

Proposing an Academic Space of “Autism and Profound Learning Disability”

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ABSTRACT

This article makes a practical suggestion to addressing the acute marginalisation of people with complex needs within academia. To do this, it first explores how the academic use of the terms “autism” and “severe/profound learning disabilities” leads to exclusionary practices where people with complex needs cannot represent themselves in research about their lives. These practices, this article contends, are epistemically and ethically unjustified. It demonstrates the former by exploring the shared ways in which people with complex needs are known in academic and social contexts. Regarding the latter, it argues that the research fields of autism and learning disabilities have favoured practices that exclude people with complex needs. To improve their academic representation, an academic space of “autism and profound learning disability” is proposed by drawing from Kraus’s (2015) theory of life-worlds and life-conditions. The aim of the space is to be open and inclusive to any person with complex needs related to the terms “autism” and “severe/profound learning disabilities”, and to develop ethical research and practices that include their perspectives, views, and values. The paper concludes by presenting a preliminary agenda for the space.

KEYWORDS

autism, severe learning disabilities, profound learning disabilities, PMLD, methodologies, representation, epistemology, complex needs, lifeworlds, life-conditions

Terminology

Within this article, the term “complex needs” refers to people who throughout their life will “require a high level of support with many aspects of [...] daily life, and rely on a range of health and social care services” (Think Local Act Personal, 2020). It adopts this term for the sake of clarity through the paper: to distinguish a group of people commonly marginalised from both learning disability and autism research. In the paper’s conclusion, a more appropriate term is suggested for future research involving this group.

In line with recommendations by Bottema-Beutel et al. (2020), and preferences of people within the autism community (Kenny et al., 2015), this research adopts identity-first language in reference to autism as it is contended that it reduces stigma. In contrast, person-first language is used in relation to learning disabilities, as it is the term most commonly adopted within research conducted by, or in partnership with, people with learning disabilities (e.g., Brownlee-Chapman et al., 2018).

Introduction: The Implications of Terminology

In a recent review of the transition of disabled people from institutional care to community-based services in Europe, Šiška and Beadle-Brown (2020: 15) state that “The role of research is critical [...], especially to create a body of research that is independent from the agendas of policy makers, service providers and other stakeholders. However, in order for this to be possible, *clear definitions and shared terminology and understanding* (emphasis added) are important”. One such area that lacks clarity relates to people with complex needs and the terms “autism” and “severe/profound learning disability”. At times, they are described under one banner, such as “developmental disabilities” or “autism with learning disabilities”, at others they are kept distinct, in the use of terms such as “profound autism” (see Lord et al., 2021) or “learning disabilities with complex needs”. As Simmons and Watson (2014b: 3) point out, even within more defined categories, such as profound and multiple learning disabilities (PMLD), terminology is manifold and inconsistent within research, policy, and practice.

Although diagnostic terminology is unclear and used variably, researchers use it to define their academic fields, who their research is about, the population they are focusing on, and who can and cannot take part. In academia, these diagnostic framings mean that people with complex needs can be excluded from representing themselves in autism or learning disability research if they do not have one related diagnosis or the other. This is despite the day-to-day circumstances of people with complex needs usually being remarkably similar, often sharing environments, support services, schools, housing, and support networks. And it is not just their circumstances that are similar, for these circumstances emanate from shared needs, characteristics, ways of communicating, and ways of engaging with the world. So, what is the justification for drawing from diagnostic terminology to define who can and cannot participate in research involving people with complex needs? And do the separate academic fields of autism and learning disabilities promote or hinder

opportunities for people with complex needs to represent themselves in research about their lives?

This paper seeks to answer the above questions, contending that there is no epistemic or ethical justification for researchers using diagnostic terminology to view and work with people with complex needs in separate academic spaces, and arguing that this practice exacerbates their deep-rooted marginalisation in academia (see Mietola et al., 2017). To address this, the paper draws from Kraus's (2015) concept of life-world and life-conditions as a way of understanding people with complex needs in relation to the terms "autism", "severe/profound learning disabilities", and "PMLD", and proposes a shared academic space aimed at promoting their participation and representation through ethical and appropriate methods and methodologies.

Who's Included? Distinguishing Autism from Severe/ Profound Learning Disability

The American Psychiatric Association (APA) is the foremost authority in defining autism and learning disability, guiding researchers through the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) (American Psychiatric Association, 2013). In the DSM-5, the "severe" and "profound" categories of learning disability (34–36) are markedly similar to that of "autism level 3" (52), all referring to people who require substantial day-to-day support. For example, level 3 autism denotes "severe deficits in verbal and nonverbal social communication skills", while profound learning disability means "the individual has very little understanding of symbolic communication in speech or gestures". Indeed, the similarity is acknowledged in the DSM-5 (58) – "intellectual disability without autism spectrum disorder may be difficult to differentiate from autism spectrum disorder..." – not only referencing shared characteristics in communication, but also the common presence of repetitive behaviours. So, while the DSM-5 has a broad guiding influence over researchers and who they include and exclude from research, they readily acknowledge the lack of difference between what they term autism level 3 and severe/profound learning disabilities.

The issue of differentiating autism and learning disability in people with complex needs was highlighted by Thurm et al. (2019), who, detailing changes in children's diagnostic rates over the past 20 years (Fombonne, 2003; Taylor et al., 2013), suggested that an increase in diagnoses of autism and a decrease in learning disability indicates a shift in how diagnostic practitioners are recognising and understanding disability. The authors recognised the common presence of sensory impairments/differences in relation to the two diagnoses, and noted that severe/profound learning disability, in comparison to mild/moderate learning disability, is more frequently diagnosed alongside autism than as a learning disability alone, indicating that practitioners correlate the two when assessing people with complex needs.

To distinguish autism from learning disabilities at point of diagnosis, Thurm et al. (2019) made six suggestions, such as using IQ assessments and observing a person's development into late childhood, though these are not useful for differentiating the

terms when considering people with complex needs. For example, the authors suggest that an autistic person may display behaviours that appear as though they have a learning disability, but that IQ scores could show them to have higher cognitive functioning than expected. However, IQ assessments are unreliable in relation to severe/profound learning disability (Whitaker, 2010) and discouraged in the DSM-5 (APA, 33), and even if they were reliable, they would not distinguish between a diagnosis of autism and severe/profound learning disability and that of severe/profound learning disability alone. Salient is the authors' (Thurm et al. 2019: 6) advice that the clinical judgement of an experienced practitioner is more reliable than that of any prescribed definition when differentiating the two diagnoses, suggesting that any research developed with such a definition as an epistemic foundation can, at best, only be considered to be nearly as reliable as the perception of a single person.

A commonly cited definition of profound learning disability that distinguishes autism as separate was developed by Bellamy et al. (2010) in the context of profound and multiple learning disabilities (PMLD). In this study, the authors drew together a range of definitions of PMLD from the PMLD and learning disability literature, though not the autism literature. Then to assess these definitions, they garnered the perspectives of parents and carers all with a personal or professional connection with PMLD, though not autism. A response from participants stands out: though they preferred a definition of PMLD by Lacey (1998) which stated that "autism can be difficult to establish if there's no communication" (230), they contended that autism was not a core feature of PMLD and its inclusion was seen as "problematic" (230). What the paper does not address, though, is why the inclusion of autism is problematic – it just *is*. There is no explanation of what participants think autism is, when they think it would be evident in a person with PMLD, or how they could distinguish such matters. Despite recognising in their earlier descriptions that autism is often present in people with PMLD, the authors conclude with a definition of PMLD that has no reference to autism, only a veiled indication if it ("may include neurological problems") (233). Thus, the study and resulting definition have clear bias, the researchers in essence asking a select number of people commonly concerned with PMLD whether they would like autism to be part of PMLD, to which they declined.

A rare empirical study that specifically aimed to determine differences between autism with severe/profound learning disability and severe/profound learning disability alone was conducted by Hoevenaars-van den Boom et al. (2009). To do this, practitioners examined behavioural differences in ten participants with severe learning disabilities, concluding that those considered autistic showed fewer social abilities, including in "openness for contact, reciprocity/join attention and communicative signals/functions" (554), which the authors claimed to be the signifying difference between the diagnoses. Issues in this study are manifold, though to begin, the recruitment methods were unsound, involving a three-person panel (a psychiatrist, psychologist, and an independent expert) using their personal judgements to assess 95 people with severe learning disabilities as to whether they had autism. The panel could not decide whether 32 of the 95 potential participants could be considered

autistic, not only demonstrating the study's lack of reliability, but also that even experienced practitioners have issues in differentiating the diagnoses.

The panel's judgements led to a notable difference between those participants considered autistic and those not, as 80% of the autism group were male, while 80% of the non-autism group were female. Understanding of autism in males and females has developed in the past decade, particularly in regards to social engagement (Dworzynski et al., 2012). For example, Hiller et al. (2016) found that social compensatory strategies (e.g. how to respond to social situations that are not fully understood) were different in autistic boys to autistic girls, with the former choosing isolation strategies (leaving or remaining a passive observer), and the latter implementing mimicking skills (copying those they were engaging with or those around them). According to this, the social domains highlighted by Hoevenaars-van den Boom et al. (2009) as being key to differentiating the presence or absence of autism in people with severe learning disabilities, may in fact be wholly explained by the gender difference of their participants. Inadvertently then, the researchers achieved the opposite of what they had aimed for, conducting a study that exemplifies the lack of rationale in distinguishing people with complex needs according to one diagnostic label or another.

In their closing section, Thurm et al. (2019: 7) made the argument that it is vital that researchers make clear their assumptions when beginning research into autism and learning disabilities, as this has a broad effect including on methodological direction, assessment tools, study aims, and who can participate. And while researchers may make an assumption that autism is different to severe/profound learning disability in the context of people with complex needs, there appears no epistemic justification for such a claim as the limited literature is unclear on what defines this separation, is heavily biased, or merely demonstrates the problem of differentiating. These assumptions have a broad impact, defining academic fields, their related outputs, and who is included and excluded, which in the case of people with complex needs reduces their already limited opportunities to participate in research about their lives and circumstances.

Distinguishing within Broader Contexts

Diagnostic labels are constructed and reified in broader contexts than research and its related literature. If within these contexts, people with complex needs are known and understood differently as relating to their diagnostic label, there could be justification for the separation of autism and severe/profound learning disability within academia. Two concepts relevant here are those of "emic and etic" perspectives (Goode, 1992 and 1994), and that of "epistemic communities" (O'Dell et al., 2016). The former was drawn from by David Goode (1992 and 1994) through his work researching the lives of children born "with congenital deaf-blindness and mental retardation" (Goode, 1994: 52–53). Goode found that in contrast to medical practitioners, people who engaged closely with such children understood them to have a social existence involving self-awareness, an engagement with others, and a capacity

to develop shared, idiosyncratic languages. Goode (1992) referred to these perspectives as the *etic* and the *emic*, the former being that of the clinical outsider, and the latter relating to the empathetic insider.

The concept of epistemic communities originates in the feminist work of Lynn Nelson (1993; Nelson, 1995) which focused on epistemology, specifically, the nature of evidence and epistemic agency. Epistemic agency relates to the ways in which people form and revise facts (Setiya, 2013) and the extent to which one intentionally acts in, as opposed to consents to, such processes (Cascio et al., 2020: 4). Nelson (1993: 121–123) makes a case that knowledge construction is a holistic process, with each supporting piece of evidence, methods, theories, and so on supporting the others. All pieces constitute evidence as they are part of a wider whole that implicates knowledge. Evidence of any sort is laden with socio-political value as it “depends on who knows, and who knows is a function of the social context” (Calvert-Minor, 2011: 347). In this regard, epistemic agency is heavily mediated by the community in which an individual is situated, as they decide what does and does not constitute evidence, guiding further knowledge construction in its mold.

Nelson’s epistemological perspective has been drawn from by O’Dell et al. (2016) in relation to diagnostic categories, particularly autism. It is the assertion of O’Dell et al. (2016) that to make sense of diagnostic labels, different social groups draw upon aspects of science and culture that result in particular epistemic communities. The authors highlight (173) how different geographical areas have different notions of what autism is and this affects how subsequent knowledge is constructed around the term. This argument is consequently expanded on through Ian Hacking’s concept of looping (Hacking, 1995; Hacking, 2002), as O’Dell et al. (2016) maintain that such knowledge constructions not only affect the definition and categorisation of autism, but also autistic people themselves.

The theories of epistemic communities and the *emic/etic* describe how diagnostic labels come to be known in different contexts. To look at this in the context of people with complex needs and explore whether their separation in academia is justified, the following section will refer to three key areas identified by Goodley (2001) in an early critical analysis of severe learning disability that remains relevant today; these are: challenging behaviour, narrative, and personhood.

The Construction of Personhood, Narrative, and Challenging Behaviour in the Social Contexts of Autism and Severe/Profound Learning Disability

Personhood has been a popular subject for philosophers (DeGrazia, 2005; McMahan, 2002; Singer, 2009) in the context of people with complex needs. This primarily relates to the philosophers’ perceptions of cognitive and social functioning, which they regard people with severe/profound learning disabilities as lacking to the greatest extent. They thus use people labelled as such as objects of moral assessment, equating their existence to dogs (McMahan, 2002) and other non-human animals

(Singer, 2009), and arguing that they are devoid of humanity, personhood and worth (DeGrazia, 2005; McMahan, 2002). These philosophical views situate learning disability within the person, who in turn is situated on a hierarchy of humanity measured through a perception of cognitive capacity. The philosophers mentioned argue that these are theoretical musings, devoid of moral or political judgement (see Keith and Keith, 2013: 72–74), and therefore require no “empirical substantiation” (McMahan referenced in Vehmas and Curtis, 2017: 508). From the epistemological perspective of Nelson (1993), however, these theories *are* evidence, derivative of and contributing to the dominant understandings of cognitive capacity and social functioning that exist within society, that which is framed through the etic perspective under autism and severe/profound learning disability. It has existed, as Keith and Keith (2013: 55–60) discuss, as the authoritative line of thought since the ancient Greek philosophers wrote about intelligence.

A counter to DeGrazia’s (2005) argument that personhood is absent in people with profound learning disabilities is provided by Simmons and Watson (2014a), who draw from their empirical, phenomenological study involving Sam, a person labelled as such (Simmons and Watson, 2014b). Personhood for DeGrazia is contingent on a human demonstrating sociality, communicative abilities, and self-awareness, all said to be deficient in relation to severe/profound learning disability and autism from the etic perspective. However, in exploring the experiences of Sam within different school settings, Simmons and Watson (2014b) found DeGrazia’s essential features of personhood to be evident in him through the ways he communicated, acted, and interacted, demonstrating the unreliable nature of the label in defining a person and therefore exposing the flawed philosophical arguments. Here, the change in evidence, theoretical (phenomenology) and empirical (observations of and close engagement with the person), provides a different knowledge of profound learning disability, showing that a person labeled as such may be seen to have varying capabilities and characteristics depending on their social and physical environments.

Turning to narrative, Goodley (2001) argued that this has been constructed in a way that victimises people with severe learning disabilities, as it has been done so from the etic perspective with little understanding of their experiences. Life story work has been a means to challenge this, shifting the focus from understanding people with learning disabilities “...as patients or subjects to considering them as people with their own unique life” (Hewitt, 2000: 90), “...not ‘what people are’ but ‘who people can be’” (Satchwell and Davidge, 2018: 349 referencing Banks, 2007). This approach is embedded in an epistemic research community that values the ways in which people make sense of their experience; this is prioritised as evidence as it is seen to construct knowledge that tells us something of the person, from their perspective.

In the context of autism for example, Smith (2016) focused on the everyday stories of a young autistic person at a dance class, showing how her friends, peers, and dance teachers did not know her “through a lens of autism and childhood” but through the way in which she constructed an embodied self, through dance. Similarly for McCormack (2017), the stories of people with PMLD and their families

were embedded in the people, schedules, and spaces that they have aligned themselves to over the course of their lives. Here, knowledge of PMLD, in the form of narrative, develops and forms at a measured pace through the small communities that people with complex needs are part of. Narrative as such complicates the distinction of autism and severe/profound learning disabilities further, as the emic perspective creates new and diverse understandings of the terms within the contexts of related communities and their everyday circumstances.

Behaviour, according to the DSM-5, is pivotal in recognising autism and/or severe/profound learning disability in a person. What Goodley (2001) drew attention to is the construction of behaviour labeled as challenging, commonly linked with complex needs, autism, and severe/profound learning disabilities (Tilley et al., 2015; Koritsas and Iacono, 2012). Service provision is one area where knowledge of challenging behaviour is constructed: for example, a discourse analysis of challenging behaviour referrals at autism and learning disability services (Nunkoosing and Haydon-Laurelut, 2011; Haydon-Laurelut et al., 2014) showed how the everyday actions of supported people were understood as challenges from the perspectives of staff: “they eat their food too quickly, and they don’t go to the toilet when others decide they need to” (2011: 415). Service managers, through the etic perspective, viewed the challenge and the diagnostic label as embodying those they supported and referring to them as such: “this is autism and quite severe challenging behaviour” (2014: 295). It was, in relation to Nelson’s (1993) theory, their theoretical evidence, supporting and reifying their knowledge of the terms, which states that the behaviour of people with complex needs is innately challenging.

The analysis of personhood, narrative, and behaviour shows that despite the separate terms of “autism” and “severe/profound learning disabilities” and the apparent potential for them to lead to divergent and diverse knowledge constructions, people with complex needs are defined and known in similar ways. Moreover, in individual circumstances and communities, the emic perspective can provide personal insight that challenges the diagnostic categories more broadly, further weakening any distinguishing factors. This analysis demonstrates the blurred and fuzzy nature of autism and severe/profound learning disability in the broader, social contexts of people with complex needs. Building on the initial section’s discussion, one can therefore argue that there is no epistemic justification for people within this group being separated within academic practices. Turning to the ethical justification for the distinction, this paper will now explore the representation of people with complex needs within the broader academic contexts of autism and learning disability.

The Representation of People with Complex Needs within the Academic Fields of Autism and Learning Disability

To address societal barriers and inequalities, the autism and learning disability fields have commonly drawn from the social model of disability to develop research

agendas, practices, and outputs that seek to better represent their respective populations' experiences, perspectives, and histories (see Woods, 2017; Chown et al., 2017; Walmsley and Johnson, 2003; Bertilsdotter Rosqvist et al., 2019). It is this aim of representation that has caused issues in regards to people with complex needs, as there has been uncertainty as to how to involve them within research processes (Nind, 2008: 16) and an acknowledgement that their impairments cannot be "explained away" through analysis of the surrounding political and social contexts (Mietola et al., 2017: 266). The result of this, Cluley et al. (2020: 251) argue, is a research field that is only partially representative of people with learning disabilities, and subsequently the production of government policy and strategies (e.g. Department of Health, 2001) that "explicitly exclude" people with complex needs.

To improve opportunities for people with severe/profound learning disabilities to be represented in research and policy, Cluley et al. (2020) propose that the concept of learning disability should be viewed from the perspective of the "ontological turn" as opposed to the social model of disability. The "ontological turn" situates the "learning disabled body" as an assemblage: "a product of ongoing and ever-changing biological and social interactions..." (Cluley et al., 2020: 253), each impacting the "becoming-bodies" (253) of people with learning disabilities. And so for researchers and policy makers who take such a perspective, Cluley et al. (2020: 253) contend that "the voices of self-advocates and government ministers thereby become equally valid" and "the voices of those who are least heard would have a fighting chance of representation". This is a bold claim as it is suggesting that it is appropriate for academics and policy makers using the social model to dedicate considerable effort to change working practices so as to bring attention to "the heterogeneous continuum of people with learning disabilities" (253), though the authors are unsure whether it would improve the current representative position of those with complex needs. Furthermore, though Cluley et al. (2020) are highlighting the absence of a population's voice from the government strategies that affect them, there is also an absence of, or reference to, the voice of autistic people within the discussion. Adopting the social model has been declared a key factor in the creation of emancipatory autism research by autistic and non-autistic researchers (Chown et al., 2017; Bertilsdotter Rosqvist et al., 2019; Woods, 2017). Therefore, it could be seen as a challenge to the values of the autism community to develop research with autistic people with complex needs that adopts a different perspective of autism to that understood through the social model.

The issue of exclusion and representation has also been explored in the context of the autism community by McCoy et al. (2020). The authors' focus was ethical and political, arguing that both parent-led, pro-cure groups and self-representing, autistic-led groups partially represent the autism community in general, and therefore both groups' perspectives should represent the views of autistic people with severe/profound learning disabilities. In a response to this paper, Chapman and Veit (2020) contend that autistic people with severe/profound learning disabilities, who they term "nonrepresenting autistic people", should be represented by "non-verbal

self-representatives” (47): autistic people who have been thought unable to communicate through childhood but who in adolescence, while remaining nonverbal, learned to competently communicate through typing (therefore demonstrating an absence of severe/profound learning disabilities). Their argument is that non-verbal self-representing and non-representing autistic people shared common experiences of disabling factors when growing up, and so it is non-verbal self-representing perspectives that should be prioritised in political debates around non-representing autistics. To do otherwise, Chapman and Veit argue, would be an act of “epistemic injustice” (47) as it disregards the knowledge that non-verbal self-representing autistics have constructed through their lived experience of autism and disability.

Within the arguments of Chapman and Veit (2020) and McCoy et al. (2020), it is clear that the knowledge of two separate epistemic communities, that of pro-cure parents and that of autistic self-advocates, is being pitted against one another on the issue of representation of autism *and* severe/profound learning disability, here termed non-representing autistics. However, both arguments are void of reference to learning disability research, communities, or cultures, suggesting that the authors are based in epistemic communities that do not draw from the learning disability field in their construction of autism. The learning disability field has a rich history of exploring advocacy and representation (see Brownlee-Chapman et al., 2018; Walmsley and Johnson, 2003; Seale et al., 2015) that has relevance through the scope of severe/profound learning disability, and would prove useful in exploring how “non-representing autistics” may in fact represent themselves. Accordingly, it is, in my view, not just McCoy et al. who are risking “epistemic injustice”, but Chapman and Veit themselves.

The “strong normative dimension” of Disability Studies, as referred to by Vehmas and Watson (2016: 4), is that life for disabled people will improve if academics can “identify and challenge what are seen as discriminatory practices and beliefs”. The authors contend that the normative dimension of Disability Studies produces arguments that “typically insinuate how things, as they currently stand, are wrong whilst providing very little practical ethical guidance as to how things ought to be” (4). In the previous cases for example, Chapman and Veit (2020) and Cluley et al. (2020) make a normative assumption that it “ought not be the case” that people with complex needs have minimal representation in academic and political life, though their subsequent suggestions are of no clear practical use in remedying the issue. “Oughts”, Vehmas and Watson (2016: 5) contend, often carry “little or no evaluation as to why they are classified as such”. So, it is quite appropriate to acknowledge the injustice of the marginalised position of people with complex needs; it is a normative assumption, though what Chapman and Veit (2020) and Cluley et al. (2020) fail to confront is why people with complex needs cannot represent themselves or how this might be addressed. Instead, they perpetuate the normative, ableist notion that has underpinned Disability Studies since the social model of disability was conceived: that people with complex needs are incapable of participating and expressing themselves within academic or societal processes (Mietola et al., 2017: 266).

It is not a lack of means that has meant people with complex needs are rarely represented within academia, for over the past 30 years, many researchers have demonstrated ways such people can meaningfully participate (e.g. Simmons and Watson, 2014b; Gaudion, 2015; McCormack, 2017; Goode, 1994; Dee-Price, 2019; Hewitt, 2000). Their related research fields have, however, promoted and favoured approaches, methods, and practices that, commonly embedded with ideas of voice, self-advocacy, and “speaking up for yourself”, exclude their participation (Palmer and Walmsley, 2020: 131). Such exclusion is no better evidenced than in the models of inclusive research developed for the learning disability (Walmsley and Johnson, 2003) and autism (Chown et al., 2017) fields, both of which have a focus on the ownership of research and its processes and the tackling of disabling barriers. These are frameworks that, as Nind (2013) commented, mean it is unlikely that any research involving people with severe/profound learning disabilities could be termed inclusive. While there are risks and uncertainties in representing the perspectives of people with complex needs within academia, this is not a reason their perspectives should be subsumed by their wider academic fields and communities. Rather, it is a reason that academia should give considerable effort to exploring the most appropriate and ethical ways to ensure they can participate and express themselves on issues salient to their circumstances and perspectives.

What these issues of representation highlight and point to is the need for a more focused research field for people with complex needs; one that as Goodley (2001) had hoped for, is open and inclusive and is specifically developed to promote their participation and involvement. Thus, the final section of this paper will, as Vehmas and Watson (2016) might hope for, make a practical suggestion, describing a way researchers can view the broad population of people with complex needs within an academic space that, over its course, can come to represent their views and experiences.

Forming an Academic Space of “Autism and Profound Learning Disability” through a Lifeworld-Life Conditions Perspective

“Lifeworld” refers to the subjective way in which each person experiences reality though “promoting and limiting” (Kraus, 2015: 5); this is their life conditions, “the material and immaterial circumstances of life” (Kraus, 2015: 4). For people with complex needs, the diagnoses of autism or severe/profound learning disability may, at times, lead to dissimilar life conditions, yet, on the whole, the structural guidance of education, social care, and so on are likely to result in markedly similar life trajectories. These trajectories are defined by particular spaces and environments, such as special education schools and day and residential support services, as well as ways of living and the continued need for support. Such trajectories necessarily mean that people with complex needs share experiences – lifeworlds – perhaps more so than any other “group” of people that identifies/are identified in relation to autism and learning disability. These can be understood as the “limiting” (Kraus, 2015: 5) and

shared life conditions of people with complex needs: a key and defining factor in how they experience the world, the opportunities they are afforded, and the lives they lead.

In acknowledging the relationship between lifeworlds and life conditions, people with complex needs can be seen within the wider communities that their diagnostic labels situate them within; it is part of their life conditions, yet it also obliges recognition that not all have to “withstand within the context of the [same] given social and material conditions” (Kraus, 2015: 4). Through the scope of lifeworlds-life conditions, it is possible to situate the terms “autism”, “severe learning disability”, “profound learning disability”, and “PMLD” within a shared academic space termed “autism and profound learning disability”. This space is not a means to divide communities or academic fields, but rather to build connections between members of those communities most acutely marginalised from academic and societal participation.

For the purpose of establishing the space, people related to it will be termed here “autistic people with profound learning disabilities”. The experiences of such people are subjective and diverse – it is the nature of lifeworlds – however there are inevitably fundamental issues and phenomena relevant to their experiences as these are subject to the life conditions that they are part of and surrounded by. The primary purpose of the space is to increase the representation of autistic people with profound learning disabilities within academia, with the intention that this would also lead to broader representation across social and political discourse. With this in mind, eleven objectives for the space are outlined below, which, in time, can grow and develop:

1. To establish “a clear and shared terminology” to enable researchers and policy makers to locate and identify research about autistic people with profound learning disabilities (Šiška and Beadle-Brown, 2020: 15).
2. For researchers to work with autistic people with profound learning disabilities to develop a research agenda that focuses on key issues, topics, and phenomena relevant to their lives and perspectives.
3. To establish ways to acknowledge and share across academic fields new and past research studies involving autistic people with profound learning disabilities expressing or representing their views and perspectives, regardless of participants’ diagnostic labels.
4. To establish an archive of methods and methodologies developed for meaningfully involving autistic people with profound learning disabilities in research, including methods that are relevant to the diverse ways they communicate and engage with the world (some examples include Cluley, 2017; Crawford and Wilkinson, 2018; Hewitt, 2000; Andrews et al., 2019).
5. To develop frameworks of inclusive and participatory research for autistic people with profound learning disabilities.

6. To critically analyse and explore ethical issues related to research where autistic people with profound learning disabilities represent themselves.
7. To promote the perspectives of autistic people with profound learning disabilities in policy and guidance made about autism, learning disabilities, and social care.
8. To establish guidance on ethical research practices for researching with autistic people with profound learning disabilities and to promote this understanding within research ethics committees (see for example Boahen, 2015; Haines, 2017; Boxall and Ralph, 2011).
9. To establish and promote ways key groups, such as family members, the broader autism and learning disability communities, and support practitioners can support autistic people with profound learning disabilities to be involved in research (Seale et al., 2015).
10. To encourage autism and learning disability researchers to work collaboratively in the context of autistic people with profound learning disabilities, including in research development, dissemination, and outputs.
11. To develop ways for autistic people with profound learning disabilities to participate or be involved in broader academic practices, such as conferences (see Palmer and Walmsley, 2020, for a brief discussion), journals, and teaching.

Conclusion

This paper sought to show that the epistemic communities which have developed in academia, within the autism and learning disability fields, have constructed knowledge in such a way that excludes people with complex needs from participating in research. Researchers that work in relation to only “autism”, or only “severe/profound learning disabilities”, or only “PMLD”, are creating barriers between a broad group of people who are rarely represented or given opportunities to represent themselves. Academic outputs, conferences, papers, books, journals, which focus on one diagnostic term while disregarding others, are weakening the collective voice of a group who share life-conditions: characteristics, circumstances, needs, and ways of living. The space of autism and profound learning disability represents these shared life conditions, and in doing so, aims to bring together the perspectives, experiences, values, and customs of related people, so they can be considered and learned from. It is a means to encourage intersectional collaboration between researchers concerned with autism and learning disabilities, so as to promote ethical ways of researching with people with complex needs in such a way that their perspectives and views gain recognition in academic, social, and political life. To do otherwise is epistemically and ethically unjustified.

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