

ARTICLE

# Listening to the experts: person-centred approaches to supporting autistic people and people with an intellectual disability in the mental health system

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**SUMMARY**

Despite numerous UK government policies aimed at reducing the number of autistic people and people with an intellectual disability in mental health hospitals, little progress has been made, with many experiencing lengthy stays that offer little therapeutic benefit. Once admitted, people are at risk of restrictive interventions and significantly delayed discharge, resulting in trauma. This article draws on the cases of four people to illustrate the limitations of current mental health system approaches to the challenges experienced by autistic people and people with an intellectual disability. The importance of relational working and listening to people is explored, and we demonstrate how this can facilitate the provision of bespoke housing and care packages to enable a successful return to life in the community. Finally, we offer recommendations on the changes urgently needed to ensure that autistic people and people with an intellectual disability can live ordinary lives in their own homes, with timely and effective support from mental health services when needed, just like everyone else.

**LEARNING OBJECTIVES**

After reading this article you will be able to:

- understand why autistic people and people with an intellectual disability are more likely to be detained in hospital and endure longer lengths of stay
- appreciate the importance of relational working and its ability to reduce patient distress and restrictive practices
- apply a strengths and assets-based view to understanding autism and intellectual disabilities and use this knowledge to inform individual service design.

**KEYWORDS**

Autism; intellectual disability; person-centred; trauma; visual literacy.

**A note about terminology**

In keeping with the preferences of the respective communities, this article uses identity-first language in relation to autism (Kenny 2016; Bury 2020; Botha 2023; Morgan 2023), but person-first language in relation to intellectual disability (Morgan 2023). We also use the term intellectual disability, although ‘learning disability’ is commonly used by the National Health Service and other organisations in the UK.

**Introduction**

Since 2012, the UK government has acknowledged the need to reduce the number of autistic people and people with an intellectual disability in in-patient hospital settings. In the wake of the scandal of abuse at Winterbourne View Hospital, a plethora of policies were introduced to ‘transform care’ (Department of Health 2012) and to ‘build the right support’ (NHS England 2015), aiming to change how care is commissioned and delivered to enable people to live ordinary lives in their own homes in ordinary streets, with community-based support when needed (Bubb 2014). Alongside this, the 2015 revision of the Mental Health Act 1983 Code of Practice made it clear that ‘Compulsory treatment in a hospital setting is rarely likely to be helpful for a person with autism’ (Department of Health 2015: para. 20.20). However, 10 years on, little progress has been made. Autistic people and people with an intellectual disability are still warehoused in mental health hospitals, rather than living meaningful lives in the community.

According to ‘Assuring Transformation’ figures for the National Health Service (NHS) there were 1965 people with an intellectual disability and/or autism in in-patient settings (including NHS and

independent sector providers) in England at the end of September 2022 (NHS England 2022). Of these, 185 (9%) were under 18 years old, an increase from 110 in March 2015, when the first data-set was published.

Once in in-patient settings, autistic people and people with an intellectual disability are at risk of being prescribed inappropriate psychotropic medication and enduring other restrictive interventions, including physical restraint, seclusion and, in some cases, long-term segregation, with a risk of abuse (Care Quality Commission 2019, 2021), iatrogenic deprivation (Hubert 2006) and trauma.

Although it is recommended that discharge planning should begin as soon as possible after admission (Bubb 2014), prolonged stays are common. The NHS data (NHS England 2022) showed that 1110 autistic people and people with an intellectual disability (57% of the total number) had been in hospital for longer than 2 years. Only 860 (44%) had a planned discharge date. The key reasons for delayed discharges were a lack of suitable social care and housing in the community. Indeed, the number of discharges during the month of September 2022 had fallen to 150, compared with 185 in March 2015. Between March 2015 and September 2022, the number of admissions per month reduced from 165 to 95, although it should be noted that the number of available beds reduced from 2900 to 2030 during this time. Over the same period, the proportion of people with a diagnosis of autism alone increased from 15% to 37%. Overall, the data demonstrate that the progress towards reducing the number of autistic people and people with an intellectual disability in mental health hospitals is disappointingly slow.

This article draws on the real-life stories of one of the authors (A.Q.) and three other people with lived experience, C, D and G (Box 1). Explored are the challenges experienced by autistic people and people with an intellectual disability in the mental health system, and how, with a person-centred approach characterised by relational working, people can be successfully supported to live in the community.

### Intellectual disability and autism in a system that sees deficit

Under the medical model, intellectual disability and autism are considered neurodevelopmental disorders. An alternative perspective holds that intellectual disability and autism are forms of neurodevelopmental difference ('neurodiversity') and that people with these conditions differ from people without them (the 'neurotypical' population) in

#### BOX 1 Case studies

C, D and G and their families gave informed consent for their stories to be told here.

C: C is a 28-year-old woman with an intellectual disability. She found the transition to high school challenging and found it hard to cope with the busy, noisy environment and different staff. C stopped eating and had various physical health investigations. She was frightened of doctors and nurses and needed to be taken from the car into the hospital under restraint. C began running away and in 2009, at the age of 15, she was detained in hospital under the Mental Health Act 1983. She was later diagnosed with autism.

G: G is a 27-year-old man who has an intellectual disability and autism. G is part of a close-knit family and likes going out and about with them. He has a particular interest in trains and coloured lights. G was living in a residential placement before being detained in hospital under the Mental Health Act 1983 at the age of 18 years because he was experiencing behaviour that challenged others.

D: D is a 25-year-old autistic woman. After the death of her brother and while struggling in school, this intelligent young woman was detained under the Mental Health Act 1983 in hospital. Here she learned how to self-harm and developed an eating disorder. D has been kept in long-term segregation for many years and she now struggles to express herself in ways that extend beyond self-harm. She currently remains detained in a women's medium secure service, having been in hospital for over 10 years.

areas including communication, social and cognitive styles, and sensory processing.

Intellectual disability is characterised by reduced abilities to understand new or complex information or to learn new skills, and a reduced ability to cope with everyday tasks independently. Communication can be a particular challenge for people with an intellectual disability, some of whom may find written or spoken words difficult to understand and may themselves communicate via means other than speech. This can result in significant communication barriers, leading to frustration when those around the person do not understand how to communicate with them effectively. People with an intellectual disability may instead, at times, communicate via their behaviour. Distressed behaviour may be a person's only way to communicate pain or other physical discomfort, or emotional states such as frustration, boredom or fear.

Autism is characterised by challenges with social communication and interaction; difficulties coping with change; intense interests; and sensory processing differences. Each autistic person will have their own areas of strength and their own challenges. However, mismatched communication styles between an autistic person and a neurotypical

person occur frequently. Difference in cognitive style poses a further challenge. Autistic people may be characterised as ‘monotropic’ thinkers – that is, singularly focused, dedicated to their interests and overly sensitive to the world around them (Murray 2005). In contrast, non-autistic people tend to be ‘polytropic’ thinkers, able to attend to and process information from multiple sources at the same time (Kapp 2013; Crompton 2020). For example, an autistic person’s attention to and processing of a particular sound may leave them in discomfort and unable to focus on anything else, which may be difficult for neurotypical people to understand.

A strengths and assets-based view to understanding autism and intellectual disability means focusing on people’s similarities, rather than highlighting and objectifying their difference. When we focus on peoples’ strengths they can build self-esteem and increase their innate value.

### Current forms of treatment and their inadequacies

When environmental stressors overwhelm a person’s ability to cope, autistic people and people with an intellectual disability react in ways most tolerable to their natural cognitive, emotional and sensory system. Such expressions of distress may differ from those of neurotypical people and may be perceived as cause for alarm. A.Q. was detained under the Mental Health Act 1983 in 2012 after she experienced an autistic grief reaction – an inability to mask feelings of distress, heightened sensory sensitivity and an all-consuming fascination. The

former schoolteacher was detained under the Act for 3.5 years. Her reaction to intervention heightened her state of dysregulation and increased risk (Fig. 1). In and of itself, her initial ‘behaviours’ might not have been considered worrisome. Indeed, they were to be expected. Had her presentation been contextualised and located in her history, the behaviour might have attracted greater understanding and validation, rather than detention.

Although the Mental Health Act Code of Practice makes it clear that, for a person with an intellectual disability or an autistic person, ‘it is important to establish whether any abnormally aggressive or seriously irresponsible behaviour stems from difficulties in communication or an underlying condition or an unmet need’ (Department of Health 2015: para. 20.13), the cause of a person’s behaviour is often not elucidated in the community. C’s difficulties coping with the transition to high school were not effectively understood and addressed in the community; the response of the mental health system in C’s case was instead to detain her in a mental health hospital.

Mental health hospitals are often noisy, busy, unpredictable places, and an autistic person, finding themselves surrounded by unfamiliar people in an unfamiliar environment that does not meet their sensory needs, is likely to become distressed. Similarly, a person with an intellectual disability may find themselves in a hospital environment in which their communication needs are not understood. Although C needed familiarity and sameness, she was moved numerous times. C said that other people on the ward set their

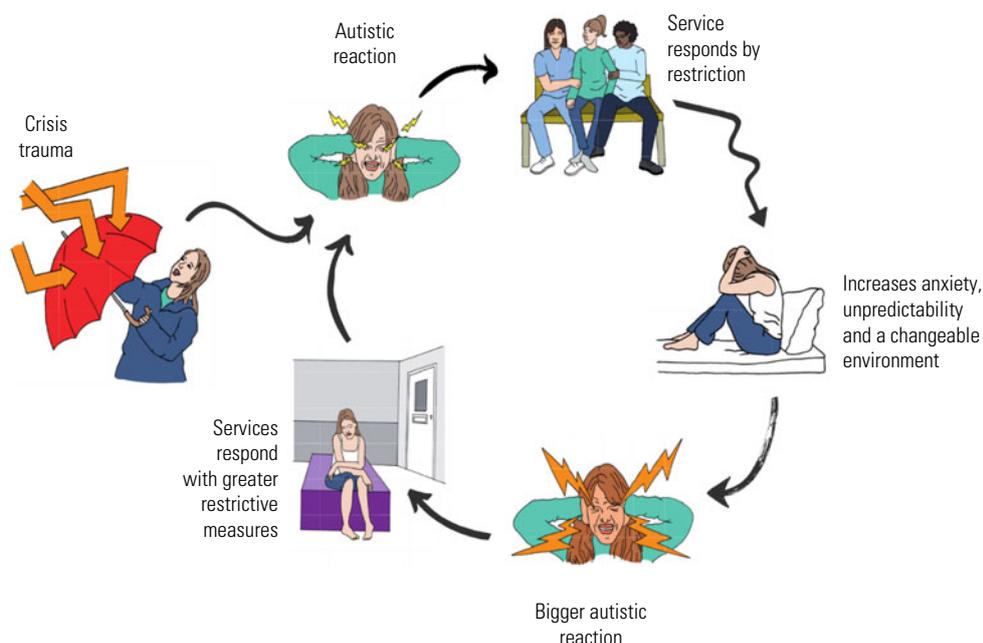


FIG 1 The distress-coercion cycle (Kilcoyne 2023).

bedrooms on fire, which frightened her. On one occasion, another patient got into her room, causing immeasurable distress. When she tried to get help from ward staff, C found them asleep in the lounge and was not believed when she complained. C described how she found it difficult to cope with lots of different staff. She had times of distressed behaviour, and recalls being held down and given injections. C was eventually moved to a medium secure forensic unit far from her family and home. She remembers being frightened by being strip-searched with a metal detector and by being on a ward with murderers and people she described as very mentally unwell.

G also experienced several hospital moves and found the noise of the wards difficult to cope with. Being in hospital increased G's levels of anxiety and his distressed behaviour. Therefore, G was often physically restrained by staff. G also spent periods of time in segregation because he was considered a risk to others, with a need for 2–3 staff at any one time to 'keep him safe'. Yet, his family were able to take him home for visits and do ordinary community activities without using any restrictive interventions. During his admission, G was left with a broken arm for 24 h before a doctor was called. His family were concerned that the staff in the hospital simply did not know how to support G. He became caught in the distress–coercion cycle (Fig. 1) and was considered not ready for discharge because of his behaviour, which itself was a consequence of being in the wrong environment.

In settings that cannot meet the needs of autistic people and people with an intellectual disability, restrictive interventions are disproportionately used to manage communications of distress (Hollins 2021; Care Quality Commission 2021). The more restriction people are subjected to in unfamiliar and inappropriate settings, the more they will be adversely affected and liable to react in ways that challenge others (Fig. 1). Consequently, people can find themselves perceived by health and social care professionals as being 'too complex' or 'too risky' to discharge. A.Q. describes how, once detained, autistic people and people with an intellectual disability are subjected to a 'Velcro system', which keeps them stuck. This is reflected in the stories of C and G, who both endured multiple hospital moves to increasingly restrictive settings to manage 'risk'. However, their 'risk' was not considered in the context of a person attempting to negotiate an anxiety-provoking, highly changeable and unpredictable environment.

Another narrative about people with an intellectual disability and autistic people in very restrictive hospital settings, such as long-term segregation, is that 'they like to be alone ... they like seclusion'.

However, this is an unacceptable forced choice: when the environment is traumatising, what other option does the person really have? They must choose between sensory and social deprivation or sensory social overwhelm – neither are acceptable.

### **Effective mental health system responses to the challenges of intellectual disability and autism**

To respond effectively to the challenges a person with an intellectual disability or an autistic person may experience, it is important to recognise that all human beings, regardless of neurodevelopmental difference, have an inherent need for meaningful connection. Distance, and a focus on behaviour, frustrate people's human desire for relationships (Mearns 2018). What autistic people and people with an intellectual disability need from the staff working with them is to be understood.

#### *Understanding the person*

For many decades, people with an intellectual disability and autistic people have been considered from a medical perspective (Asperger 1944; Kanner 1944; Kapp 2019) in need of intervention, remediation and cure, resulting in stigma, marginalisation and othering (Botha 2020). Since infancy, parents and their neurodiverse offspring may have endured comments such as 'What's wrong with you/your child?', 'Why are they behaving like that?', 'Have you tried disciplining them?' Autistic people and people with an intellectual disability are often left burdened by such negative messaging. Indeed, bullying and micro-trauma suffered in many areas of life accrue and can result in significant trauma (Crastrnopol 2015; Rumball 2020).

G was eventually diagnosed with post-traumatic stress disorder following his years in in-patient settings. Staff within mental health services need to be able to identify trauma in people with an intellectual disability and autistic people, and provide care and support that addresses this and that, crucially, does not further traumatise. Where mental health systems do not directly address trauma, they may exacerbate it by adopting behavioural approaches to behavioural distress. For example, it is not uncommon for staff to say a person is 'difficult to manage'. Such language reinforces disconnection and increases power differentials. Language can be indicative of culture. Cultures that prioritise the humanity of individuals, engage experts by experience, focus on connection and pay attention to power differentials are less likely to create distressed behaviour and therefore to use restrictive practices (Huckshorn 2004; Mearns 2018). Rather than seeing a set of problems or a collection of diagnoses,

staff need to see the person and seek a deep understanding of who they are.

### *Working relationally*

To enable a person to feel understood, staff need to work relationally – that is, with a focus on the importance of relationships and how they affect well-being. A.Q. describes her social death (Guenther 2013) in segregation – not being perceived by staff and therefore, owing to lack of interaction, not being able to perceive herself. She communicated her immense distress through behaviour, which she would escalate just to be seen. When staff worked relationally, she recalls, ‘the fact that someone was willing to listen, was interested in knowing me, able to enjoy being with me and willing to stay with me when I was “challenging” has had greater significance than any other intervention or environment or investment in care’. This requires attunement to the person’s physicality, emotions and thoughts. Developing new ways of relating creates opportunities to reduce frustration, distressed behaviour and the use of restrictive interventions.

Crucial to working relationally is reaching out to the person and profoundly valuing and acknowledging their uniqueness (Boardman 2014). Staff affirmation must be extended to not just one part of the person or one aspect of their behaviour but rather to the totality of their being (Rogers 1959; Stern 2003). When we honour and value deeply the way the person is in the world, we will be better able to understand their needs, desires, hopes and dreams, and to adjust the ways we interact with and support them.

Relational working is important not only in hospital settings, but also in the place a person is discharged to. In a study of post-institutionalised men with severe intellectual disabilities, Hubert & Hollins (2010) found that the men still experienced denial of individual identity and autonomy, with limited change in professional and social attitudes towards them even though they had left long-stay institutions. In another study, of women with severe intellectual disabilities who returned to the community from locked wards, Owen et al (2007) found that, although the women had more opportunities to make choices, learn new skills and explore new activities in the community, in general, their individual pasts, relationships and emotional lives continued to be ignored. In other words, they were not revived from their social death once they had returned to the community. For discharges from hospital to the community to be successful, there must be a handover of a person’s life history, not just their risk history and

medicine chart, and those organisations supporting the person in the community must demonstrate their commitment to really knowing and valuing the individual. Staff in hospitals and in organisations supporting people on discharge should invest in spending time with the individual and their families/carers to build relationships based on understanding who the person is, what matters to them and how they have come to be where they are now (Kalb 2019).

### *Enhanced communication skills*

Communication is fundamental to working relationally. Staff must develop enhanced communication skills, particularly when supporting people who communicate by means other than speech and/or who have sensory impairments, such as visual impairment. In their study of men with a severe intellectual disability in NHS long-stay hospitals, Hubert & Hollins (2006) found that all of the men, even those who could not speak, spent a considerable amount of time trying to communicate with the staff around them, but their attempts often met with no response or acknowledgement, leading to a rejection of these men as interactive social beings.

Beyond Words offers word-free books specifically designed with adults with word-processing or other communication difficulties, to enhance emotional and health literacy. Beyond Words books about issues such as abuse, bereavement and feeling upset and angry can support people to express themselves, but also help develop staff empathy (Hollins 2017), facilitating a relational working approach. D is being helped by the hospital’s new approach to better listen to, communicate and build relationships with patients. The hospital is using Beyond Words books and staff training to help patients work out and express their feelings and needs (Boardman 2014; Hollins 2017). Staff working with D report that ‘D is really enjoying showing us [staff] how to use visual storytelling to help her understand things. We understand more clearly who she really is’. Employing enhanced communication skills to work relationally offers an antidote to feelings of isolation, frustration and aloneness, which are often chronic for autistic people and people with an intellectual disability.

### *Bespoke housing and support*

Understanding the person is key to designing effective person-centred community-based support. Creating ‘model services’ to fit neurodivergent people is not the right solution. Like anyone else, autistic people and people with an intellectual disability have diverse preferences and needs. Each person requires a bespoke home. Only then can they

experience agency and control over what happens in their lives – feeling stability in connectedness to family and friends, places and things that are important to them. This is no different from any other person. These are basic human needs for everyone, but the consequences of not having these needs met has a disproportionately greater impact on neurodivergent people than for most neurotypical people.

In the Small Supports programme, the National Development Team for Inclusion, NHS England, the Local Government Association and some care providers are successfully working with people whom others have failed (Wood 2021). They have set out the characteristics of systems and organisations that successfully support people in communities. Key to this is starting from a ‘blank sheet of paper’ and asking the person and the people who know them best to fill this in with the person’s aspirations, therapeutic needs and preferences for their living space. Care organisations that successfully support people in the community have also provided clear recommendations on how to do this (Box 2).

For someone like G, who needs control of his environment, living with other people poses a significant challenge. He needed a bespoke home, designed around his sensory needs, with a bespoke care package. He now lives close to his family, with

staff who understand him and are supporting him to slowly recover from the trauma he experienced during his hospital admission. G can enjoy life again and spends time absorbed in his love of trains. He recently became ‘Uncle G’ and is enamoured with his baby nephew.

Asking people what they want, what makes them happy, what makes them feel safe and well, the kind of people they want in their lives, and making sure they have something to get up for in the morning, is the basis of getting support right for most people who need care, but even more important for those who have been failed by traditional models of care. C was finally discharged after her family sought legal advice. She returned home to live with her parents, with support from paid carers who understand her. She describes in Box 3 what she needed to return to living in the community.

Providing person-centred bespoke housing and care packages that have, at their core, an understanding of the individual and the trauma they have experienced can enable even those deemed most difficult to move out of restrictive hospital settings to live in the community. *Helping People Thrive* (Wood 2021) sets out examples of how people with histories of living long-term in inpatient settings, often in segregation, were no longer considered ‘dangerous’ when they moved into their new bespoke home environment.

We note that some people may be discharged to small community group-living settings, rather than their own bespoke home – what remains key is

### BOX 2 Features of care providers that successfully support autistic people and people with an intellectual disability to live in the community

- The person comes first – they are people, not service users
- Love, relationships and meaningful connection are central to living and therefore to support
- The support a person needs or has needed in the past does not define them
- The person has to have their own bespoke home
- Communities and partnerships are central to supporting people
- Everyone has something to give – support people to do that
- Being relentlessly positive – stick with people even when the going gets tough
- Maintaining and building relationships with families is a central part of the support
- A robust focus on providing the right support so that there becomes little need to think about avoiding readmission to hospital, prison or institutional care
- Breaking the rules when it is about what a person needs
- Keeping money and power as close to the person as possible

(Kelly & Wood, 2023)

### BOX 3 C’s description of what she needed to live in the community

We present here C’s own words, but have removed people’s names.

‘C live at home with mami dadi J and B and 2 dogs. C love C family lots and C has good friends. She has 2 dogs at home – C like 2 call dogs companions.

C is not thick or stupid sow please do not talk or wispa about C in frunt of C. Or if need talk about C inclood C.

C like keep in bisy C like walking miles and miles trampoline swimming shopping cooking bikeability arts and crafts woodwork pottery.

C is very clever in C own way. Never lie to C. Never bee scared of C. Please Trust C coz C never want to hurt anyone or anything.

C need 2:1 staff to help keep C safe and help C and in a meltdown. C needs staff to intervene to help calm C.

C wood like own safe proof bungalow with a drive and a lounge a bathroom a kitchen a garden with a swing and 1 staff sleep room and a bedroom for C and a room for a sensory room.’

that people with an intellectual disability and autistic people have choice over where they live and who they live with, and that wherever they live, they are understood and valued as individuals.

### Preventive mental health strategies

In addition to underpinning mental health system responses to autistic people and people with an intellectual disability, we argue that a relational working approach should be taken to public mental health strategies. For example, Beyond Words book clubs are proving effective in encouraging children and adults to explore and describe their own understanding and their own needs, developing visual and emotional literacy in a trusting and friendly setting (Carpenter 2016; Egerton 2020). There should also be a focus on providing peer-led support for autistic people and people with an intellectual disability and on tailored social prescribing.

Preventing unnecessary admissions to hospital is central to the approach of successful providers of support in the community. In the USA, the START model (National Center for START Services 2022) at the University of New Hampshire works with a whole-system approach to improve the mental health of people with intellectual disabilities and reduce hospital admissions (Kalb 2019). To achieve this, START (which stands for ‘systemic, therapeutic, assessment, resources and treatment’) works across systems to prevent crises and provide short-term therapy, interventions and family support. This cross-system interdisciplinary approach is essentially what successful community providers try to create to prevent readmission, but it is not a systematic approach across health, social care, education and the criminal justice systems.

### Accountability

The 2020 Health and Social Care Select Committee Inquiry into the treatment of autistic people and people with intellectual disabilities concluded that the provision of community support was ‘totally inadequate’ (House of Commons Health and Social Care Committee 2021: p. 5). Most health and social care commissioners are not specialist enough to understand what the right type of support looks like. We recommend that commissioners of services for autistic people and people with an intellectual disability should gain first-hand experience of what a good life in the community looks like for people in these populations. There must also be clear accountability for failures to commission effective community-based support. Similarly, there needs to be clear accountability for care providers who fail to meet the needs of people, particularly when this results in readmission to hospital (Hubert 2010).

It is our experience that mental health hospitals often do not understand how the right type of community support can work (Hollins 2021) or what this would look like. We suggest that, along with commissioners, health and social care professionals making decisions about accommodation, care and support for autistic people and people with an intellectual disability on discharge should have training in what good support looks like, delivered by experts by experience.

Further measures are urgently needed to prevent avoidable admissions and address delayed discharges. One key recommendation we offer is that the intellectual disability and autism leads on NHS integrated care boards should report to the Board when certain red flags are raised. These red flags could include: any mental health hospital admission of a person with an intellectual disability and/or autism of any age; any person with intellectual disability and/or autism who has been in a mental health hospital for more than 3 months; any primary carer of a person with intellectual disability and/or autism who does not have an ‘in case of emergency’ care plan in place.

### Co-production and training in partnership

The Health and Care Act 2022 introduced a requirement that regulated service providers ensure their staff receive training on intellectual disability and autism, and the standardised, tiered training developed in co-production with (and to be delivered in partnership with) people with lived experience of intellectual disability and autism (the Oliver McGowan Mandatory Training on Learning Disability and Autism) is a welcome move towards improving staff knowledge of intellectual disability and autism. However, we suggest that healthcare and social care professionals must prioritise training in trauma-informed care and improving their skills in relational working and enhanced communication.

### Discussion

The stories of A.Q., C, G and D highlight that there remains much to be done to improve the mental health system for autistic people and people with an intellectual disability. Despite the clear policy agenda to prevent hospital admissions, current approaches to people in these populations at times of distress continue to result in too many admissions to mental health hospitals. It is accepted that community-based support, provided by people known and trusted by the person, in a place they know, is needed. However, we have highlighted that relational working is of fundamental importance to any attempts to improve the care and treatment of autistic people and people with an intellectual

disability. We have emphasised the need for a cultural and attitudinal shift that recognises the essential humanity of each person, empathising with their losses and other adverse life experiences, and that seeks to establish a deep understanding of the person and their life. Acceptance of who the person is, how best to communicate and listen, will help them to feel safe and connected. This is key to providing effective care and support, minimising the use of restrictive interventions and, importantly, allowing a person to tentatively put their trust in services that have previously failed them.

We acknowledge that a lack of adequate funding has an impact on the provision of suitable housing and tailored care packages in the community, and call for urgent ring-fenced funding to address this. However, we believe there is scope for commissioners to be more creative in their approach to developing person-centred community-based solutions, informed by a deep understanding of the individual, to enable people to be discharged from hospital and to prevent admissions, starting now.

In their own homes, with tailored support and good community care, autistic people and people with an intellectual disability thrive (Wood 2021). Currently, the right kind of support and interventions do exist, but they are brought about by individuals and families fighting to get what is needed, underlined by their clear vision of a better way of living for the person. We urge commissioners to share learning across integrated care boards about how to incentivise the right type of care providers – those in which staff are well-trained, well-paid, well-supported and provide a culture of relational working. There needs to be clear accountability when this does not happen.

A.Q., C, G and D, and the stories of thousands of other autistic people and people with an intellectual disability, make it clear that current crisis provision remains unfit for purpose. Instead of papering over the cracks of a failing system, a commitment to working preventively – providing agile, well-funded and tailored support throughout a person's life – is needed, with clear accountability for failings. People like A.Q., C, G and D and their families need to be confident that, in times of distress, the services they turn to will understand them and will offer appropriate and effective care, rather than misunderstanding them and traumatising them. Without investment in whole-system reform, people like A.Q., C, G and D will continue to find themselves stuck in a system that doesn't care. We need real change and we need it now.

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## Author contributions

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## Declaration of interest

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## References

- Asperger H (1944) Autistic psychopathy in children. *Archiv für Psychiatrie und Nervenkrankheiten*, **117**: 76–136.
- Boardman E, Bernal J, Hollins S (2014) Communicating with people with intellectual disabilities: a guide for general psychiatrists. *Advances in Psychiatric Treatment*, **20**: 27–36.
- Botha M, Frost DM (2020) Extending the minority stress model to understand mental health problems experienced by the autistic population. *Society and Mental Health*, **10**: 20–34.
- Botha M, Hanlon J., Williams GL (2023) Does language matter? Identity-first versus person-first language use in autism research: a response to Vivanti. *Journal of Autism and Developmental Disorder*, **53**, 870–8.
- Bubb S (2014) *Winterbourne View: Time for Change. Transforming the Commissioning of Services for People with Learning Disabilities and/or Autism*. Transforming Care and Commissioning Steering Group.
- Bury SM, Jellet R, Spoor JR, Hedley D (2020) "It defines who I am" or "It's something I have": what language do [autistic] Australian adults [on the autism spectrum] prefer? *Journal of Autism and Developmental Disorders*, **53**, 677–87.
- Care Quality Commission (2019) *Interim Report: Review of Restraint, Prolonged Seclusion and Segregation for People with a Mental Health Problem, a Learning Disability and or Autism*. Care Quality Commission.
- Care Quality Commission (2021) *Restraint, Segregation and Seclusion Review: Progress Report (December 2021)*. Care Quality Commission.
- Carpenter B, Egerton J, Hollins S (2016) Book clubs for people with intellectual disabilities: the evidence and impact on wellbeing and community participation of reading wordless books. *Advances in Mental Health and Intellectual Disabilities*, **10**: 284–92.
- Crastopol M (2015) *Micro-Trauma: A Psychoanalytic Understanding of Cumulative Psychic Injury*. Routledge.
- Crompton CJ, Ropar D, Evans-Williams CV, et al (2020) Autistic peer-to-peer information transfer is highly effective. *Autism*, **24**: 1704–12.
- Department of Health (2012) *Transforming Care: A National Response to Winterbourne View Hospital Department of Health Review: Final Report*. Department of Health.

### MCQ answers

1 e 2 a 3 e 4 b 5 d

- Department of Health (2015) *Mental Health Act 1983: Code of Practice*. Department of Health.
- Egerton J, Carpenter B, Hollins S (2020) *Supporting Pupils with Wordless Books*. Nasen Monthly Membership Magazine. pp. 24–26.
- Guenther L (2013) *Solitary Confinement: Social Death and Its Afterlives*. University of Minnesota Press.
- Hollins S, Carpenter B, Bradley E, et al (2017) Using wordless books to support clinical consultations. *Journal of Mental Health Training Education and Practice*, **12**, 260–71.
- Hollins S, Wood A (2021) *Thematic Review of the Independent Care (Education) and Treatment Reviews*. Department of Health and Social Care.
- House of Commons Health and Social Care Committee (2021) *The Treatment of Autistic People and People with Learning Disabilities: Fifth Report of Session 2021–22*. House of Commons (<https://committees.parliament.uk/publications/6669/documents/71689/default>).
- Hubert J, Hollins S (2006) Men with severe learning disabilities and challenging behaviour in long-stay NHS hospital care: qualitative study. *British Journal of Psychiatry*, **188**: 70–4.
- Hubert J, Hollins S (2007) Ethnographic research in closed institutions: ethical issues. *Research Ethics Review*, **3**:122–6.
- Hubert J, Hollins S (2010) A study of post-institutionalized men with severe intellectual disabilities and challenging behavior. *Journal of Policy and Practice in Intellectual Disability*, **7**: 189–95.
- Huckshorn KA (2004) Reducing seclusion restraint in mental health use settings: core strategies for prevention. *Journal of Psychosocial Nursing and Mental Health Services*, **42**: 22–33.
- Kalb LG, Beasley J, Caioli A, et al (2019) Improvement in mental health outcomes and caregiver service experiences associated with the START program. *American Journal on Intellectual and Developmental Disabilities*, **124**: 25–34.
- Kanner L (1944) Early infantile autism. *Journal of Pediatrics*, **25**: 211–7.
- Kapp S, Gillespie-Lynch K, Sherman L, et al (2013) Deficit, difference or both? Autism and neurodiversity. *Developmental Psychology*, **49**: 59–71.
- Kapp S (2019) How social deficit models exacerbate the medical model: autism as a case in point. *Autism Policy & Practice*, **2**: 3–28.
- Kelly D, Wood A (2023) *Made to Measure: Love, Respect and Radical Approaches to Care* [eBook]. ISBN: 9798854282369.
- Kenny L, Hattersley C, Molins B, et al (2016) Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, **20**, 442–62.
- Kilcoyne J, Angus D (2023) *The HOPE(S) Model: A guide to reduce long-term segregation in learning disability, autism and mental health services*. Mersey Care NHS Foundation Trust (<https://www.merseycare.nhs.uk/hopes-model>).
- Mearns D, Cooper M (2018) *Working at Relational Depth in Counselling and Psychotherapy* (2nd edn). SAGE Publications.
- Morgan D, Nisbet B, Richardson A (2023) *Learning Disability, Autism and Neurodiversity Bill: Scoping Analysis 2022*. Scottish Government.
- Murray D, Lesser M, Lawson W (2005) Attention, monotropism and the diagnostic criteria for autism. *Autism*, **9**: 139–56.
- National Center for START Services (2022) START MODEL. National Center for START Services (<https://centerforstartservices.org/START-Model>).
- NHS England (2015) *Building the Right Support*. NHS England.
- NHS England (2022) Learning Disability Services Monthly Statistics, AT: November 2022, MHSDS: September 2022 Final. NHS England (<https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics>).
- Owen K, Hubert J, Hollins S (2007) Moving home: the experiences of women with severe intellectual disabilities in transition from a locked ward. *British Journal of Learning Disabilities*, **36**: 220–6.
- Rogers C (1959) A theory of therapy, personality and interpersonal relationships as developed in the client-centred framework. In *Psychology: A Study of Science*, Vol. 3 (ed S Koch): 184–256. McGraw-Hill.
- Rumball F, Happé F, Grey N (2020) Experience of trauma and PTSD symptoms in autistic adults: risk of PTSD development following DSM-5 and non-DSM-5 traumatic life events. *Autism Research*, **13**: 2122–32.
- Social Care, Local Government and Care Partnership Directorate (2014) *Positive and Proactive Care: Reducing the Need for Restrictive Interventions*. Department of Health.
- Stern DN (2003) *The Interpersonal World of the Infant: A View from Psychoanalysis and Developmental Theory*. Karnac.
- Wood A *Helping People Thrive*. Department of Health and Social Care, 2021 (<https://www.bild.org.uk/helpingpeoplethrive>).

**MCQs**

Select the single best option for each question stem

**1 In England, the detail of best community support is most likely to be determined by:**

- a national guidance
- b the Mental Health Act
- c specialist NHS commissioning
- d local clinical commissioning
- e social workers.

**2 Of the following, the best way to work with people with an intellectual disability and/or autistic people is:**

- a relationally
- b to isolate them so that other people do not invade their space
- c to professionalise their care and support
- d to wait for a legal opinion before planning an individual child's or adult's care and support
- e to admit them to hospital for an assessment.

**3 According to the authors, what needs to change to create person-centred care?**

- a easier access to psychological assessments
- b community teams for people with learning disabilities (CTPLDs) and community mental health teams (CMHTs) will need to work together
- c children's social care will need to integrate with child and adolescent mental health services
- d specialist mental health units will need to be created in each commissioning area
- e local organisations will need to focus on culture change.

**4 The best descriptor of autistic thinking is:**

- a stereotopic
- b monotropic
- c dysregulated
- d lacking insight
- e self-focused.

**5 The strongest predictors of a settled ordinary life for autistic people and people with an intellectual disability are:**

- a clinical outcome measurements
- b service funding
- c staff sickness rates
- d bespoke person-centred life plans
- e rates of unplanned admissions.