

CLINICAL REFLECTION

Autism: social care, reasonable adjustments and the personal passport

Samuel Tromans , Zandrea Stewart & Traolach Brugha

Samuel Tromans is Associate Professor of Psychiatry in the Department of Population Health Sciences, University of Leicester, UK, and an Honorary Consultant in the Psychiatry of Intellectual Disability in the Adult Learning Disability Service, Leicestershire Partnership NHS Trust, Leicester, UK. **Zandrea Stewart** is founder of Inspired Purpose, Newport, UK, where she is an executive and well-being coach and leads on partnership working in the not-for-profit, business and public sectors. **Traolach Brugha** is Professor of Psychiatry in the Department of Population Health Sciences, University of Leicester, UK, and an Honorary Consultant in General Adult Psychiatry in the Adult Autism Assessment Service, Leicestershire Partnership NHS Trust, Leicester, UK.

Correspondence Samuel Tromans. Email: st386@leicester.ac.uk

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SUMMARY

Autism is a neurodevelopmental condition associated with differences in social communication and interaction, as well as a restricted, repetitive repertoire of behaviours and interests. Autistic people will have areas of interest and can possess abilities that are of potential benefit to both themselves and wider society. However, many find that their opportunities are limited. Here, we will discuss how a social model of care can help meet the needs of autistic people.

KEYWORDS

Autism; psychosocial interventions; social functioning; autism spectrum disorders; neurodevelopment.

Autism, once considered predominantly through the medical model, is being increasingly viewed through the lens of neurodiversity, where the individual does not experience difficulties from having autism *per se*, but rather ‘from living in a society which tends to be physically, socially and emotionally inhospitable towards autistic people’ (Den Houting 2019). Although neurodiversity is a term used to describe a broader range of psychological characteristics, it remains a concept frequently used in autism discourse. The ever-changing conceptualisation of autism has contributed to policy changes, such as the recently published draft Mental Health Bill (Department of Health and Social Care 2022a), which proposes numerous reforms, including removing autism and intellectual disability as criteria that would permit compulsory in-patient detention for treatment under section 3 of the Mental Health Act 1983 (covering England and Wales), in the absence of co-occurring mental illness.

A potential unintended consequence of the neurodiversity viewpoint is that the de-medicalisation of autism risks it not being viewed as the core business of mental health professionals. However, whether autism is considered through the medical or neurodiversity model, or both, possessing a good knowledge of autism is of paramount importance to

health and social care professionals. This is particularly important as autistic people face health inequalities and challenges in receiving equitable healthcare. It is also key to appreciate that these individuals may present differently with health conditions; understanding this is essential to ensuring timely diagnosis and treatment. Furthermore, diagnosed autistic individuals have significantly higher rates of mental and physical illness relative to their peers (Croen 2015). Factors potentially contributing to such inequality and increased morbidity include social isolation, discrimination and a lack of reasonable adjustments being made in healthcare settings (Croen 2015). However, it is less clear whether undiagnosed autistic people, representing a significant proportion of the population with the condition (Brugha 2011), also have higher rates of co-occurring conditions.

The increasing visibility of autism and the need for upskilling of health and social care professionals

Research on the prevalence of autism among adults living in the community suggests that most of those with the condition are unidentified (Brugha 2011). As recognition of autism in childhood grows, it is likely that fewer individuals will have unrecognised autism on entering adulthood. Furthermore, the UK’s Autism Act 2009 represented a landmark step forward in autism diagnosis, needs assessment and support provision.

The needs of autistic people vary widely, depending on numerous factors, including how their profile of autistic traits affects them, the presence of co-occurring conditions, the environment in which they live, their social circle, their coping strategies and their ability to navigate life’s demands.

Although not all medical practitioners are autism experts, they are increasingly aware of a need to recognise autism and work with patients holistically, considering both their health and social care needs. Initiatives such as the Oliver McGowan Mandatory Training in Learning Disability and Autism (Health Education England 2022) are intended to

ensure that all health and social care professionals receive training appropriate to their role. Furthermore, there has been a move wherever possible to supporting autistic individuals in the community, with related ‘Homes not Hospitals’ guidance developed for health and social care professionals (British Association of Social Workers 2022).

Social care and autism

The importance of social care for autistic people is becoming increasingly familiar to the medical profession. In societies lacking social care resources, as well as historically within the UK, clinicians have told families when they felt there was nothing more they could do and advised them to ‘take their loved one home’ (Brugha 2018). However, if there is no home or direct family input, depending on the individual’s well-being, needs and life circumstances, social care could be viewed as a state responsibility; regardless of the type of support one may receive, it is imperative that social care providers are valued and understood.

In both health and social care contexts, autistic people have the right to make decisions about their lives. Much like their peers, they might wish to make choices that health and social care professionals may not always recommend. However, autistic adults have a legal right and unless otherwise determined have the mental capacity to make decision and their wishes should be respected. Nevertheless, there may be circumstances where, despite having capacity and making their wishes clear, certain choices are not an option for them, such as wishing to remain in the family home if their carers feel unable to continue supporting them (Brugha 2018).

The roles of social care professionals in supporting autistic people are diverse (Box 1). There is a need for an individualised approach, which also recognises the strengths that the person possesses. Although the person is the central focus of health and social care support, it is important to also consider the needs of their carers, particularly unpaid carers, who are often family members. Carers may be vulnerable to strain related to a variety of factors, including the amount of caregiving being provided, the level of needs of the person they are caring for, the caregiver’s coping styles and unmet service needs (Shivers 2017). It is important to identify this in the interests of both the carer’s own well-being and that of the person they are caring for.

As previously described, autistic people represent a heterogeneous group, with widely varying needs. Thus, there is a need to recognise the individual beyond the diagnostic label; a one-size-fits-all

BOX 1 Various roles and working contexts of social care professionals supporting autistic adults

- Advocacy
- Social care needs assessment
- Capacity assessment
- Deprivation of Liberty Safeguards assessment
- Supporting families who are providing care
- Mental health services (including Mental Health Act assessment)
- Adult safeguarding
- Physical health services
- Welfare and benefits systems
- Education
- Housing
- Employment
- Community activities
- Charitable, voluntary and non-profit work
- Criminal justice services
- Religious communities

(Brugha 2018)

approach to care is inappropriate. Currently, there are no widely available tools for assessment of the health and social care needs specific to autistic people. Development of such a tool, or indeed adaptation of an existing tool, would be invaluable in ensuring a standardised approach to needs assessment that is also sensitive to individual differences and supports a wider strengths-based holistic approach. Furthermore, the person themselves should be central to formulating an assessment of their needs.

The personal passport

The idea of a ‘personal passport’ has been suggested as a means of bridging communication gaps between an autistic person and their peers, as well as signalling to other people and to services that they are autistic (Brugha 2018). Such passports have been widely used for persons with intellectual disability, many of whom have co-occurring autism, but the benefit of this approach may extend to most persons with specific communication needs, irrespective of cause.

This personal passport document would confirm the person’s autism diagnosis, as well as summarising their specific communication needs. For example, they might need others to use direct language (i.e. avoiding abstract terms and metaphor), to speak slowly (to allow for information processing) and to recognise their difficulties attending to more

than one aspect of communication simultaneously (e.g. both verbal and non-verbal communication). These passports are often developed by autistic people (and their carers) collaborating with speech and language therapists, considering their expertise in communication.

A personal passport can also serve wider functions, such as listing details of the person's likes and dislikes (e.g. distressing sensory sensitivities such as bright lights) and protecting them in interactions where they are at risk of being misunderstood, such as with retail staff and the police.

The promotion of social inclusion, tackling inequality and social need

Inequalities and, at the time of writing, austerity in the public sector coupled with a food, fuel and cost-of-living crisis threaten both the fulfilment of fundamental needs and the attainment of personal well-being. Some autistic people may be experiencing significant deprivation, and for these individuals, their basic physiological and safety needs must be met first. These include ensuring they have a safe place to live, with access to basic resources. However, meeting these needs alone does not ensure a good quality of life, and our

shared ambitions for the lives of autistic people should extend far beyond this.

Recent UK social care strategies relevant to autistic adults are summarised in [Box 2](#).

Employment and reasonable adjustments

Under-employment of autistic adults remains a significant national and global issue. Although some autistic adults are unable to participate in employment, many more can work if they have a supportive, understanding employer and a role centred on their strengths that includes reasonable adjustments for their difficulties.

'Reasonable adjustment' is a broad concept, extending to employing organisations making changes to the recruitment process, workplace environment and access to occupational healthcare, to support people with disabilities in the workplace. This concept is enshrined in the UK's Equality Act 2010. Reasonable adjustments can also be considered outside of the realm of employment, for example general practice (GP) surgeries making changes to ensure that their services are sensitive to the needs of autistic people.

The wider benefits of the supportive employment of autistic people should not be underestimated. They will likely experience improvements in both their economic circumstances and well-being. Furthermore, their valuable skills will be utilised to the benefit of wider society.

BOX 2 Recent key social care legislation relevant to autistic adults in the UK

People at the Heart of Care: Adult Social Care Reform (Department of Health and Social Care 2022b)

Sets out a 10-year view of transforming social care in England, focused on three key priorities:

- people have choice, control and support to live independent lives
- people can access outstanding quality and tailored care and support
- people find adult social care fair and accessible.

The enabling of self-directed support described here could be of particular benefit to autistic people, whose needs may not be met by more traditional models of delivery.

The National Strategy for Autistic Young People and Adults: 2021 to 2026 (Department of Health and Social Care 2021)

The strategy outlines key priority areas of focus, including:

- autism understanding and acceptance
- access to education and transitions to adulthood
- employment opportunities
- health and care inequalities
- support in the community and in-patient care
- support within the criminal and youth justice systems.

Current challenges and future directions

Autistic people have varied and often complex health and social care needs, presenting a challenge to the limited resources available in health and social care services. Mental health professionals can be powerful advocates for autistic people, and they need to do their utmost to ensure these individuals are supported in living meaningful, happy lives. In addition to this clear ethical imperative, it is also important to recognise the wider economic and societal benefits of ensuring they receive a high standard of health and social care support. When combined with other measures, effective, individualised support packages may contribute to making the difference between long-term unemployment and sustained employment, or between psychiatric hospital admissions and being safely supported in the community.

Author contributions

All authors conceived of and collaborated on this Clinical Reflection.

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Declaration of interest

S.T. was a chief investigator for a study supported by the National Institute for Health and Care Research (NIHR) pertaining to the prevalence of autism in adult psychiatric in-patient settings, for which he was supervised by T.B.; S.T. was also a co-applicant for an NHS Small Business Research Initiative funded study pertaining to a hybrid device for supporting autistic adults. Z.S. was a former lead on autism for the Association of Directors of Adult Social Services, supporting the Department of Health and Social Care on the development of national strategies, as well as being a member of national advisory/programme boards, including NHS England. She currently works as a critical friend, coach and system/transformation lead within integrated care systems and social care on autism, mental health and intellectual disabilities, commissioned via her business, Inspired Purpose. T.B. is a professor of psychiatry at the University of Leicester, which has held contracts for the Adult Psychiatric Morbidity Survey, which includes autism case identification and community prevalence estimates.

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