Providing effective care and support for autistic adults with mental health issues

Christopher Francis Barber

Abstract

Autism is a neurodevelopmental condition that is characterised by features such as persistent differences in social interaction and communication, specialised interests and sensory processing issues. It has been identified that autistic people are increasingly likely to experience various mental health issues, and often encounter challenges in accessing appropriate healthcare and a lack of understanding from healthcare professionals. This article explores the co-occurrence of autism and mental health issues in adults, and explains the role of nurses in providing care and support for this population.

Defining autism and mental health issues

Knowledge of autism appears to have improved among the general public (Dillenburger et al 2015, White et al 2019), with Zeidan et al (2022) stating that: ‘In recent years, the international community witnessed tremendous positive improvements in public awareness and public health response for autism.’ However, Shand et al (2020) suggested there is a lack of research into people’s attitudes towards autism and those who are autistic.

This article defines autism and mental health issues, and explores the co-occurrence of these conditions. It also discusses the various issues in accessing healthcare that people with co-occurring autism and mental health issues may experience, and explains how nurses can provide effective care and support for this group. The terms ‘autism’ and ‘autistic’ used throughout this article will refer to adults unless it is necessary to refer to autistic children and/or adolescents specifically.

Definitions of autism and mental health issues

It is important for nurses and other healthcare professionals to understand the meaning and characteristics of autism and mental health issues. There are two main sources for diagnosing these conditions: the Diagnostic and Statistical Manual of Mental Disorders Fifth Edition, Text Revision (DSM-V-TR) (American Psychiatric Association 2022), which is favoured in the US, and the International Classification of Diseases 11th Revision (ICD-11) (World Health Organization (WHO) 2023), which is widely used in Europe. However, the DSM-V-TR criteria are also influential in Europe (The Open University 2022).
Autism

Autism is a lifelong neurodevelopmental condition (Anorson et al 2021, National Institute for Health and Care Excellence (NICE) 2021) which involves a different, but no less valid, way of communicating and interacting with the world and the people in it. The core features of autism are (NICE 2021):

- Persistent difficulties or differences in social interaction and communication.
- Presence of rigid and repetitive behaviours, resistance to change or specialised interests.
- Challenges with cognitive and behavioural flexibility.
- Altered sensory sensitivity.
- Sensory processing issues.
- Emotional regulation differences.

Historically, it was often believed that autistic people could not experience or express empathy towards other people, since to do so requires an individual to be able to observe, process, understand and respond appropriately to the outward signs of other people’s emotions (Fletcher-Watson and Bird 2020). However, the author suggests that such a position on empathy and emotions is overly simplistic and is based on flawed terminology, measurement and theory, together with the lack of a clear definition of empathy. These issues have all contributed to the misrepresentation of autistic people as lacking empathy, which has led to autistic people being further misunderstood and stigmatised (Fletcher-Watson and Bird 2020). Therefore, it is important to recognise that autistic people will experience and show empathy but may do so in a different way compared with non-autistic people.

Mental health issues

Various terms are often used interchangeably in relation to mental health, such as mental health issues or problems, mental illness and mental health disorders (Meltzer et al 2000, Leighton and Dougra 2009). The ICD-11 (WHO 2023) uses the broad term ‘mental, behavioural or neurodevelopmental disorders’, which includes mood disorders such as depression and bipolar disorder, anxiety disorders, personality disorders, eating disorders, substance use disorders and neurocognitive disorders such as dementia. Hampshire Child and Adolescent Mental Health Services (2023) stated that a mental illness negatively affects the way people think, feel, behave or interact with others and subsequently hinders their ability to function. They also emphasised that suboptimal mental health and struggling to cope are different from having a mental illness.

The WHO (2022) defines mental health as ‘a state of mental well-being that enables people to cope with the stresses of life, realise their abilities, learn well and work well, and contribute to their community’. However, Galdersi et al (2017) critiqued this definition, asserting that its emphasis on well-being and productivity might not be applicable to some groups. The author of this article suggests that there needs to be an open, honest and constructive dialogue around the narrative of what is considered ‘good’ mental health in autistic people, since this may differ to what is considered good mental health in non-autistic people. This dialogue could result in a tentative definition of mental health that would be acceptable to autistic and non-autistic people alike.

Co-occurring autism and mental health issues

Several studies have indicated that autistic people are likely to be more at risk of developing and experiencing mental health issues. However, it should be noted that the means used to assess mental health issues in autistic people are inconsistent across studies, and this may have contributed to the variations in the prevalence of such issues among this population (Hossain et al 2020).

Hossain et al (2020) undertook a multi-national review of 26 systematic reviews and 12 meta-analyses that focused on co-occurrence of autism and mental health issues, identifying that most autistic people had at least one co-occurring mental health issue. The synthesised findings found an increased likelihood of co-occurring conditions such as attention-deficit hyperactivity disorder (ADHD) and other neurodivergent conditions, anxiety disorders, depressive disorders, bipolar and mood disorders and schizophrenia among autistic people. Each of the individual research authors that were included in this meta-analysis suggested that the prevalence of co-occurring mental health issues was higher in autistic people than in the general population. Similarly, a systematic review and meta-analysis by Lai et al (2019) reviewed 96 articles that focused on autism and co-occurring mental health issues. They found that the prevalence of ADHD, anxiety disorders, sleep-wake disorders, depressive disorders, obsessive-compulsive disorder, bipolar disorder and schizophrenia were all increased in autistic people.

Stadnick et al’s (2017) research investigated the links between, and co-occurrences of, autism and mental health issues in children, suggesting that more than 70% of autistic children met the criteria for at least one co-occurring mental health issue when assessed using structured diagnostic interviews, and these conditions often persisted into adolescence.

While Stadnick et al’s (2017) research focused on the experiences of co-occurring mental health issues in children, many of these mental health issues will persist into adulthood, including older adulthood (NHS England et al 2019). Therefore, there is a need for research into the links between autism in older adults and various mental health issues, including dementia, in terms of prevalence, presentation and management. The aim should be for seamless, well-researched, well-resourced, ‘all-age’ person-centred care to become the norm.

A report by the All-Party Parliamentary Group on Autism and National Autistic Society (2019) identified that:

- 76% of autistic adults have ‘reached out’ for mental health support during the previous five years.
- 82% of autistic adults have said that the waiting times for receiving support from mental health services are too long.
- 86% of autistic adults have
suggested that there are not enough mental health services in their areas to meet their needs. Furthermore, the National Autistic Society and Mind (2021) reported that 83% of autistic people will experience depression and Young Minds (2022) stated that 70% of autistic people will experience a mental health issue. Doughty et al (2021) suggested 51% of autistic people have mental health issues, which is more than 4.5 times higher than people who are not autistic (11%). Doughty et al (2021) further suggested that the severity of mental health issues is increased among autistic people, stating that more than 25% of them have been diagnosed with two or more mental health issues and that 15% of autistic people are hospitalised as a result of mental health issues, compared with 3% of non-autistic people.

While autistic people are at increased risk or likelihood of developing and experiencing a range of mental health issues, it should be noted that not all of this population will experience mental health issues and it should not be assumed that a person’s mental health issues are caused by their autism. Autism and mental health issues are separate entities and must not be confused; to do so would be seen as ‘diagnostic overshadowing’, which occurs when an individual’s mental health issues are attributed to their primary diagnosis – in this case autism (Middleton et al 2022). Such diagnostic overshadowing would mean that opportunities for accurate diagnosis of a mental health issue along with appropriate therapeutic interventions would be missed, and would in turn affect the range, type and quality of care experienced by autistic people who also have mental health issues (Fodstad 2019).

Cage et al’s (2018) study focused on the prevalence of mental health issues in relation to people’s acceptance of an autism diagnosis. They found that an increased acceptance of autism both as a diagnosis and a lived condition on the part of autistic people, their families and social networks led to a decrease in diagnosable mental health issues, specifically depression and anxiety. Cage et al (2018) also found that there was a greater prevalence of depression, anxiety and stress symptoms among autistic adults who were less accepting of the diagnosis and/or experienced less acceptance from others.

**Challenges with accessing healthcare**

Mental health care and support for autistic people is often inadequate, with a lack of availability of appropriate mental health services and long waiting times for accessing these services (Mind 2022). Furthermore, many autistic people with mental health issues experience inadequate or low-quality care, with a qualitative study by Weir et al (2022) identifying that autistic patients were more likely to experience lower quality healthcare than non-autistic patients. The author suggests that this may be due in part to a lack of understanding of what autism is and the links between mental health and autism, alongside a possible lack of willingness for different services to communicate and work together. Therefore, healthcare organisations need to address these issues when designing and delivering care to autistic patients.

A systematic review of 35 international studies suggested that healthcare professionals’ limited knowledge and self-efficacy in working with autistic people is variable and may be a barrier to the provision of effective healthcare for this population (Corden et al 2021). Camm-Crosbie et al (2019) explored the unmet or inadequately met needs of autistic adults who experience mental health issues, which included issues in accessing diagnosis, assessment and appropriate treatment or management of co-occurring mental health issues. They and other authors have suggested that there is a potential risk of these individuals’ autism and/or any co-occurring mental health issues being overlooked by healthcare service providers (Tam 2013, Ono et al 2019).

**Key points**

- Autism is a lifelong neurodevelopmental condition, which involves a different, but no less valid, way of communicating and interacting with the world and the people in it.
- There needs to be an open, honest and constructive dialogue around the narrative of what is considered ‘good’ mental health in autistic people, since this may differ to what is considered good mental health in non-autistic people.
- Mental health care and support for autistic people is often inadequate, with a lack of availability of appropriate mental health services and long waiting times for accessing these services.
- The role of the nurse in supporting autistic people who experience mental health issues may involve active listening, putting reasonable adjustments in place and ensuring that the healthcare environment is autism-aware and friendly.

The Health and Care Act 2022 introduced a requirement that regulated service providers must ensure their staff receive learning disability and autism training appropriate to their role. The Oliver McGowan Mandatory Training on Learning Disability and Autism is the standardised training that was developed for this purpose and is the UK government’s recommended training for health and social care staff (Health Education England (HEE) 2023). The training is co-delivered by autistic people and is divided into two tiers: the first tier is for health and social care staff who require general awareness of the support autistic people may need, and the second tier is for care staff who provide ongoing care to autistic people (HEE 2023). The Oliver McGowan training programme and resources (House of Lords 2021, HEE 2023) should lead to significant improvements in healthcare professionals’ knowledge regarding autism, although further research is needed to ascertain whether this subsequently results in improved services and care.
Importance of using appropriate language

Healthcare professionals need to consider and understand how the use of language can affect the care of all patients, regardless of their diagnosis or population group. When caring for autistic people, it is important to be aware that most of this group prefer identity-first terms such as ‘autistic’ or ‘autistic person or patient’ rather than person-first terms such as ‘person with autism’ (Monk et al 2022). Therefore, nurses and other healthcare professionals should promote and adhere to the terminology preferred by the autistic community to ensure that humane, acceptable and appropriate language and ways of addressing autistic patients are used.

Table 1 shows the preferred terminology in relation to autism.

Role of the nurse

The role of the nurse in supporting autistic people who experience mental health issues may involve active listening, putting reasonable adjustments in place and ensuring that the healthcare environment is autism-aware and friendly. Nurses also need to be aware that disclosing that another person is autistic or is experiencing mental health issues without their consent is a breach of confidentiality that may lead to disciplinary procedures (Department of Health 2003, Nursing and Midwifery Council 2018).

McKenzie (2016) focused on the roles of the primary care nurse in supporting autistic people and suggested that these roles may include:

» Being aware of the differences in how autism presents in children and adults, as well as in those with co-occurring mental health issues. Such differences could include communication and social abilities, for example adults are typically more skilled than children at hiding their autism to ‘fit in’ (NHS 2022a).

» Recognising that autistic people may have different sensory sensitivities – for example they may find certain sounds, smells, textures and types of touch aversive – and taking that into consideration when providing care and support.

» Identifying people who are or who may be autistic, with or without co-occurring mental health issues, then referring them to the local mental health team, psychology services, the National Autistic Society and/or local autism organisations for appropriate diagnosis and support, in accordance with the person’s wishes.

» Providing clear information and communicating in a manner that the patient can process. For example, some autistic people may prefer information in written form, in visual forms such as diagrams, photos or pictures, or in auditory forms such as audio tapes or CDs.

Additional nursing roles in supporting autistic people could include:

» Obtaining and recording the person’s history. This involves asking questions about their medical, family, social and psychological history, as well as how the person experiences their autism and mental health issues, in an appropriate way. Doing so will encourage the person to be forthcoming in their responses and consequently enable appropriate care and support to be provided.

» Supporting medicines optimisation. There is evidence that many autistic people have been inappropriately or over-prescribed psychotropics (Royal College of Paediatrics and Child Health and NHS England 2019), or are taking medicines that were appropriately prescribed but may no longer be needed. Deprescribing and medication reviews should be considered where this has been identified as an issue.

» Referring individuals to mindfulness programmes and ‘talking therapies’ such as counselling and cognitive behavioural therapy (CBT), which

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<th>Table 1. Preferred terminology in relation to autism</th>
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<td><strong>Terms to avoid</strong></td>
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<tr>
<td>Autism spectrum disorder (ASD)</td>
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<td>Person-first language, for example ‘person with autism’</td>
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<tr>
<td>Autism symptoms and impairments</td>
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<tr>
<td>At risk of autism</td>
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<tr>
<td>Co-morbidity</td>
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<tr>
<td>Functioning (for example high or low functioning) and severity (for example mild, moderate or severe) labels</td>
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<tr>
<td>Cure, treatment or intervention</td>
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<tr>
<td>Restricted interests and obsessions</td>
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<td>Normal person</td>
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(Adapted from Monk et al 2022)
have been used to manage anxiety and depression (Mental Health Foundation 2021). The NHS (2022b) provides an informative online resource that explains the range of talking therapies that are available.

Table 2 details some of the considerations for nurses when caring for autistic adults with mental health issues.

Mandy (2022) indicated that further research is needed on how various health and social care facilities and environments can affect the mental health of autistic people and to modify the environment if possible. For example, in hospital settings such modifications could include: using a health passport (a document designed to assist autistic people in communicating their needs to healthcare professionals); enabling family members to stay with the patient; asking how the autistic person prefers to communicate; mitigating the risk of sensory overstimulation where possible; and conducting pre-admission visits for the autistic person (National Autistic Society 2023b).

Nurses need to actively engage in evidence-based, autistic-led continuing professional development (CPD) regarding autism and mental health issues to improve their knowledge regarding people’s narratives and lived experiences (Livingston and Cooper 2018, Mandy 2022). It is important that the learning outcomes of any CPD activities nurses undertake are then implemented and monitored in practice, and that they gain clinical experience of providing care and support that is tailored to meet the needs of the autistic person.

**Conclusion**

Many people with co-occurring autism and mental health issues receive inadequate healthcare and support from services. Therefore, it is important that nurses work towards providing effective care for this population by using appropriate language, adapting their communication, ensuring modifications to the healthcare environment are made where possible, and undertaking relevant CPD activities to enhance their knowledge. By doing so, nurses can become champions of inclusion, diversity and equality for those with co-occurring autism and mental health issues.

<table>
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<th>Table 2. Considerations for nurses when caring for autistic adults with mental health issues</th>
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| Before the consultation | » Ask the patient or carer to bring their personal health record  
» Determine any specific mobility or sensory requirements  
» Arrange for a longer appointment time where appropriate  
» Taking these measures can improve clinical assessments and optimise the person's experience during subsequent appointments  |
| Communication | » Use simple, non-ambiguous language  
» Leave pauses when speaking and wait for the person to respond  
» Communicate one idea at a time  
» Speak in a normal tone  
» Consider the most appropriate communication style to use, for example written or verbal  
» Consider using multiple techniques, for example verbal communication supported by written materials  
» Be aware that changes in the person's communication may reflect changes in their mental health  
» Improved communication can improve the accuracy and quality of an assessment  |
| Behaviour that challenges | » Untreated physical and mental health issues commonly exacerbate behaviour that challenges. This may then lead to exclusion from participation, which may have a negative effect on mental health  
» Perform an assessment that considers how the person's physical and mental health issues might be contributing to behaviour that challenges  
» Refer the person to appropriate specialist behaviour support or a specialist psychiatrist  |
| Carers | » Carers can provide important information about the autistic adult, for example about their changes in behaviour,  
communication, nutritional uptake and medical history  
» Refer carers to support services where appropriate, since they may be experiencing suboptimal mental health that in turn affects the mental health of the autistic adult  |
| Co-occurring physical health conditions | » Chronic conditions such as pain, epilepsy and gastrointestinal disorders may increase the likelihood of mental health issues and behaviour that challenges  
» Autistic people experience similar physical health issues to the general population  
» Screen for common co-occurring physical health conditions  
» Annual general health checkups and routine preventive screening measures are recommended  |
| Sensory environment | » Overwhelming sensory environments can increase stress and anxiety, subsequently complicating the assessment and management of mental health disorders  
» Consider the lighting of waiting rooms and offices, for example avoid bright fluorescent lights if possible  
» Consider a referral to an occupational therapist for an assessment of the adult's sensory processing  |

(Adapted from Foley and Trollor 2015)

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