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Title: **Seen but not understood, responding to emotional distress at the intersection of neurodivergence and learning disability.**

Abstract

People who are neurodivergent and have lived experience of learning disabilities may communicate their distress through behaviours which people around them may interpret as challenging. Responses to their complex behaviour may focus on behaviour modification rather than acknowledging and responding to the distress of neurodivergent people with learning disabilities. Distress may be as a result of the trauma of living, learning, working or socialising in unsuitable environments. Some learning disabled, neurodivergent people have had the additional trauma of experiencing physical restraint, chemical restraint and isolation. Practitioners and families supporting them must of necessity be equipped to recognise and respond to their distress appropriately.

Keywords

Learning Disability; Neurodivergence; Autism; Distress; Behaviour; Neurodiverse interventions

Aims and intended learning outcomes

The aim of this article is to support practitioners who work with people with learning disabilities to recognise and respond to the distress of people who are neurodivergent. After reading this article and completing the time out activities you should be able to:

- Explain how distress may be recognised in neurodivergent people with learning disabilities.
- Identify causes of distress in neurodivergent people with learning disabilities.
- Describe the physiological processes that underpin distress.
- Reflect on how you have responded to distress in the past and how you might respond to distress in the future based on current research.
- Write an action plan for your further development in responding to distress

Introduction

The World Health Organisation, (2022) defines a learning disability as significantly reduced ability to understand new or complex information and to learn as well as apply new skills (impaired intelligence). This in turn leads to a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development, (World Health Organisation, 2022). The percentage of people with both a learning disability and autism has been increasing steadily from 19.8% in 2016 to 2017 to 28.6% in 2020 to 2021, showing a rise of 8.8 percentage

points, (NHS Digital, 2021). In contrast, the diagnosis of autism in people without a learning disability only increased by 0.3 percentage points, from 0.5% in 2016 to 2017 to 0.8% in 2020 to 2021, during the same period, (NHS Digital, 2021). This data indicates a significant increase in the co-occurrence of autism and learning disabilities over the specified period. It is estimated that approximately one third of autistic people have a learning disability, (Loomes, et al, 2017). People with a learning disability were 26 times more likely to be diagnosed with autism compared to those without a learning disability in 2016-17, (NHS Digital, 2021). The stark difference in the likelihood of autism diagnosis between people with and without a learning disability is notable. This highlights the strong association between these two conditions and reinforces the need for healthcare providers to consider both autism/neurodivergence and learning disabilities in their assessments and intervention strategies.

The expressions of emotional distress may be overshadowed by the perceived negative impact of distressed behaviours displayed by people with learning disabilities on their caregivers or family members. Conversations regarding people's behaviour which challenge services may focus on the risks presented by the behaviour to the person displaying it and the people around them, (Willis & LaVigna, 2003). Consequently, interventions may focus on the application of contingent reinforcement and positive behaviour support (PBS) for selected behaviours or teaching important skills to overcome the challenging behaviours. PBS focuses on supporting people to change their behaviours when they are deemed to be problematic for them and the people they interact with. It is acknowledged that some behaviours displayed by neurodivergent people have at times been wrongly

assessed as requiring intervention and change by neurotypically designed services with poor understanding of the natural expression of neurodiversity, (Gore et al, 2022).

PBS seeks to improve people's quality of life with accompanying reductions in the use of restrictive procedures such as physical intervention, seclusion and as required medication, (Gore et al, 2022). The improvement of quality of life cannot stop at the point of PBS as some behaviours people display are an expression of distress on a deeper psychological level. In seeking to modify these behaviours, the person with lived experience of neurodivergence and learning disabilities may be left in a continuous distressed state. Distress can be described as a negative and unpleasant state that occurs when a person fails to restore their physical and/or mental balance, (National Research Council, 2008). Various experts define distress in similar ways, emphasizing its negative impact on the human body's ability to cope and adapt in order to maintain a state of well-being, (Sapolsky, 2017; Higgs, Cooper & Lee, 2023). A distressed individual will have difficulties in recovering from episodes which they find triggering. In such instances, focusing on behaviour modification may divert interventions away from addressing the underlying causes of distress in learning disabled, neurodivergent people. Autism amongst other factors is noted as increasing the likelihood of individuals with a learning disability developing behaviours which challenge, (National Institute for Health and Care Excellence, NICE 2015). These behaviours are largely defined by Emerson and Einfeld (2011) as increasing the risks of harm to self, harm to others, or negatively impacting quality of life.

People with a learning disability who have been diagnosed with autism are significantly more likely to be prescribed antipsychotics and benzodiazepine medication compared to autistic people who do not have a learning disability, (NHS Digital, 2021). Specifically, people with autism and a learning disability were 66 times more likely to be prescribed antipsychotics and 66 times more likely to be prescribed benzodiazepines compared to those without a learning disability, (NHS Digital, 2021). This suggests a higher use of these medications among individuals with both autism and a learning disability, highlighting the potential misinterpretation of their distress and the challenges practitioners encounter in maintaining their psychological and mental well-being.

Neurodivergence, Intellectual Disabilities, and Communication of Distress

A learning disability may be defined as a significantly reduced ability in understanding new or complex information combined with a reduced ability in learning or applying new skills due to reduced cognitive abilities. This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development, (World Health Organisation, 2022). Some people with learning disabilities may have significant difficulties with both expressive and receptive communication skills. They may communicate non-verbally or give up communicating their needs leading to internalised frustration and distress. When learning disabled people are neurodivergent as well, it may further enhance the barriers they face in seeking to communicate their needs or receiving information from our predominantly neurotypical world.

It is acknowledged that people with learning disabilities may interact with their environments in unique ways that may not always fit in with societal norms. This

difference may be enhanced if they have an additional diagnosis of neurodivergence. Neurodiversity theory explains that conditions such as autism, attention deficit hyperactivity disorder (ADHD), developmental co-ordination disorder, and dyslexia are natural variations in human minds (Chapman and Botha, 2023). According to this theory, individuals who diverge from the typical functioning (referred to as neurominorities) should be treated with dignity, respect, and provided with appropriate accommodations (Chapman and Botha, 2023). Morrison (2019) further asserts that neurodiversity is a natural and valuable fact of life and all members of our society exist on a nuanced spectrum between neurotypical and neurodivergent functioning.

Historically neurotypical people have perceived the actions of neurodivergent people through the lens of negative stereotypes and unhelpful interventions, (Silberman, 2015). “By *neurodivergent people’s* standards the neurotypical brain is easily distractible, is obsessively social, and suffers from a deficit of attention to detail and routine. Thus, people on the spectrum experience the neurotypical world as relentlessly unpredictable and chaotic, perpetually turned up too loud, and full of people who have little respect for personal space, (Silberman, 2015:471).” As such, environments designed for the neurotypical brain will consequentially trigger distress in neurodivergent people.

In recent years social justice advocates have campaigned for movement away from a pathological paradigm whereby manifestations of neurodiversity are treated as behavioural disorders that require prevention, remediation, or a cure. Gore et al, (2022), caution against interventions that seek to make neurodivergent people conform to neurotypical preferences. There is a call to recognise that cognitive or communicative ‘dysfunctions’ in neurodivergent people occur as a result of the

relationship between them and neurotypical individuals, rather than viewing these dysfunctions as inherent within them, (Chapman and Botha, 2023). The triggers for what we would call behavioural challenges in neurodiverse people are usually located in environments that are disabling. Most learning disability services are designed and led by neurotypical people who decide how best people who are neurodivergent should be supported sometimes without relevant research to inform their decisions, (Udonsi, 2022).

When neurodivergent people with learning disabilities display emotions such as sadness, anger and fear, it is important to note that there are specific biological responses that accompany these emotions. The human body operates by balancing the work of the sympathetic and parasympathetic nervous systems (Sapolsky, 2017). The sympathetic nervous system is responsible for how our bodies respond to danger through the fight, flight, freeze or fawn responses. The parasympathetic system on the other hand works to put brakes on the sympathetic nervous system by relaxing the body thereby helping it to conserve and restore energy (Sapolsky, 2017). It is worth noting that these biological responses are designed to escape imminent danger, aid survival and return the body to a position of homeostasis (Higgs, Cooper and Lee, 2023). For a neurodivergent person, the perception of danger may be through overwhelming sensory experiences. Throughout the course of our daily lives, our brains will receive a multitude of sensory stimuli through the visual, auditory, tactile, gustatory, and proprioceptive senses. Most neurotypical brains will filter out background noises and any sensations that do not warrant attention. However, neurodivergent people may have sensory processing difficulties which may lead to non-threatening sensations becoming a trigger for distress.

Instead of filtering out stimuli in the environment such as noise, feel of clothes or the taste of food, the brain mistakenly perceives them as threats that require a defensive response. As a result, adrenalin is secreted and the body enters fight or flight mode in a bid to eliminate these perceived dangers, (Sapolsky, 2017).

Responses to distress must not seek to silence, modify, contain, drug and restrain people whose behaviours are in actual fact the outworking of a nervous system, simply doing what it was wired to do (Sapolsky, 2017). For a neurodivergent person, the perception of danger may be through a neurotypically designed inter-personal/ physical environment. Neurodivergent individuals with intellectual disabilities often face challenges in environments that are not well-suited to their specific needs.

These environments are typically designed with the health and well-being of neurotypical individuals in mind (Silberman, 2015; Higashida, 2014 & 2017).

Anthropological studies in proxemics have advanced knowledge regarding individual personal space requirements which may be determined by cultural norms or by the particular manner their brain functions (Brown, 2001). Proxemics deals with how humans use personal space and the effects that population density has on behaviour, communication and social interaction, (The British Standards Institution BSI, 2022). Proxemics is a subcategory within the realm of non-verbal communication, alongside haptics (touch), kinesics (body movement), vocalics (paralanguage), and chronemics/ structure of time, (BSI, 2022). This builds on the work of Edward T. Hall (Brown, 2001), whose theory suggested the following personal space requirements for generic populations:

- intimate space, close to the body

- personal space, within 0.45 m of the person
- social space, within 1.2 m of the person and
- public space, within 3.6 m and 7.6 m of the person

According to this theory people can have different requirements for personal and social space (proxemics) as a result of cultural or neurological reasons, (BSI, 2022).

When a person is unable to get the personal space they require it can cause anxiety, furthermore for neurodivergent people this may lead to heightened levels of anxiety or distress, (BSI, 2022). Studies by Asada et al, (2016) noted that neurodivergent people preferred larger inter-personal social distances especially where eye contact was initiated. Neurotypical health and social care practitioners may overlook how we may at times trigger fight or flight responses in people by invading their territory or overlooking personal space requirements, (Sapolsky, 2017).

TIME OUT 1

Whom do you allow into your intimate, personal and social spaces? How much control do you have over who might come into these spaces? Think back to a time when someone might have come into your intimate personal space at work or in a public space. How did this make you feel and what did you do to mitigate against the discomfort/threat? In your opinion, would a neurodivergent person with learning disabilities have the resources that you used to reduce the discomfort of the invasion of their personal space?

TIME OUT 2

Now reflect on work you have done recently with a learning disabled, neurodivergent person. Did you have any prior knowledge about their personal space requirements? Think about the previously mentioned personal space requirements suggested by Edward T. Hall (Brown, 2001). Do you think these may apply to the person you have been working with? How often did you come into the person's intimate or personal space zones? What impact do you think this would have had on the person's nervous system? How could you apply your knowledge of personal space requirements within your specific area of work?

Once you have completed the 1st and 2nd Time Out Activity, please consider the scenarios below and reflect on the impact of the person's experiences on their nervous system and their reactions to the possible triggers of distress.

Scenario 1

Charlie is 19 years old; he has a diagnosis of learning disabilities and autism. Charlie lives in a supported living house with two co-tenants. They are supported by a staff team who work shifts that ensure the house has staff for 24 hours daily. Charlie attends a local College where he is doing an Information Technology course. One of his classmates died six months ago following an epileptic seizure. His grandfather with whom Charlie has a close relationship is currently ill with a diagnosis of cancer. Charlie has been told that his grandfather can no longer go on activities with him and is unable to get out of bed. Charlie has recently started acting out a scene from a film he watched in high school years ago. The re-enactment involves Charlie attempting to choke his female support workers. It is acknowledged that Charlie is distressed by memories of the film which had a number of death related themes. Charlie has

recently started refusing to go into his class. He is spending most of his time at home with no structure to his day due to the risk of him running away from his staff team whenever is taken out into the local community. Whilst at home staff report that he has been hitting, kicking, throwing objects at staff, attempting to choke staff and breaking valuable items in the house. Staff are re-directing him to his bedroom following the display of the behaviours of concern. Consequently, Charlie is becoming more isolated.

TIME OUT 3

What signs of distress can you identify in Charlie's presentation? How would you support Charlie with regards to his classmate's death and grandfather's life limiting illness? What services are available within your local work area that would be suitable for supporting Charlie with his distress?

Eagleman, (2015) explains that the physical makeup of a person's brain is shaped by various factors such as genetic expression, upbringing, cultural background, social circle, daily life experiences and any interactions one has been engaged in from birth. All these factors imprint themselves on the nervous system, accumulating to define identity and also to impose limits on a person's capacity to adapt to typical environments, (Eagleman, 2015). In the scenario mentioned above, the interpersonal and physical environments would be impacting Charlie. However, without attention being paid to his distress and its triggers, families and paid workers would be unable to provide relevant support. Charlie may be perceived as threatening by the people around them. In instances where caregivers and staff are threatened by the people they are looking after, this would activate their sympathetic nervous system (SNS)

with physical effects such as heart rate and respiratory rate increases. This would cause them to become more preoccupied with their own distress rather than responding to the distress of the person they are supporting or caring for (Sapolsky, 2017). However, if caregivers are operating under the parasympathetic nervous system (PNS), they will be more likely to respond to the distress of the person that they are supporting, (Sapolsky, 2017). The parasympathetic nervous system is linked to our soothing system which lowers the heart rate and blood pressure placing people in a calm and restful state. As such it is imperative that caregivers and staff working with neurodivergent learning disabled people develop frameworks for recognising distress and being able to respond to it without feeling threatened. There is a need for carers and staff to develop strategies for managing their own emotional states in order to respond appropriately to distressed behaviours.

Distressed people are at times labelled as being too risky to be looked after in ordinary community settings leading to inappropriate hospital or assessment and treatment hospital units admissions. There must be some acknowledgement that cultures, behaviour, and the design of services do not always suit the people they are set up to help, (Care Quality Commission CQC, 2022). Hospital settings are often not built to meet the needs of neurodivergent people. This gives rise to the use of restrictive interventions, such as restraint, seclusion and segregation which may cause trauma, (CQC, 2022). Trauma is defined as lasting adverse effects caused by threatening circumstances which an individual experiences as harmful physically and emotionally (Substance Abuse and Mental Health Services Administration, SAMHSA 2014). It is accompanied by a negative impact on the individual's physical, social, emotional, or spiritual wellbeing thereby limiting an individual's ability to cope with

their circumstances or recover from them, (Substance Abuse and Mental Health Services Administration, SAMHSA 2014). The impact of trauma on an individual can be felt by people have not directly experienced it. Those who have endured severe trauma, whether through personal assault or witnessing the assault of another can unconsciously transmit their unspoken horror and overwhelming emotions to others, causing them to be affected by the trauma as well. People with learning disabilities/ neurodivergence may additionally experience trauma vicariously from witnessing other people in their lived environments becoming distressed or being put into restraint (Boulanger, 2018). Vicarious trauma refers to the trauma we may experience from being indirectly exposed to a traumatic event or series of events (Boulanger, 2018).

TIME OUT 4

Read the Report titled “Lived Experience of Restraint, Seclusion & Segregation

(RSS) produced by the advocacy service Advonet [online] available from

URL:https://www.cqc.org.uk/sites/default/files/20201021_rssreview_livedex.pdf

What do you find concerning about the use of Restraint, Seclusion and Segregation in the report? What actions do you think learning disability services need to take in view of this report?

Trauma informed practice is a necessity when working with distressed individuals in order to embed an understanding of trauma within the systemic aspects of health and social care support (Harris & Fallot, 2001). Trauma-informed practice does not aim to directly treat trauma-related distress. Rather, it is about recognising and addressing the obstacles that individuals affected by trauma may encounter when

seeking the care, support, and treatment that they require, (Wall, Higgins & Hunter 2016). By acknowledging and responding to these barriers, trauma-informed practice aims to create an environment that fosters accessible, non-discriminatory, and effective care for those impacted by trauma.

When a person with learning disabilities has an additional neurodivergent diagnosis such as autism, they may face the challenge of the dyad of impairments which is the co-occurrence of difficulties in social interaction and communication, (DSM-V-TR 2022). Consequently, this creates obstacles in, comprehending social norms, engaging in verbal expression, actively listening, comprehending other people's speech, interpreting nonverbal cues, expressing emotions and interpreting other people's emotions, (DSM-V-TR 2022). Higgs, Cooper and Lee, (2023) note the importance of being able to express and recognise emotions in ourselves and in other people so that we may tailor our reactions to avert confrontations, distress and danger. People may express their emotional state through changes in posture, noises, sounds and facial expressions (Higgs, Cooper and Lee, 2023). The pioneering work of psychotherapist Valerie Sinasson (Galton, 2018) demonstrated that cognitive and social impairments in people with learning disabilities do not hinder them from developing in their linguistic and emotional functioning following treatment with psychoanalytic psychotherapy. There must be consideration for engaging people in therapy when distressed behaviours are noted.

Neurodivergence-informed therapy can change how we understand and address the manifestations of distress in neurodivergent learning disabled people. Instead of focusing on perceived deficits in individuals, the emphasis needs to be on the importance of developing good working relationships when supporting distressed

people. According to Chapman and Botha (2023), this approach recognizes the significance of relational dynamics in therapeutic interventions.

CQC (2022) recommends that neurodivergent people with learning disabilities be supported by staff in health and social care who have good understanding of their needs. When people's needs are met appropriately, it reduces the likelihood of distressed people being restrained. In the event that it becomes absolutely necessary to protect people through safe holds, the restraint should only be undertaken by staff whose training in the use of restrictive interventions is certified as compliant with the Restraint Reduction Network, RRN training standards, (Ridley & Leitch 2021). The implementation of RRN standards is a requirement under the Mental Health Units Use of Force Act (2018). Furthermore, areas of need should be identified through the use of tools such as sensory assessments, communication assessments and any other interventions necessary to enable people to participate fully within their communities in line with the Equality Act (2010). Guidance from Public Health England (2020) in conjunction with the Equality Act, (2010) places a duty on health and social care providers to make reasonable adjustments to ensure that their services are accessible to people with disabilities. This duty is anticipatory rather than reactionary, forward planning must be undertaken to ensure that the needs of neurodivergent, disabled people are met as and when service interventions are required.

TIME OUT 5

What barriers can you identify in the service where you work that need to be removed as part of trauma informed practice? Is your service compliant with the

Mental Health Units Use of Force Act (2018) and the Equality Act? In what ways can services for distressed individuals in your area of work be enhanced?

People who work with neurodivergent people must be aware of their own privilege and power. Walker (2023) calls out what he terms 'neurotypical privilege' which is the advantage that neurotypical individuals, especially those in positions of professional authority, have when interacting with neurodivergent people. This privilege blinds neurotypical people to their own limitations in empathy and communication when relating to neurodivergent people as they can conveniently attribute any failures in these areas to the supposed deficits of autistic individuals, (Walker, 2023). Higashida, (2014 & 2017), shares from his lived experience how his communication abilities were initially overlooked and how his actions were often misinterpreted by the people around him. Neurodivergent people are often disadvantaged by varied sources of oppression based on identifiers such as race, culture, gender, identity, disability and religion, (Cho, Crenshaw & McCall, 2013). A neurodivergent person with learning disabilities will face interlocking oppressions from their experiences of both disability and neurodivergence in a neurotypical world. As such, when supporting them with distress practitioners would need to of necessity work in an intersectional manner. A person's neurodivergence cannot be separated from their learning disability diagnosis.

The British Standards Institution BSI (2022) has released standards for the re-designing of environments to ensure inclusion for neurodivergent people. "An inclusive environment recognizes and accommodates differences in the way people

use the built environment. It facilitates dignified, equal, and intuitive use by everyone. It does not physically or socially separate, discriminate, or isolate. It readily accommodates human diversity from childhood to adulthood through to old age, across all neurological profiles, abilities, impairments, and embraces every background, gender, sexual orientation, race, religion, or belief (i.e., protected characteristics as defined in the Equality Act 2010). It helps people to live independently and participate fully in all aspects of life, (BSI 2022, Clause 4, BS 8300).”

Suggested Actions for working with neurodivergent learning disabled people

The following actions are suggested as means of mitigating against the likelihood of neurodivergent people developing distress which has a negative impact on their health and well-being.

Health and Social care providers must:

- Seek to establish and document commitment to delivering an accessible, sensory-friendly and inclusive environment.
- Identify a named person on their management team to champion neurodiversity and inclusion.
- Provide training on neurodiversity and learning disability.
- Provide awareness training to families and carers of people about sensory and/or information processing differences and any other specific areas of need.
- Work with people with lived experience of neurodivergence and learning disabilities when designing homes and relevant community spaces for this target group.

- Recruit people experienced in designing inclusive spaces when developing public spaces within our communities e.g., schools, colleges, hospitals, GP practices and leisure facilities.

[List adapted from resources from BSI, (2022); Walker, (2023) and Higashida, (2014 & 2017)]

TIME OUT 6

Which of the actions listed above can be implemented in the organisation that you work for? Who will you speak to within your organisation in order to advance this work? What can you do within your own job role to become a social justice advocate for neurodivergent people with learning disabilities?

Conclusion

It is crucial to recognise that individuals who are neurodivergent and have lived experience of learning disabilities often express their distress through behaviours that may be perceived as challenging by those around them. Unfortunately, the responses to these complex behaviours tend to focus on behaviour modification rather than addressing the underlying distress experienced by neurodivergent individuals with learning disabilities. This distress can stem from the trauma of navigating unsuitable neurotypical environments in various aspects of life such as education, health services and community daily interactions. Moreover, some individuals with learning disabilities and neurodivergent traits have also endured additional traumatic experiences such as physical restraint, chemical restraint, and isolation. Consequently, it is imperative for practitioners and families providing

support to these individuals to acquire and develop the necessary skills and knowledge to appropriately recognise and respond to their distress. By prioritising the acknowledgment and response to the underlying distress, rather than solely focusing on behaviour modification, we can create more inclusive and supportive environments for neurodivergent individuals with learning disabilities. Further research is required into effective interventions in response to the intersections of learning disability, neurodivergence, distress and trauma.

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