Guest editorial

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Special edition trauma and intellectual disabilities. Are intellectual disabilities an intersection of exclusion in trauma policy, guidance and research?

It is a genuine pleasure to introduce the current special edition focusing on people with intellectual disabilities who present with psychological trauma needs. This volume provides a platform for highlighting the trauma needs of people with intellectual disabilities and the positive contributions of clinicians and researchers in this area of practice.

While the pervasive and life changing impact of trauma exposure on psychological wellbeing, neurological development, physical health and educational and workplace outcomes, are well-known, considerably less has been documented relating to the experiences of people with intellectual disabilities. This is despite evidence consistently demonstrating that people with intellectual disabilities present with an elevated risk of exposure to trauma in child and adulthood that is evident across the different levels of severity of intellectual disability (Goad, 2021) and extends to traumas in addition to the Adverse Childhood Experiences (ACES; Felitti *et al.*, 1998) framework. Similarly, the impact of such exposure may also be comparatively greater than for neurotypical populations (Davies *et al.*, 2021), with greater difficulties in recovery also noted (Skelly, 2020). Yet, at an academic and clinical level (Rich *et al.*, 2020); and to a degree policy level, trauma needs and Trauma Informed Care (TIC) frameworks have received comparatively less focus in people with intellectual disabilities. As such, people with intellectual disabilities represent a key intersectional group who are comparatively less visible in the trauma policy and literature.

The development of specialist trauma, and trauma informed care services are key features in The NHS long-term plan for mental health (NHS, 2019). By contrast, chapters of the plan relating to Learning Disabilities and Autism (NHS, 2019) omitted trauma related needs in its list of priorities and goals. While extending initiatives such as STOMP (stopping over medication and people with learning disabilities, autism or both; Public Health England, 2015) and reduction inpatient services are much needed initiatives included in the plan, the inclusion of the role of trauma, a factor that may *underpin* the need to use of psychotropic medication and inpatient admissions, would significantly strengthen this document. Arguably, exploring the relationship between trauma exposure and resulting symptoms, and the use of medication and detention, would greatly increase our understanding of the use of such restrictive practices and support the development of alternative psychological therapeutic approaches.

Similarly, the trauma needs of people with intellectual disabilities are minimally present clinical guidance for trauma. For example, NICE guidance for post-traumatic stress disorder (PTSD) (NG116; National Institute for Health and Care Excellence, 2018a) offers clinical guidance for specific populations, including different age groups, those who present with language or cultural barriers to engaging with trauma work and those with "complex needs" including the those with significant of comorbidities. Yet, while NICE guidance outlines that, "Recommendations…relate to everyone, [including] people with neurodevelopmental disorders" (p. 50, National Institute for Health and Care Excellence, 2018b), it does not articulate the differential trauma needs of people with an intellectual disability with comparable consideration afforded to other high trauma exposure group such as military and refugee populations. Given the elevated risk of exposure across the life span and the differential presentations of trauma symptoms in people with intellectual disabilities (McNally

et al., 2021), including this key information in future, NICE guidance would greatly help increase the visibility and understanding of the differential trauma needs of this population.

The development and validation of the new ICD-11 Complex PTSD diagnosis (WHO, 2019) is yet to meaningfully include people with intellectual disabilities in its growing body of work and clinical recommendations. A similar challenge exists with developmental trauma disorder (DTD; Spinazzola *et al.*, 2021), which seeks to account for the pervasive impact of trauma, that extends beyond a PTSD framework. As an attachment-based disorder DTD formulates trauma responses in the domains of emotional and somatic dysregulation, attention and behavioural dysregulation and relational and self-dysregulation. The manifestations of DTD, which is less reliant on cognitive elements of trauma, and encompasses a wider range of symptomatology, is arguably a useful paradigm to explore for conceptualising the differential trauma symptomatology experienced by people with intellectual disabilities (Morris *et al.*, 2020). Whether complex PTSD or DTD reflect the manifestations of trauma symptoms in people with intellectual disabilities remains relatively unexplored. In the case of DTD in particular, the inclusion of people with intellectual disabilities in its field trials and evidence base would arguably strengthen the case for the diagnosis to be included in future diagnostic manuals.

As such, on opportunity exists for leading trauma researchers to work proactively with intellectual disability specialists. The inclusion of people with intellectual disabilities would provide a much-needed diversification of current nosology to ensure that it is inclusive [and valid) of different manifestations of trauma in different populations. Relatedly, intellectual disability specialists have highly specialist expertise relating to relationship between the environment, distress and the functions of behaviours that challenge, which could greatly enhance our understanding of trauma informed care approaches.

It is customary in special editions of journals to issue a "call to action" for practitioners and academics working in this area to rise to the challenge of meeting the needs of the population in focus. Yet, arguably, of greater importance is the need for specialists in intellectual disabilities to partner with trauma experts to ensure the needs of this population are given greater visibly and parity of esteem to neurotypical populations. People with intellectual disabilities often represent membership of multiple intersections and experience the accumulative impact "double" or "triple" discrimination based on intellectual disability, class, gender, sexuality and ethnicity. While psychological research in general has been slower in incorporating intersectionality into research frameworks (Buchanan and Wiklund, 2021), trauma and intellectual disability practitioners have an opportunity to innovate. Increasing the presence of people with intellectual disabilities in trauma initiatives not only represents a human rights priority but also offers a unique opportunity to innovate and embed intersectionality into research and practice.

The current edition therefore highlights the importance placing the trauma needs of people with intellectual disabilities firmly on the healthcare and research agenda. In this volume, trauma is explored through a systemic lens, exploring different psychologic models and concepts in different intellectual disability populations. Specifically, we explore the experience of exposure to trauma and trauma related needs through the experiences of the individual, their family and professional systems and through different theoretical perspectives.

Opening with the experiences of people with intellectual disabilities, Crompton *et al.* (this issue) explore exposure to ACEs. This paper highlights the gaps in the literature that relate specifically to people with *intellectual disabilities*, as opposed to studies that have adopted a more generic approach of exploring "developmental disorders". In doing so they remind us of the importance of exploring the differential experiences of trauma with neurologically atypical populations.

Gregson and Delaney (this issue) explore the importance of team based psychological formulation to ensure that trauma needs are incorporated into the understanding of

someone's presentation. Their paper highlights the critical importance of the relational impacts of trauma in the lives of people with intellectual disabilities, and how behaviours that challenge can be mis-formulated in prerogative frameworks, if not considered through a relational trauma lens. The role of trauma in the development and maintenance of behaviours that challenge is increasing being recognised (Rittmannsberger *et al.*, 2020), with NICE guidance for Challenging behaviour and learning disabilities (NG11), stressing that the role of trauma should be considered in the assessment and treatment planning. Behaviours that challenge have a profound impact on the lives of people with intellectual disabilities and it is critical that, as a speciality, we continue to improve our understanding of the role that trauma plays in the development and maintenance of behaviours that challenge. Such understanding is critical to developing psychological theories of trauma that reflect the elevated trauma exposure and differential trauma responses of people with intellectual disabilities.

Building on the importance of placing trauma within the parameters of psychological theory and formulation, Taylor (this issue) and Rye *et al.* (this issue) highlight the importance and value of embracing different theoretical perspectives in developing trauma informed models of care. Taylor reports on the high levels of trauma experienced in the lives of people with intellectual disabilities detained, and significantly disadvantaged, in the secure care system. Using a compassion focused treatment framework, he highlights the importance of formulating and treating trauma beyond its roots as an anxiety "disorder" and to explore and address trauma as a *response* that can manifest in shame and guilt, with marked challenges for this population to demonstrate compassion to self and others.

Rye *et al.* (this issue) remind us of the importance of psychological theory underpinning approaches to understanding trauma, in this instance to staff training. Using core psychodynamic concepts, Rye *et al.* demonstrate the importance of organisations developing ongoing models of staff training and support. Describing their journey in developing, delivering and reflecting on a training programme, Rye *et al.* highlight that the key principles of TIC, namely, safety, trust, co-production, trust and empowerment (Sweeney *et al.*, 2018) apply equally to our work in supporting staff to develop critical skills in this area of practice.

The importance of adopting a systemic lens to trauma needs is further explored by Webb *et al.* (this issue) and Baker *et al.* (this issue). Webb *et al.* report on the importance of ensuring trauma focused support for health professionals working with people intellectual disabilities who have complex trauma needs. While we are all familiar with chronic challenges in recruitment of staff and heightened concerns about staff well-being, Webb *et al.* offer a timely reminder of the importance supporting health-care professionals to keep *systems* healthy. Webb *et al.* stress the importance of meeting the trauma needs of staff, which may be more prevalent in health-care staff working in intellectual disability services. This paper also reminds us that the "R"s in trauma informed care, namely, realising the impact of trauma, recognising the signs and symptoms, responding to trauma and resisting re-traumatisation are also of paramount importance to apply to staff groups to ensure the well-being of health-care professionals. As such, Webb *et al.*'s paper illustrates while much of the emphasis in TIC relates to promoting education and awareness of trauma in health professionals, parity of esteem needs to be given to promoting and ensuring the well-being of health-care professionals working in these systems.

The final paper in this edition draws in key systemic group, namely, families of people with intellectual disabilities. Baker *et al.* provide a critical insight into the trauma experiences of family members of people with intellectual disabilities, and the roles that services can inadvertently play in traumatising or re-traumatising families. Services and health professionals hold considerable power and influence in the lives of people with intellectual disabilities, and Baker *et al.* powerfully remind us that our positions of relative power can be experienced by others as re-enacting, or enacting, trauma. Baker *et al.* invite services to adopt an enquiring stance working with families who are challenging to engage with and traditionally conceptualised as "problem families." They emphasise the importance of

stressing "what has happened to you" rather than "what is wrong with you" in working with such families. In doing so they illustrates Goad's (2021) position that as health professionals we are also able to use our relationships with service users to offer reparative relational experiences to prevent further traumatisation. Given the undeniable role of families in the lives of people with intellectual disabilities and the inequality of power with services, this paper offers a much-needed invitation to intellectual disability services to reframe their formulations of their relationships with families and to adopt more compassionate stances.

Finally, I am mindful that the current special issue was nurtured through the height of the pandemic by clinicians who continued to work on the frontline as well as find the time to complete studies and research. Similarly, contributions by researchers are noted who were able to deliver large studies despite ongoing disruptions and challenges. Such dedication is testimony to the passion and resilience that exists within health professionals and researchers working with people with intellectual disabilities. While exclusion and marginalisation from mainstream trauma may exist, the commitment shown to developing the papers in this volume is reason to be optimistic that practitioners in this area will continue to grow and influence the national trauma agenda and improve the lives of the people we strive to support.

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