which treated school attendance as a meaningful end in itself. All participants described challenges engaging their children with mainstream education, noting specialist school placements ('Lizzie, Claire'), school refusal ('Donna'), behavioural difficulties in school and repeat exclusions ('Amy') and elective home education ('Heidi, Susan, Jane'). These failures to meet normative expectations that children should attend school regularly and successfully were a consistent source of friction between social workers and parents.

At times, an association between school attendance and well-being had the effect of mediating harsh judgements about the mother—albeit at the cost of a loss of support for the child. Heidi's parenting was initially judged in positive terms because her daughter, Samantha's, 'behaviour was so good at school. She was the quiet girl who never caused any trouble, which didn't even open her mouth'. Her daughter appeared normal and this was enough to alleviate concerns. Although Samantha might have seemed 'fine' when judged against neuro-normative benchmarks, she was in fact in the grip of a severe eating disorder and ultimately required hospitalisation for anorexia nervosa. 'Heidi' felt that school was contributing to her daughter's illness and chose to de-register her. This decision met resistance from social workers and led to a re-evaluation of previous, positive assessments of her parenting capacity:

There was a child protection meeting called because I had taken her out of school age 15 when she was supposed to get all A*s. They thought she was really brilliant. But she was losing weight and really unwell under the stress of the academic stuff... I argued that it didn't matter to me if she didn't get any A Levels, as long as she didn't starve to death.

Echoing Heidi's experiences, 'Jane' also described her choice to withdraw her child from school for well-being reasons meeting fierce resistance from school and social workers:

I pulled him out of school. So that's why they got social workers involved. They didn't like the fact that I'd been the person that recognised my son's depression, and actually sought support for his depression

Professionals were 'perplexed' as to why a mother would choose to withdraw a high achieving, compliant child from school. The 'appearance' of normalcy at any cost appeared preferable to a scenario in which a seemingly 'normal' child did not follow a neuro-normative trajectory of school attendance and academic success.

Donna's child Samuel often refused to attend school. Donna contends that this was due to severe anxiety and an inappropriate school environment which failed to meet his sensory needs. Samuel was placed on a statutory child protection plan as a result of her 'failure' to ensure his attendance. 'Donna' describes the blame directed towards her by her social services worker:

She decided that...Samuel's needs were being met [in school], it was a problem from home. And that we were giving him a choice to attend school...There were days where he would not be able to go to school, we'd take him to the gate and he couldn't go. And 'you're not trying hard enough'. She said this clearly to staff at school, 'they are not trying hard enough'.

Such practices and attitudes mean that neurodivergent parents are actively shamed, blamed and punished when their neurodivergent children have inevitable difficulties attending environments that do not support their needs.

In Claire's case, as a multiply-disabled mother to a child with complex needs and learning disabilities, her reliance on social services-funded respite provision was even used as leverage against her when her son refused to attend:

I was told that this [the respite] was a professional service, it was very full, it's there to give you a break. If you're not gonna send him to school, we're not gonna provide you with that, okay

This focus on parents as the source of problems resulted in a failure to consider the possibility that 'school itself' might be a 'safeguarding risk'. And yet, mothers consistently described the damage that exclusionary,

neuro-normative school environments caused to their disabled children. This included self-harm ('Donna and Amy'), eating disorders ('Heidi'), distress behaviours in a non-speaking child ('Claire') and severe depression ('Jane').

This is reflected in the broader literature, too, which consistently highlights how damaging and traumatic school environments can be for autistic children (Goodall, 2018).

There are some clear lessons here, for social workers. First, they should not be falsely reassured that children are 'fine' based on an outward appearance of compliance and normalcy leading them to discount parental testimony. Secondly, using punitive and aggressive practices to pressurise children—and their parents—into attendance does not negate the 'reasons' they struggle with attendance in the first place. Rather, it causes distress to children, places a devastating further strain on families and undermines collaborative, relationship-based practice. And thirdly, as a profession rooted in emancipatory values, as agents of social change and proponents of social justice, it is important that they look beyond mothers and consider the 'safeguarding risks' presented by neuro-normative institutions and hostile social conditions too.

Support? Here is a parenting course

A disregard of broader structural and social factors in favour of a focus on mothers as the source of problems extended to the type of support women were offered or presumed to need, too.

'Amy' describes a relentless battle to obtain practical support when faced with violent and volatile behaviour from her disabled son, Steven:

A few times over the years, I called Children Services and said 'Look, I'm desperate for help. I don't know what to do with this kid. Can I have some respite care?' To which the answer is always 'No, you can't have respite care'...So I had a breakdown. Because I thought this child is going to kill me one day...I can't get any more desperate than this. There's no level of desperation underneath this. This is it. And they're like 'Yeah... no'... they were doing their intensive support, which basically consisted of sending someone out every day for half an hour to, to chat to me and have a cup of tea and ask me about how I felt and you know, and I still felt crap.

Ultimately, 'Amy' did not receive the support she clearly and repeatedly stated that she needed. Her son required a long-term residential placement as a result. 'Amy' contends the need for this would have been negated by timely provision of the type of support she would have actually requested rather than the type of support she was presumed to need.

There are, of course, real and serious financial constraints in the provision of support. Social work is operating within resource-starved terrain

having suffered heavy, sustained losses from years of austerity (Murphy, 2021). However, whilst this may be a contributory factor, it does not easily explain the attitudes encountered by mothers nor a willingness to fund cost-equivalent—or more expensive alternatives.

In lieu of the practical support mothers say they needed and valued, they describe being offered—and encouraged to access—forms of support that focused on teaching ‘parenting skills’ and developing ‘emotional regulation’. As ‘Donna’ stated: ‘It just seems like the first port of call is putting the family on a course and then it feels like it’s the family who lacks skills.’ This willingness to fund interventions aimed at teaching women ‘better mothering’ instead of the practical help requested suggests an element of moralism in how resources are used (Jensen, 2018). It also speaks to the co-constitutive nature of testimonial and hermeneutical injustices; in which a failure to treat autistic mothers as credible sources of knowledge led to the imposition of support based on a paternalistic, neuro-normative interpretation of the problems faced by these families.

Not bloody boundaries again

This was particularly evident in the repeated prescription of ‘boundaries’ to autistic mothers.

Susan said:

The social worker felt we needed more in the way of boundaries...Yes, that’s the one she still likes to use. They’ve always used that in reports and stuff. Boundaries and routines. And forever pointing out that we didn’t have, like, bedtime routine

A conviction in enforcing boundaries is noted elsewhere in the literature, where it is argued to form part of a broader discourse that positions parenting as a skill; and non-compliant children as a result of feckless or uninformed parenting (Jensen, 2018).

In a similar vein, ‘Donna’ was given a list of neuro-normative family rules that she was expected to impose on her autistic child as part of a child protection plan to coerce them into attending school:

He finds screens and screen activities regulating, but the school had insisted that if he’s not at school, he must not be playing at all. Right. So, between nine and three part of the plan was not to do gaming, which caused him really serious outbursts, but we had no choice but to comply with this, obviously, because that was the plan.

This is a recommendation that was also made to me, and at first, I complied with it until I began to question the wisdom of attempting to force my child into a distressing environment by attempting to make his home environment even more distressing.

A neuro-normative interpretation of this situation fails to account for the differences in autistic brains that make school attendance particularly hard, and the withdrawal of cherished, self-regulatory items particularly distressing. The theorised harms of school absence and excessive screen time are seen to justify harsh, punitive measures which cause significant, visible distress to children.

In the case of Donna's son, the meltdowns caused by the withdrawal of his console were seen as evidence that her son had an 'unhealthy' relationship with his console that needed to be severed. This, it was theorised, would encourage him to engage with the 'real world', to attend school, build 'real' friendships and develop 'normal', valid hobbies. Through a neuro-normative lens, the online world he inhabited was not seen as meaningful and valuable.

Similarly, I have had a family support worker dispatched to our home, who was convinced that meltdowns could be prevented with the adoption of family rules, strict mealtimes with a single dinner to be served at the table so we could discuss our day, elaborate reward-and-consequence systems, a full schedule of demanding social activities. Many of the changes I was encouraged to make seemed geared towards giving our family an appearance of 'neurotypicality'. But, these practices just did not work for us as a neurodivergent family.

Imposing a single meal on a family full of individuals with sensory aversions is impossible and ensures 'nobody' eats. As a neurodivergent family, we do not 'do' small talk and so, chit-chat over the dinner table is awkward, stilted and unpleasant. Consequence systems cause frustration and meltdowns and do nothing to address the lagging skills which make it hard for my children to meet expectations. Screen time limits remove an important self-regulatory and communicative tool. Enforced socialising is hellish for all of us.

As 'Susan' notes, when explaining why her family did not adhere to the boundaries and routines her social worker considered essential 'We didn't not do it for philosophical reasons. It just doesn't work mostly'.

Epistemic authority and the 'normals'

As noted earlier, in a neuro-normative world, those who are designated 'normal' are also those who map the contours of what 'normal' and 'acceptable' are understood to mean. In the case of social work practice, this allows for the creation of impactful, damaging narratives about our lives, identities, motivations and experiences which are afforded a degree of epistemic authority we can feel powerless to challenge.

As 'Amy' states:

You're working with this sort of juggernaut of bureaucracy that once it has this idea in its mind about who you are, and what's happening...you

can't change that. And there's another thing about when they write stuff down, you know, Mum is this or child is that it rewrites history, because people read that then and they write it down in their own notes. And then the next person does it and the next person does it. And before you know it, this this thing is written down 50 times and you saying that it's not true means nothing anymore.

Ultimately, this focus on neurodivergent people as the cause of the difficulties, challenges and adversity they encounter serves to divert attention away from the broader systems, structures and processes which make autism disabling.

Discussion

To conclude, I have argued that being perplexing has deleterious implications for autistic mothers of autistic children who come to the attention of social services. This was considered against a neuro-normative social context that denies neurominorities access to epistemic resources. Perplexing children were viewed as innately problematic, with neurodivergent traits—such as unusual modes of dress or difficulty with unexpected visitors—reconfigured into a reflection of maternal failures.

This focus on mothers as the source of problems meant social workers failed to acknowledge the harm that hostile social conditions caused to autistic children. This was particularly evident in the punitive, aggressive practices adopted to promote school attendance. The responsibility for 'inclusion' was, ironically, placed onto individual families and pupils rather than schools.

This neuro-normative and individualist philosophy was also evident in the types of support mothers were offered and presumed to need. In lieu of the practical support requested, mothers were instead offered forms of support that focused on teaching parenting skills and enforcing boundaries. I concluded with a brief discussion of the sense of powerlessness that results from the imposition of harmful narratives about ourselves that we cannot challenge or change.

I will now move on to discussing the implications of my study, which are 2-fold.

First, my work applies concepts from queer/feminist theory and disability studies to a novel context; proposing 'compulsory neuro-normativity' as a neologism that describes a social privileging of normalcy. It describes a fundamentally individualistic philosophy; a view that structural and socio-political harms can be mediated on an 'individual' level through mimicking the praxis of 'normal' families as though this will grant them access to the cultural capital that normalcy provides (Garland-Thomson, 2002). I suggest the applicability of Campbell's (2009, p. 131) work on ableism here, who argues that 'compulsory

ableness and its conviction to and seduction of sameness as the basis to equality claims results in a resistance to consider ontologically peripheral lives as distinct ways of being human lest they produce a heightened devaluation.’ My work suggests a reluctance, by social workers, to consider the ‘ontologically peripheral’ praxis of autistic mothers as valid. Furthermore, their non-normalcy is inextricably linked, in the minds of practitioners, with the adversity they encounter allowing a view of inequity that is dislocated from its structural, political and social roots.

Secondly, my work contributes to a broader body of social work literature attending to facets of marginalisation. Despite the centrality of social work intervention in the lives of many autistic mothers (Rodgers *et al.*, 2018), their plight remains largely absent in social work literature. With this article, I have made a preliminary step towards filling this gap. In particular, I have added my voice to a budding literature that seeks to extend theorisations of epistemic injustice, considering how cognitive marginalisation operates in social work practice with autistic mothers. Hermeneutic injustices were shown to have a symbiotic relationship with testimonial injustices. This allowed social workers to fill gaps in knowledge with malign interpretations of perplexing autistic presentations and behaviours, despite having frequently created those gaps by discounting the credibility of autistic mothers and children.

Having summarised the key theoretical implications of my study, I will now move on to a brief discussion of implications for social work practice. Given the strong theme of discriminatory practices I have identified, it might appear fitting at this point to suggest a need for enhanced training and education.

And yet, I am sceptical that the answers lay solely here, given that epistemic injustice is a universal reality for marginalised groups and is experienced in multiple, intersecting and compounding ways. Just as I argue against locating structural, systemic issues within mothers, I also argue against locating them at the feet of individual social work practitioners. Cognitive marginalisation is, in my view, a deliberate feature of a neoliberal society that weaponises hostile social conditions as a means of marginalising and subjugating certain groups of people to benefit the interests of others.

It is clear that there are no easy or obvious solutions. I do not discount the importance of practitioner-level training altogether; indeed, I argue that practice with neuro-minorities should be considered an important facet of culturally competent social work practice. However, this must not be reductionist, tokenistic ‘awareness raising’ which severs the matter at hand from its socio-political context.

In line with Fricker’s ‘epistemic virtues’ (Fricker 2009), I propose to a role for social work research in challenging cognitive marginalisation and epistemic injustices. This must include concerted and serious efforts to allow those with lived experiences of social work intervention to play a central role in developing and evaluating social work’s knowledge base;

in proposing counter-narratives to socio-culturally maintained hegemonic discourses and in developing models of cultural competence to assist practice with minority populations.

I mentioned in my Introduction section that the effect of social work surveillance remains with me. I will now conclude by elaborating a little further on that. I feel it important to emphasise, first, that I was more fortunate than many of the mothers I interviewed. I retained custody of my children. I held privileges that many of the mothers did not in terms of my ethnicity, sexuality, family background and verbal fluency. And yet, despite these privileges, the spectre of social work judgement continues to haunt my day-to-day life. To this day, when I buy food for my family, I find myself buying many items that I know will remain un-eaten and be thrown away. Somehow, it feels as though lettuces, fresh herbs and hummus might act as a talisman against damning social work judgement, ‘balancing out’ the large quantities of chicken nuggets and microwave burgers that are among the only foods my children will reliably eat. It is always in the back of my mind that one day, a social worker might turn up at my door unannounced and demand to look in my fridge. If that day comes, at least my fridge might look like the fridge of a ‘normal caring mother’ to borrow the words of a participant.

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