

Autism: recognition, referral, diagnosis
and management of adults on the autism
spectrum

Support for education and learning: clinical case scenarios

June 2012

These clinical case scenarios accompany the clinical guideline: 'Autism: recognition, referral, diagnosis and management of adults on the autism spectrum' (available at www.nice.org.uk/guidance/CG142). Issue date: June 2012.

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Introduction

NICE clinical case scenarios

Clinical case scenarios are an educational resource that can be used for individual or group learning. Each question should be considered by the individual or group before referring to the answers.

These nine clinical case scenarios have been put together to improve your knowledge of the autism in adults guideline and its application in practice. They illustrate how the recommendations from 'Autism: recognition, referral, diagnosis and management of adults on the autism spectrum', (NICE clinical guideline 142 (www.nice.org.uk/guidance/CG142)) can be applied to the care of adults presenting to primary, community, secondary, tertiary and other health and social care settings.

The clinical case scenarios are available in two formats: this PDF, which can be used for individual learning, and a slide set that can be used for groups.

You will need to refer to the NICE clinical guideline to help you decide what steps you would need to follow to diagnose and manage each case, so make sure that users have access to a copy (either online at www.nice.org.uk/guidance/CG142 or as a printout). You may also want to refer to the autism in adults NICE pathway (<http://pathways.nice.org.uk/pathways/autism>) and the specialist library page on NHS Evidence (www.evidence.nhs.uk/topic/autism).

Each case scenario includes details of the adult's initial presentation. The clinical decisions about recognition, referral, diagnosis and management are then examined using a question and answer approach. Relevant recommendations from the NICE guideline are quoted in the text (after the answer), with corresponding recommendation numbers. The likely care setting to which each case or part of case is relevant has been highlighted.

Autism

Autism is a lifelong neurodevelopmental condition, the core features of which are persistent difficulties in the reciprocity of social interaction and communication and the presence of stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests. The way that autism is expressed in individual people differs at different stages of life, in response to interventions, and with the presence of coexisting conditions such as learning disabilities (also called 'intellectual disabilities'). People with autism also commonly experience difficulty with cognitive and behavioural flexibility, altered sensory sensitivity, sensory processing difficulties and emotional regulation difficulties. These features may range from mild to severe and may fluctuate over time or in response to changes in circumstances.

A significant proportion of adults with autism across the whole autistic spectrum experience social and economic exclusion. Their condition is often overlooked by healthcare, education and social care professionals, which creates barriers to accessing the support and services they need to live independently. In addition, people with autism are more likely to have coexisting mental and physical disorders, and other developmental disorders. Some may have contact with the criminal justice system as either victims of crime or offenders and it is important that their needs are recognised.

There is wide variation in rates of identification and referral for diagnostic assessment, waiting times for diagnosis, models of multi-professional working, assessment criteria and diagnostic practice for adults with features of autism. These factors contribute to delays in reaching a diagnosis and subsequent access to appropriate services.

When the diagnostic assessment process works well, professionals, the person with autism and their family, partner or carer(s) communicate right from the start and the person with autism is involved in the decisions relating to their care. This lays the foundation for a long-term understanding between the person with autism, their family, partner or carer(s) and the professionals supporting their needs. However, many adults with suspected autism have difficulties accessing a diagnostic assessment. Even if they manage to obtain a diagnosis they may

receive no follow-up support because of the absence of appropriate services or an agreed care pathway.

In the NICE guideline 'autism' refers to 'autism spectrum disorders' encompassing autism, Asperger's syndrome and atypical autism (or pervasive developmental disorder not otherwise specified). The Guideline Development Group recognised, however, that different individuals and groups prefer a variety of terms for autism including autistic spectrum condition, autistic spectrum difference and neurodiversity (in recent Department of Health, National Audit Office and Public Accounts Committee documents, 'autism' is used to cover all of these terms).

The NICE guideline supports the autism strategy 'fulfilling and rewarding lives: the strategy for adults with autism in England' found at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369. Published on 3 March 2010, the strategy sets a clear framework for all mainstream services across the public sector to work together for adults with autism.

Learning objectives

Those using these clinical case scenarios will gain:

- improved understanding of how to apply the recommendations to the care of adults with autism and suspected autism
- increased awareness of the signs and symptoms of autism in adults
- understand when a referral for autism assessment should be made
- understanding of what a comprehensive assessment of autism should include
- increased awareness about how and when to confirm a diagnosis of autism
- understanding of some of the interventions for which adults with autism may be referred.

Clinical case scenarios for adults with autism

Case scenario 1: John

This case is relevant to those working in secondary and tertiary care settings. This case also contains a learning point for primary care.

History

John is 32 years old, and has a mild learning disability. He lives in supported living with staff visiting him for half an hour each evening to see if he is OK, and offer problem-solving advice around daily living skills. John has a part time job as a gardener's assistant, which he has held for 9 years.

Presentation

John's support staff encourage him to see his GP because they notice that his hands and forearms have become red and raw in places because he is washing his hands and arms frequently and for increasingly long periods of time. They have tried to divert him from this behaviour but he became anxious and quite agitated if interrupted when in 'washing routine'. This is a relatively new problem.

John's GP is concerned that John has developed obsessive compulsive disorder, and wants some advice about treatment and support, so he refers John to the consultant psychiatrist in the community learning disability team.

John attends his outpatient appointment with the psychiatrist accompanied by a member of his support team. It is immediately apparent that John has been over-washing his hands and forearms. Both hands are extremely red, with cracked skin, and look very sore. Both forearms are red, the right more so, with very dry skin and some areas where the top layer of skin has been removed and there is light scabbing.

When questioned about any problems, John denies having any. When asked about his hands and arms John gives the doctor a formal lecture on the importance of cleanliness and hand hygiene in the prevention of disease. He is very literal in his interpretation of the information and says several times that "you need to wash until you are squeaky clean". The support worker advises

that John had been sick several times the previous year, and following concerns that this was caused by his own poor hygiene when preparing meals they had arranged for him to have education on food handling and hygiene.

Concerns are also shared that John has begun to stalk a member of staff. He stands for hours outside her house and if she comes out to go to her car or the shop he talks incessantly to her. It has got so bad that her husband has asked John to stop going round and has also threatened to call the police.

He describes the staff member as being his friend. She had lived in the next street to him when they were children, and he had played running races with her brother and knew her well at that time. John sees nothing wrong with standing outside her house for hours. He says he visits her because she is his friend. When asked how he knows where she lives he replies "I asked her where she lived now and she told me". She confirmed this to be true, although initially her husband had accused John of following her home from work. John has no insight into the impact his standing outside her house may have on her.

John then begins to question the psychiatrist about plugs, asking him if he knows how to wire a plug, and describing in detail how it should be done. He volunteers that he has his own plug collection, of 47 three-pin plugs. John does not use eye contact with the psychiatrist.

1.1 Question

What should the psychiatrist consider and how should they approach caring for John?

1.1 Answer

Consider assessment for possible autism because John is demonstrating rigid and repetitive behaviour with restricted interests in the form of hand washing, and collecting plugs. John also demonstrates a difficulty in initiating and sustaining social relationships by inappropriately following his colleague. John also has a learning disability which often coexists with autism.

Reasons to suspect that John may be on the autism spectrum include his formal manner and overly formal use of language, his lack of insight into the fact that a doctor would already have knowledge of health and hygiene, his literal interpretations and lack of eye contact.

Work in partnership with John and his support worker and take time to build a trusting, non-judgemental relationship with him.

Learning point for primary care: autism should be considered in the differential diagnosis for those with a learning disability and repetitive behaviours.

Relevant recommendations

Consider assessment for possible autism when a person has:

- one or more of the following:
 - persistent difficulties in social interaction
 - persistent difficulties in social communication
 - stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests, **and**
- one or more of the following:
 - problems in obtaining or sustaining employment or education
 - difficulties in initiating or sustaining social relationships
 - previous or current contact with mental health or learning disability services
 - history of a neurodevelopmental condition (including learning disabilities and attention deficit hyperactivity disorder) or mental disorder. **[1.2.2]**

All staff working with adults with autism should:

- work in partnership with adults with autism and, where appropriate, with their families, partners or carers
- offer support and care respectfully
- take time to build a trusting, supportive, empathic and non-judgemental relationship as an essential part of care. **[1.1.1]**

The specialist autism team should have a key role in the delivery and coordination of:

- specialist diagnostic and assessment services
- specialist care and interventions
- advice and training to other health and social care professionals on the diagnosis, assessment, care and interventions for adults with autism (as not all may be in the care of a specialist team)
- support in accessing and maintaining contact with, housing, educational and employment services
- support to families, partners and carers where appropriate
- care and interventions for adults with autism living in specialist residential accommodation
- training, support and consultation for staff who care for adults with autism in residential and community settings. **[1.1.14]**

Next steps

The psychiatrist refers John to the specialist autism team for an autism assessment.

1.2 Question

How should John's autism assessment be carried out?

1.2 Answer

Adapt the procedure if necessary to ensure its effective delivery. John has a learning disability, so consider a brief assessment to ascertain whether there are difficulties in reciprocal social interaction, limited social demonstration of empathy, rigid routines and resistance to change or marked repetitive activities. Consider this before conducting a comprehensive assessment of needs and risks.

Carry out the comprehensive assessment with trained health and social care professionals and draw upon a range of professions and skills. If possible involve a parent or carer. Explain the purpose of the assessment to John at the beginning. Assess core autism signs and symptoms that have been present in childhood and adulthood. Ask about early developmental history, behavioural problems, functioning at home, in education or in employment. Consider differential diagnoses and coexisting conditions.

Do not routinely use biological tests, genetic tests or diagnostic neuroimaging as part of the assessment.

Relevant recommendations

Staff who have responsibility for the identification or assessment of adults with autism should adapt these procedures, if necessary, to ensure their effective delivery, including modifications to the setting in which assessment is delivered (see recommendation 1.1.8 in the NICE guideline) and the duration and pacing of the assessment. **[1.2.1]**

For adults with possible autism who have a moderate or severe learning disability, consider a brief assessment to ascertain whether the following behaviours are present (if necessary using information from a family member, partner or carer):

- difficulties in reciprocal social interaction including:
 - limited interaction with others (for example, being aloof, indifferent or unusual)
 - interaction to fulfil needs only
 - interaction that is naive or one-sided

- lack of responsiveness to others
- little or no change in behaviour in response to different social situations
- limited social demonstration of empathy
- rigid routines and resistance to change
- marked repetitive activities (for example, rocking and hand or finger flapping), especially when under stress or expressing emotion.

If two or more of the above categories of behaviour are present, offer a comprehensive assessment for autism. **[1.2.4]**

A comprehensive assessment should:

- be undertaken by professionals who are trained and competent
- be team-based and draw on a range of professions and skills
- where possible involve a family member, partner, carer or other informant or use documentary evidence (such as school reports) of current and past behaviour and early development. **[1.2.5]**

At the beginning of a comprehensive assessment, discuss with the person the purpose of the assessment and how the outcome of the assessment will be fed back to them. Feedback should be individualised, and consider involving a family member, partner, carer or advocate, where appropriate, to support the person and help explain the feedback. **[1.2.6]**

During a comprehensive assessment, enquire about and assess the following:

- core autism signs and symptoms (difficulties in social interaction and communication and the presence of stereotypic behaviour, resistance to change or restricted interests) that have been present in childhood and continuing into adulthood
- early developmental history, where possible
- behavioural problems
- functioning at home, in education or in employment
- past and current physical and mental disorders
- other neurodevelopmental conditions
- hyper- and hypo-sensory sensitivities and attention to detail.

Carry out direct observation of core autism signs and symptoms especially in social situations. **[1.2.7]**

During a comprehensive assessment, take into account and assess for possible differential diagnoses and coexisting disorders or conditions, such as:

- other neurodevelopmental conditions (use formal assessment tools for learning disability)
- mental disorders (for example, schizophrenia, depression or other mood disorders, and anxiety disorders, in particular, social anxiety disorder and obsessive–compulsive disorder)
- neurological disorders (for example, epilepsy)
- physical disorders
- communication difficulties (for example, speech and language problems, and selective mutism)
- hyper- or hypo-sensory sensitivities. **[1.2.10]**

Do not use biological tests, genetic tests or neuroimaging for diagnostic purposes routinely as part of a comprehensive assessment. **[1.2.11]**

During the assessment John's mother reports that John has had a fascination with plugs and plug sockets and electrical appliances since the age of around 2 years. He did not play with toys or games, but coveted plugs. Every shop or house they went into John would check out the sockets, switching unused switches to the off position if they had been left on. If they were switched back again without the appliance being used he would become distressed. John disliked change and had a strong need for routine. He attended a special needs school, and was diagnosed as having a learning disability at age 4. John's language development was delayed and he had speech and language therapy up until the age of 7. He had no true friends and was described as being 'pompous' with others.

John meets the ICD-10 criteria for autism. The assessment also highlights that John is unable to measure the passage of time.

1.3 Question

John is diagnosed with autism, what are the next steps?

1.3 Answer

Develop a care plan for John. Base this on the assessment and take into account the needs of his family and carers. Provide John with a 'health passport' that details information for all staff about John's care and support needs.

At diagnosis offer John a follow-up appointment to discuss the implications of the diagnosis and any concerns he may have.

Discuss John's autism with him during this follow-up appointment. Adapt the appointment where possible to help John understand what is said. For example social stories may help him understand what the diagnosis means and how the specialist autism team could help him.

Relevant recommendations

Develop a care plan based on the comprehensive assessment, incorporating the risk management plan and including any particular needs (such as adaptations to the social or physical environment), and also taking into account the needs of the family, partner or carer(s). **[1.2.13]**

Provide a 'health passport' (for example, a laminated card) for adults with autism, which includes information for all staff about the person's care and support needs. Advise the person to carry the health passport at all times.

[1.2.14]

Offer all adults who have received a diagnosis of autism (irrespective of whether they need or have refused further care and support) a follow-up appointment to discuss the implications of the diagnosis, any concerns they have about the diagnosis, and any future care and support they may require. **[1.2.18]**

In all settings, take into account the physical environment in which adults with autism are assessed, supported and cared for, including any factors that may trigger challenging behaviour. If necessary make adjustments or adaptations to the:

- amount of personal space given (at least an arm's length)

- setting using visual supports (for example, use labels with words or symbols to provide visual cues about expected behaviour)
- colour of walls and furnishings (avoid patterns and use low-arousal colours such as cream)
- lighting (reduce fluorescent lighting, use blackout curtains or advise use of dark glasses or increase natural light)
- noise levels (reduce external sounds or advise use of earplugs or ear defenders).

Where it is not possible to adjust or adapt the environment, consider varying the duration or nature of any assessment or intervention (including taking regular breaks) to limit the negative impact of the environment. **[1.1.8]**

1.4 Question

What intervention should be offered to John and what should this intervention consist of?

1.4 Answer

Offer a structured and predictable training programme based on behavioural principles. The aim of the structured training programme would be to address John's hand washing and his stalking-like behaviour.

The programme may consist of the following.

Draw up a set of hand washing instructions, using a mixture of photographs, and words that John could understand and read.

Introduce a timer, because the assessment showed that John is not able to measure the passage of time, which is a factor in the length of time he spends hand washing. He can recognise numbers and is able to set the timer to the number 2 and then begin washing his hands for 2 minutes, stopping when the timer buzzes.

John had been using a rough flannel and sometimes a pan scrub to wash his forearms. The new instructions could stipulate that nothing material should be used, with a red cross on pictures of the pan scrub and flannels. Support him in this washing method approximately 10 times, after which he may be able to follow the instructions independently.

Give clear times for hand washing, such as after using the toilet, before preparing food, before eating food. John had been unsure when to wash his hands so had done so at frequent intervals. His anxiety had been increasing because he did not want to be sick again. Taking a day off work and the change to his routine had been more distressing to him than the sickness. Encourage John to use a gentle soap, and to use an emollient cream to moisturise his hands afterwards. Discourage washing of his forearms.

Relevant recommendations

For adults with autism of all ranges of intellectual ability, who need help with activities of daily living, consider a structured and predictable training programme based on behavioural principles. **[1.4.4]**

Next steps

Within a fortnight John's skin has healed, and the redness is barely noticeable. It is explained to John that it could not be guaranteed that he would never be sick again even with his new hand washing instructions because other factors can cause sickness. John is not happy with this but accepts it.

John feels very angry with his colleague for not being his friend anymore because she was his friend when they were children. Use social stories with John to help him to understand about friendship, and what it means to be a friend. Offer support, and draw up instructions to help him when he feels compelled to go and stand outside his colleague's house. Investigate funding for extra support hours for John to work with him on his social skills, and support him in attending some different activities so that he could make friends with similar interests.

Case scenario 2: Adam

This case is relevant to those working in secondary and tertiary care settings.

History

Adam is an 18 year old man who has a diagnosis of autism and schizophrenia. He was banned from the family home after repeated physical attacks to his mother, and has been living in his own flat for several months. His male family members bring him food every day.

Presentation

Adam's family contact mental health services several times, but Adam will not engage with the services. Adam tells his mother several times that he will kill himself, but when being assessed under the Mental Health Act says that he was 'kidding' and just trying to get his mother's attention. He regularly complains about the neighbours being noisy, but the neighbouring flat is unoccupied. It is unclear whether he is hallucinating or has very sensitive hearing. He has threatened to 'deal with the neighbours' if nothing is done.

2.1 Question

How should secondary and tertiary mental healthcare staff engage with and approach caring for Adam?

2.1 Answer

Consider how Adam's autism and the physical environment may affect his personal and social functioning. This may encourage Adam to engage with the service. Adam's move to his own flat may have influenced his recent threats of self-harm. When Adam does engage, promote his active participation in treatment decisions and support self-management wherever possible. It is important to maintain the continuity of the relationship between Adam and healthcare professionals.

Address Adam by a name/title he prefers, and clearly communicate your role and title. Continually check that Adam understands what you have told him in terms of treatment and providing information.

Work in partnership with Adam and, if appropriate, his family. Offer care respectfully and take time to build a supportive and empathic relationship.

Relevant recommendations

All staff working with adults with autism should:

- work in partnership with adults with autism and, where appropriate, with their families, partners or carers
- offer support and care respectfully
- take time to build a trusting, supportive, empathic and non-judgemental relationship as an essential part of care. **[1.1.1]**

All staff working with adults with autism should have an understanding of the:

- nature, development and course of autism
- impact on personal, social, educational and occupational functioning
- impact of the social and physical environment. **[1.1.2]**

All health and social care professionals providing care and support for adults with autism should have a broad understanding of the:

- nature, development and course of autism
- impact on personal, social, educational and occupational functioning
- impact of and interaction with the social and physical environment

- impact on and interaction with other coexisting mental and physical disorders and their management
- potential discrepancy between intellectual functioning as measured by IQ and adaptive functioning as reflected, for example, by difficulties in planning and performing activities of daily living including education or employment.

[1.1.3]

All health and social care professionals providing care and support for adults with autism should:

- aim to foster the person's autonomy, promote active participation in decisions about care and support self-management
- maintain continuity of individual relationships wherever possible
- ensure that comprehensive information about the nature of, and interventions and services for, their difficulties is available in an appropriate language or format (including various visual, verbal and aural, easy-read and different colour and font formats)
- consider whether the person may benefit from access to a trained advocate.

[1.1.4]

All health and social care professionals providing care and support for adults with autism and their families, partners or carers should:

- ensure that they are easily identifiable (for example, by producing or wearing appropriate identification) and approachable
- clearly communicate their role and function
- address the person using the name and title they prefer
- clearly explain any clinical language and check that the person with autism understands what is being said
- take into account communication needs, including those arising from a learning disability, sight or hearing problems or language difficulties, and provide communication aids or independent interpreters (someone who does not have a personal relationship with the person with autism) if required. **[1.1.5]**

2.2 Question

How should secondary and tertiary healthcare staff involve Adam's family?

2.2 Answer

Discuss with Adam whether, and how, he would like his mother and family involved in his care and take into account any implications of the Mental Capacity Act (2005).

If Adam would like his family involved, encourage this and negotiate ongoing confidentiality between Adam and his family. Explain to both Adam and his family how they can help with his care plan.

Whether Adam wants them involved or not, staff should give his family information about autism and its management, local support groups for families and their right to a formal carer's assessment and how to access this.

If Adam does not want his family involved, give his family information about who they can contact if they are concerned about his care. Inform Adam's mother to bear in mind that he may be being negative towards her because of his coexisting schizophrenia.

Relevant recommendations

Discuss with adults with autism if and how they want their families, partners or carers to be involved in their care. During discussions, take into account any implications of the Mental Capacity Act (2005) and any communication needs the person may have (see recommendation 0 in the NICE guideline). **[1.1.15]**

If the person with autism wants their family, partner or carer(s) to be involved, encourage this involvement and:

- negotiate between the person with autism and their family, partner or carer(s) about confidentiality and sharing of information on an ongoing basis
- explain how families, partners or carers can help support the person with autism and help with care plans
- make sure that no services are withdrawn because of involvement of the family, partner or carer(s), unless this has been clearly agreed with both the person with autism and their family, partner or carer(s). **[1.1.16]**

Give all families, partners and carer(s) (whether or not the person wants them to

be involved in their care) verbal and written information about:

- autism and its management
- local support groups and services specifically for families, partners and carers
- their right to a formal carer's assessment of their own physical and mental health needs, and how to access this. **[1.1.17]**

If a person with autism does not want their family, partners or carer(s) to be involved in their care:

- give the family, partner or carer(s) verbal and written information about who they can contact if they are concerned about the person's care
- bear in mind that people with autism may be ambivalent or negative towards their family or partner. This may be for many different reasons, including a coexisting mental disorder or prior experience of violence or abuse. **[1.1.18]**

2.3 Question

What should be taken into account when identifying the correct interventions for Adam?

2.3 Answer

When discussing interventions with Adam, consider his experience and response to previous interventions, the nature of his autism and the extent of his schizophrenia, and identify predisposing factors that could lead to crises if not addressed.

Take into account the increased propensity for elevated anxiety about decision making and the greater risk of altered sensitivity and unpredicted responses to medications.

Give Adam information about the proposed intervention.

Relevant recommendations

When discussing and deciding on interventions with adults with autism, consider:

- experience of, and response to, previous interventions
- the nature and severity of autism
- the extent of any associated functional impairment arising from the autism, a learning disability or mental or physical disorder
- the presence of any social or personal factors that may have a role in the development or maintenance of any identified problem(s)
- the presence, and nature, severity and duration, of any coexisting disorders
- the identification of predisposing and possible precipitating factors that could lead to crises if not addressed¹. **[1.3.1]**

When discussing and deciding on care and interventions with adults with autism, take into account the:

- increased propensity for elevated anxiety about decision-making in people with autism
- greater risk of altered sensitivity and unpredictable responses to medication or other physical interventions
- environment, for example whether it is suitably adapted for people with

¹ Adapted from 'Common mental health disorders: identification and pathways to care' (NICE clinical guideline 123). Available from www.nice.org.uk/guidance/CG123

autism, in particular those with hyper- or hypo-sensory sensitivities (see recommendation 1.1.8 in the NICE guideline)

- presence and nature of hyper- or hypo-sensory sensitivities and how these might impact on the delivery of the intervention
- importance of predictability, clarity, structure and routine for people with autism
- nature of support needed to access interventions. **[1.3.2]**

When discussing and deciding on interventions with adults with autism, provide information about:

- the nature, content and duration of any proposed intervention
 - the acceptability and tolerability of any proposed intervention
 - possible interactions with any current interventions and possible side effects
 - the implications for the continuing provision of any current interventions².
- [1.3.3]**

2.4 Question

What interventions should be offered to Adam for his coexisting mental disorder, schizophrenia and his challenging behaviour, and what should be considered?

² Adapted from 'Common mental health disorders: identification and pathways to care' (NICE clinical guideline 123). Available from www.nice.org.uk/guidance/CG123

2.4 Answer

Pharmacological and psychosocial interventions in line with the NICE clinical guideline on schizophrenia (available from <http://guidance.nice.org.uk/CG82>).

When delivering an intervention for Adam's coexisting schizophrenia it is important to have an understanding of the core symptoms of his autism and their potential impact on the treatment for schizophrenia. Consider seeking advice from the specialist autism team about delivering and adapting interventions for people with autism.

Use a concrete and structured approach to deliver cognitive and behavioural interventions for Adam's schizophrenia, with use of written and visual information. Incorporate regular breaks to help maintain Adam's attention, and explain rules. The intervention should address any identified factors which may trigger Adam's challenging behaviour (attacking his mother)

If Adam's schizophrenia is not triggering his challenging behaviour, offer Adam a psychosocial intervention for this. Base the choice of intervention on the nature and severity of the attacks, Adam's physical needs and capabilities, the capacity for staff and family to provide support, Adam's preferences and his past history of care and support.

Relevant recommendations

Staff delivering interventions for coexisting mental disorders for adults with autism should:

- have an understanding of the core symptoms of autism and their possible impact on the treatment of coexisting mental disorders
- consider seeking advice from a specialist autism team regarding delivering and adapting these interventions for people with autism. **[1.6.1]**

The specialist autism team should have a key role in the delivery and coordination of:

- specialist diagnostic and assessment services
- specialist care and interventions

- advice and training to other health and social care professionals on the diagnosis, assessment, care and interventions for adults with autism (as not all may be in the care of a specialist team)
- support in accessing and maintaining contact with, housing, educational and employment services
- support to families, partners and carers where appropriate
- care and interventions for adults with autism living in specialist residential accommodation
- training, support and consultation for staff who care for adults with autism in residential and community settings. **[1.1.14]**

For adults with autism and coexisting mental disorders, offer psychosocial interventions informed by existing NICE guidance for the specific disorder.

[1.6.2]

Adaptations to the method of delivery of cognitive and behavioural interventions for adults with autism and coexisting common mental disorders should include:

- a more concrete and structured approach with a greater use of written and visual information (which may include worksheets, thought bubbles, images and 'tool boxes')
- placing greater emphasis on changing behaviour, rather than cognitions, and using the behaviour as the starting point for intervention
- making rules explicit and explaining their context
- using plain English and avoiding excessive use of metaphor, ambiguity or and hypothetical situations
- involving a family member, partner, carer or professional (if the person with autism agrees) to support the implementation of an intervention
- maintaining the person's attention by offering regular breaks and incorporating their special interests into therapy if possible (such as using computers to present information). **[1.6.3]**

Before initiating other interventions for challenging behaviour, address any identified factors that may trigger or maintain the behaviour (see

recommendation 1.2.20 of the NICE guideline) by offering:

- the appropriate care for physical disorders (for example, gastrointestinal problems or chronic pain)
- treatment for any coexisting mental disorders, including psychological and pharmacological interventions (for example, anxiolytic, antidepressant or antipsychotic medication), informed by existing NICE guidance
- interventions aimed at changing the physical or social environment (for example, who the person lives with) when problems are identified, such as:
- advice to the family, partner or carer(s)
- changes or accommodations to the physical environment (see recommendation 0 of the NICE guideline). **[1.5.1]**

Offer a psychosocial intervention for the challenging behaviour first if no coexisting mental or physical disorder, or problem related to the physical or social environment, has been identified as triggering or maintaining challenging behaviour. **[1.5.2]**

In addition to the functional analysis, base the choice of intervention(s) on:

- the nature and severity of the behaviour
- the person's physical needs and capabilities
- the physical and social environment
- the capacity of staff and families, partners or carers to provide support
- the preferences of the person with autism and, where appropriate, their family, partner or carer(s)
- past history of care and support. **[1.5.4]**

2.5 Question

What should be offered to Adam's family in terms of assessment and intervention?

2.5 Answer

An assessment of Adam's family needs, including personal, social and emotional support, support in their caring role and information on obtaining practical support.

Provide information about support groups.

Relevant recommendations

Offer families, partners and carers of adults with autism an assessment of their own needs including:

- personal, social and emotional support
- support in their caring role, including respite care and emergency plans
- advice on and support in obtaining practical support
- planning of future care for the person with autism. **[1.7.1]**

When the needs of families, partners and carers have been identified, provide information about, and facilitate contact with, a range of support groups including those specifically designed to address the needs of families, partners and carers of people with autism. **[1.7.2]**

Case scenario 3: Mike

This case is relevant to those working in primary, secondary and tertiary care settings.

Presentation

Mike is arrested following a serious assault on a colleague at work. The victim explains the assault occurred when he had inadvertently used Mike's mug. He describes Mike as being 'odd' with few friends.

Mike is quiet and polite but makes the police officers feel uncomfortable because of his 'odd' manner. The police officers contact the on-call GP who arranges for a psychiatric assessment. Mike is assessed by the on-call psychiatry registrar while in the police station. The psychiatrist interviews him and Mike does not make eye contact during the assessment.

The psychiatrist is unable to contact Mike's next of kin because Mike will not answer questions. Mike rocks throughout the assessment. The psychiatrist writes in Mike's notes "no evidence of psychosis, fit for interview".

3.1 Question

What should the psychiatrist consider and suspect?

3.1 Answer

Further mental health assessment and assessment for possible autism because Mike has persistent difficulties in social interaction and displays repetitive behaviour in the form of rocking. The reason Mike gives for the assault also demonstrates a resistance to change. Mike's colleague's description may suggest that Mike has problems with sustaining social relationships.

Consider using the AQ-10 (Autism-Spectrum Quotient – 10 items) to help decide whether referral for an autism assessment is needed.

Relevant recommendations

Consider assessment for possible autism when a person has:

- one or more of the following:
 - persistent difficulties in social interaction
 - persistent difficulties in social communication
 - stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests, **and**
- one or more of the following:
 - problems in obtaining or sustaining employment or education
 - difficulties in initiating or sustaining social relationships
 - previous or current contact with mental health or learning disability services
 - history of a neurodevelopmental condition (including learning disabilities and attention deficit hyperactivity disorder) or mental disorder. **[1.2.2]**

For adults with possible autism who do not have a moderate or severe learning disability, consider using the Autism-Spectrum Quotient – 10 items (AQ-10)³. (If a person has reading difficulties, read out the AQ-10.) If a person scores above six on the AQ-10, or autism is suspected based on clinical judgement (taking into account any past history provided by an informant), offer a comprehensive assessment for autism. **[1.2.3]**

³ Allison C, Auyeung B, Baron-Cohen S (2012) Towards brief 'red flags' for autism screening: the short Autism Spectrum Quotient and the short Quantitative Checklist in 1000 cases and 3000 controls. *Journal of the American Academy of Child and Adolescent Psychiatry* 51: 202–12.

Next steps

The police try to interview Mike without an appropriate adult. Identifying an appropriate adult is difficult when no next of kin has been identified but the police could contact any family member, friend, volunteer, colleague or social/healthcare professional. They could also get information from Mike's workplace. The interview results in little success. When they try to move him to a different cell; he becomes physically aggressive and is remanded into custody.

Mike does not cope well in prison. He finds it difficult to talk to the other prisoners and is verbally abused and bullied. He spends most of his time alone in his cell and although prison officers try to communicate with him, it is clear that he is not looking after himself properly. He repeatedly complains that the fluorescent strip lighting is too bright and keeps trying to cover it with paper.

Mike only leaves his cell for meal times. He always rushes to the food serving hatch and then eats as much as he is able to get. He has to be given a cell to himself because his cellmate reports that Mike kept him awake at night by talking to himself. When the officers go in to clean Mike's cell, they find a pile of papers covered in diagrams of machines.

After about 2 weeks, Mike attempts to hang himself in his cell with sheets. The prison psychiatrist assesses him, and he again does not make any eye contact during the assessment and provides very little information. The psychiatrist is concerned about Mike's mental health and arranges for him to be transferred to hospital under a section to be assessed.

In hospital, Mike keeps himself to himself but takes the antipsychotic medication that he is prescribed because "he was told to". A bank nurse who is new to the ward mispronounces his surname and he becomes very distressed. He tries to cut his arm with a piece of broken glass he finds in the hospital gardens. The other patients on the ward complain that Mike can be heard talking out aloud until the early hours of the morning. He spends the majority of his time in his room, avoiding social interactions. At his next psychiatric review, his antipsychotic is stopped and an antidepressant started.

The psychiatrist is struggling to give a clinical diagnosis for Mike, although autism is considered a possibility. He has improved since being prescribed an antidepressant, but he still says little and appears cold and distant.

3.2 Question

The psychiatrist is struggling to diagnose Mike, what should they do?

3.2 Answer

Ask another health professional to assess Mike, to obtain a second opinion.

Autism should have been suspected earlier, and if unsure the psychiatrist should have contacted the specialist autism team for advice.

Relevant recommendations

Consider obtaining a second opinion (including referral to another specialist autism team if necessary), if there is uncertainty about the diagnosis or if any of the following apply after diagnostic assessment:

- disagreement about the diagnosis within the autism team
- disagreement with the person, their family, partner, carer(s) or advocate about the diagnosis
- a lack of local expertise in the skills and competencies needed to reach diagnosis in adults with autism
- the person has a complex coexisting disorder, such as a severe learning disability, a severe behavioural, visual, hearing or motor problem or a severe mental disorder⁴. **[1.2.16]**

In each area a specialist community-based multidisciplinary team for adults with autism (the specialist autism team) should be established. The membership should include:

- clinical psychologists
- nurses
- occupational therapists
- psychiatrists
- social workers
- speech and language therapists
- support staff (for example, staff supporting access to housing, educational and employment services, financial advice, and personal and community safety skills). **[1.1.13]**

⁴ Adapted from the 'Autism: recognition, referral and diagnosis of children and young people on the autism spectrum' (NICE clinical guideline 128). Available from www.nice.org.uk/guidance/CG128

The specialist autism team should have a key role in the delivery and coordination of:

- specialist diagnostic and assessment services
- specialist care and interventions
- advice and training to other health and social care professionals on the diagnosis, assessment, care and interventions for adults with autism (as not all may be in the care of a specialist team)
- support in accessing and maintaining contact with, housing, educational and employment services
- support to families, partners and carers where appropriate
- care and interventions for adults with autism living in specialist residential accommodation
- training, support and consultation for staff who care for adults with autism in residential and community settings. **[1.1.14]**

Next steps

Mike is eventually assessed by a clinical psychologist and his full scale IQ is estimated at 68. The psychologist refers Mike for a comprehensive assessment of suspected autism.

3.3 Question

What principles should the staff conducting the assessment adhere to and what should be included in the assessment?

3.3 Answer

Be aware of the adaptations that may need to be made to the assessment to ensure it is effectively delivered. Staff conducting the assessment should be competent and draw on a range of professions and skills.

Explain the purpose of the assessment to Mike and tell him the outcome. Cover the core autism signs and symptoms, early developmental history, behavioural problems, functioning in employment, past and current physical and mental health and hyper- and hypo-sensory sensitivities, for example Mike's apparent sensitivity to florescent lighting.

Consider using a formal assessment tool to structure and aid diagnosis if the assessment is complex.

Assess for differential diagnosis and coexisting disorders. Do not routinely use biological tests, genetic tests or diagnostic neuroimaging as part of assessment.

Assess risks. Focus on Mike's self-harm but also consider: rapid escalation of problems, harm to others, self-neglect and the possible breakdown of the relationship with his mother.

Develop a care plan for Mike based on the comprehensive and risk assessment.

Relevant recommendations

Staff who have responsibility for the identification or assessment of adults with autism should adapt these procedures, if necessary, to ensure their effective delivery, including modifications to the setting in which assessment is delivered (see recommendation 1.1.8 in the NICE guideline) and the duration and pacing of the assessment. **[1.2.1]**

A comprehensive assessment should:

- be undertaken by professionals who are trained and competent
- be team-based and draw on a range of professions and skills
- where possible involve a family member, partner, carer or other informant or use documentary evidence (such as school reports) of

current and past behaviour and early development. **[1.2.5]**

At the beginning of a comprehensive assessment, discuss with the person the purpose of the assessment and how the outcome of the assessment will be fed back to them. Feedback should be individualised, and consider involving a family member, partner, carer or advocate, where appropriate, to support the person and help explain the feedback. **[1.2.6]**

During a comprehensive assessment, enquire about and assess the following:

- core autism signs and symptoms (difficulties in social interaction and communication and the presence of stereotypic behaviour, resistance to change or restricted interests) that have been present in childhood and continuing into adulthood
- early developmental history, where possible
- behavioural problems
- functioning at home, in education or in employment
- past and current physical and mental disorders
- other neurodevelopmental conditions
- hyper- and hypo-sensory sensitivities and attention to detail.

Carry out direct observation of core autism signs and symptoms especially in social situations. **[1.2.7]**

To aid more complex diagnosis and assessment for adults, consider using a formal assessment tool, such as:

- the following tools for people who do not have a learning disability:
 - the Adult Asperger Assessment (AAA; includes the Autism-Spectrum Quotient [AQ] and the Empathy Quotient [EQ])⁵
 - the Autism Diagnostic Interview – Revised (ADI-R)⁶
 - the Autism Diagnostic Observation Schedule – Generic (ADOS-G)⁷

⁵ Baron-Cohen S, Wheelwright S, Robinson J et al. (2005) The Adult Asperger Assessment (AAA): a diagnostic method. *Journal of Autism and Developmental Disorders* 35: 807–19

⁶ Lord C, Pickles A, McLennan J et al. (1997) Diagnosing autism: analyses of data from the Autism Diagnostic Interview. *Journal of Autism and Developmental Disorders* 27: 501–17.

⁷ Lord C, Risi S, Lambrecht L et al. (2000) The Autism Diagnostic Observation Schedule – Generic: a standard measure of social and communication deficits associated with the spectrum of autism. *Journal of Autism and Developmental Disorders* 30: 205–23.

- the Asperger Syndrome (and high-functioning autism) Diagnostic Interview (ASDI)⁸
- the Ritvo Autism Asperger Diagnostic Scale – Revised (RAADS-R)⁹
- the following tools in particular for people with a learning disability:
 - the ADOS-G
 - the ADI-R. **[1.2.8]**

To organise and structure the process of a more complex assessment, consider using a formal assessment tool, such as the Diagnostic Interview for Social and Communication Disorders (DISCO)¹⁰, the ADOS-G, or the ADI-R. **[1.2.9]**

During a comprehensive assessment, take into account and assess for possible differential diagnoses and coexisting disorders or conditions, such as:

- other neurodevelopmental conditions (use formal assessment tools for learning disability)
- mental disorders (for example, schizophrenia, depression or other mood disorders, and anxiety disorders, in particular, social anxiety disorder and obsessive–compulsive disorder)
- neurological disorders (for example, epilepsy)
- physical disorders
- communication difficulties (for example, speech and language problems, and selective mutism)
- hyper- or hypo-sensory sensitivities. **[1.2.10]**

During a comprehensive assessment, assess the following risks:

- self-harm (in particular in people with depression or moderate or severe learning disability)

⁸ Gillberg C, Gillberg C, Rastam M et al. (2001) The Asperger Syndrome (and high-functioning autism) Diagnostic Interview (ASDI): a preliminary study of a new structured clinical interview. *Autism* 5: 57–66.

⁹ Ritvo RA, Ritvo ER, Guthrie D et al. (2011) The Ritvo Autism Asperger Diagnostic Scale – Revised (RAADS-R): a scale used to assist the diagnosis of autism spectrum disorders in adults: an international validation study. *Journal of Autism and Developmental Disorders* 41: 1076–89.

¹⁰ Wing L, Leekam L, Libby S et al. (2002) The Diagnostic Interview for Social and Communication Disorders: background, inter-rater reliability and clinical use. *Journal of Child Psychology and Psychiatry* 43: 307–25.

- rapid escalation of problems
- harm to others
- self-neglect
- breakdown of family or residential support
- exploitation or abuse by others.

Develop a risk management plan if needed. **[1.2.12]**

Develop a care plan based on the comprehensive assessment, incorporating the risk management plan and including any particular needs (such as adaptations to the social or physical environment), and also taking into account the needs of the family, partner or carer(s). **[1.2.13]**

Do not use biological tests, genetic tests or neuroimaging for diagnostic purposes routinely as part of a comprehensive assessment. **[1.2.11]**

Next steps

Mike is diagnosed with autism. Mike's social worker manages to track down Mike's mother via information collected by the police.

3.4 Question

How should health and social care professionals involve Mike's mother?

3.4 Answer

Discuss with Mike whether and how he would like his mother involved in his care. If so, encourage this involvement, and ensure that no services are withdrawn because of it.

Give Mike's mother information about autism and its management. Provide details of support groups and her right to a formal carer's assessment.

Relevant recommendations

Discuss with adults with autism if and how they want their families, partners or carers to be involved in their care. During discussions, take into account any implications of the Mental Capacity Act (2005) and any communication needs the person may have (see recommendation 1.1.5 in the NICE guideline).

[1.1.15]

If the person with autism wants their family, partner or carer(s) to be involved, encourage this involvement and:

- negotiate between the person with autism and their family, partner or carer(s) about confidentiality and sharing of information on an ongoing basis
- explain how families, partners or carers can help support the person with autism and help with care plans
- make sure that no services are withdrawn because of involvement of the family, partner or carer(s), unless this has been clearly agreed with both the person with autism and their family, partner or carer(s). **[1.1.16]**

Give all families, partners and carer(s) (whether or not the person wants them to be involved in their care) verbal and written information about:

- autism and its management
- local support groups and services specifically for families, partners and carers
- their right to a formal carer's assessment of their own physical and mental health needs, and how to access this. **[1.1.17]**

Next steps

Mike decides he would like his mother to be involved.

The social worker talks to Mike's mother about her son, and notices that she avoids eye contact. Mike's mother's house is untidy and she tells the social worker that he had always been as he had presented in hospital since his childhood. She does not consider there is anything wrong with Mike. She wants him at home to support her. She asks if he is entitled to benefits because previously she has been told he was not. Following an occupational therapy, carers and social services assessment, Mike is discharged to his mother's house. Arrangements are made for a package of after-care to be put in place to support him.

Regarding Mike's criminal charges, the psychiatrist might be successful in making the case that his autism should be taken into account to avoid a custodial sentence. Social support would need to be high to minimise the risk of Mike acting in this way in the future.

Consider 'supported employment' if it is thought that Mike could work again as he cannot return to his former employment.

Case scenario 4: Sue

This case is relevant to those working in secondary, tertiary and community care settings.

History

Barry is a 3 year old boy who has had diagnosed asthma for 3 years. There have been no previous concerns about his development. He is an only child who lives with his mother, Sue. The father is not known and does not live with them. Sue's parents live nearby and her mother helps care for Barry when Sue is at work and also helps at weekends.

Presentation

Barry is admitted as an inpatient with an acute asthmatic attack from his nursery. His mother is reluctant to finish work early and come into hospital. When visiting Barry, Sue keeps closing the curtains around the bed although the staff tell her not to. She is also found to be adjusting his drip. Healthcare staff feel that Sue behaves a little coldly towards her son, but Barry appears well cared for.

Sue is a 25 year old talkative, anxious woman who is difficult to converse with. She keeps going off on tangents or complaining about specific failings of the nurses: for example, that they had not monitored the drip adequately and that they had not checked on Barry at the prescribed times. Sue says that she was adjusting the drip because staff failed to do so. She explains that she closed the curtains because she found the ward too distracting and unpleasant. Sue asks for a side room for her and Barry.

Next steps

After discussions Sue and Barry are put in a side room but the nurses still have concerns because she keeps closing the door despite their instructions not to. However Barry improves and within 3 days is able to be discharged. There is no concrete evidence of harm so he is sent home with Sue but their GP is alerted to the paediatrician's concerns. Sue is also referred to social services for further assessment.

Sue's social worker establishes that Sue is a junior accountant in the local council. She has little social life and gives the impression of keeping an over-tidy, spotless house. Barry's asthma is usually well controlled and Sue keeps a diary recording the times he has his inhalers each day. Sue seems to have a very ordered home and life and has problems making time in it to see the social worker.

4.1 Question

What should Sue's social worker consider and what are the next steps?

4.1 Answer

Suspect autism because Sue is difficult to converse with and seems keen on routine. This is demonstrated by Sue not wanting to interrupt her work routine by coming into hospital to see Barry when he was admitted. She also gets upset if Barry is not seen by healthcare staff at the prescribed times. Another indication that Sue may have autism is her lack of a social life, indicating she may have difficulty initiating or sustaining social relationships.

Contact the specialist autism team for advice about whether to refer Sue for an autism assessment, or use the Autism-Spectrum Quotient – 10 items (AQ-10), to establish whether Sue should be offered a comprehensive assessment for autism.

Relevant recommendations

Consider assessment for possible autism when a person has:

- one or more of the following:
 - persistent difficulties in social interaction
 - persistent difficulties in social communication
 - stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests, **and**
- one or more of the following:
 - problems in obtaining or sustaining employment or education
 - difficulties in initiating or sustaining social relationships
 - previous or current contact with mental health or learning disability services
 - history of a neurodevelopmental condition (including learning disabilities and attention deficit hyperactivity disorder) or mental disorder. **[1.2.2]**

The specialist autism team should have a key role in the delivery and coordination of:

- specialist diagnostic and assessment services
- specialist care and interventions
- advice and training to other health and social care professionals on the

diagnosis, assessment, care and interventions for adults with autism (as not all may be in the care of a specialist team)

- support in accessing and maintaining contact with, housing, educational and employment services
- support to families, partners and carers where appropriate
- care and interventions for adults with autism living in specialist residential accommodation
- training, support and consultation for staff who care for adults with autism in residential and community settings. **[1.1.14]**

For adults with possible autism who do not have a moderate or severe learning disability, consider using the Autism-Spectrum Quotient – 10 items (AQ-10)¹¹. (If a person has reading difficulties, read out the AQ-10.) If a person scores above six on the AQ-10, or autism is suspected based on clinical judgement (taking into account any past history provided by an informant), offer a comprehensive assessment for autism. **[1.2.3]**

Next steps

The specialist autism team and the AQ-10 confirm that Sue should be referred for a comprehensive autism assessment. The social worker asks Sue whether she is happy to be referred for assessment and she confirms that she is.

4.2 Question

What should be included in Sue's comprehensive autism assessment?

¹¹ Allison C, Auyeung B, Baron-Cohen S (2012) Towards brief 'red flags' for autism screening: the short Autism Spectrum Quotient and the short Quantitative Checklist in 1000 cases and 3000 controls. *Journal of the American Academy of Child and Adolescent Psychiatry* 51: 202–12.

4.2 Answer

A multidisciplinary assessment, enquiring about and assessing: the core signs and symptoms for autism, early developmental history, behavioural problems, functioning at home and employment, past and current physical and mental health, other neurodevelopmental conditions and hyper- or hypo-sensory sensitivities and attention to detail.

A formal assessment tool could be used to aid diagnosis.

Take into account differential diagnosis and coexisting conditions as part of the assessment. Do not routinely use biological tests, genetic tests or diagnostic neuroimaging as part of assessment.

Assess risks. Consider self-harm, escalation of problems, harm to others, self-neglect, breakdown and exploitation of others and develop a risk management plan developed if needed. A plan is not needed in Sue's case.

Develop a care plan for Sue, including the needs of Barry and Sue's mother.

Relevant recommendations

In each area a specialist community-based multidisciplinary team for adults with autism (the specialist autism team) should be established. The membership should include:

- clinical psychologists
- nurses
- occupational therapists
- psychiatrists
- social workers
- speech and language therapists
- support staff (for example, supporting access to housing, educational and employment services, financial advice, and personal and community safety skills). **[1.1.13]**

The specialist autism team should have a key role in the delivery and coordination of:

- specialist diagnostic and assessment services
- specialist care and interventions
- advice and training to other health and social care professionals on the diagnosis, assessment, care and interventions for adults with autism (as not all may be in the care of a specialist team)
- support in accessing and maintaining contact with, housing, educational and employment services
- support to families, partners and carers where appropriate
- care and interventions for adults with autism living in specialist residential accommodation
- training, support and consultation for staff who care for adults with autism in residential and community settings. **[1.1.14]**

During a comprehensive assessment, enquire about and assess the following:

- core autism signs and symptoms (difficulties in social interaction and communication and the presence of stereotypic behaviour, resistance to change or restricted interests) that have been present in childhood and continuing into adulthood
- early developmental history, where possible
- behavioural problems
- functioning at home, in education or in employment
- past and current physical and mental disorders
- other neurodevelopmental conditions
- hyper- and hypo-sensory sensitivities and attention to detail.

Carry out direct observation of core autism signs and symptoms especially in social situations. **[1.2.7]**

To aid more complex diagnosis and assessment for adults, consider using a formal assessment tool, such as:

- the following tools for people who do not have a learning disability:
 - the Adult Asperger Assessment (AAA; includes the Autism-Spectrum Quotient [AQ] and the Empathy Quotient [EQ])¹²
 - the Autism Diagnostic Interview – Revised (ADI-R)¹³
 - the Autism Diagnostic Observation Schedule – Generic (ADOS-G)¹⁴
 - the Asperger Syndrome (and high-functioning autism) Diagnostic Interview (ASDI)¹⁵
 - the Ritvo Autism Asperger Diagnostic Scale – Revised (RAADS-R)¹⁶
- the following tools in particular for people with a learning disability:
 - the ADOS-G
 - the ADI-R **[1.2.8]**

During a comprehensive assessment, take into account and assess for possible differential diagnoses and coexisting disorders or conditions, such as:

- other neurodevelopmental conditions (use formal assessment tools for learning disability)
- mental disorders (for example, schizophrenia, depression or other mood disorders, and anxiety disorders, in particular, social anxiety disorder and obsessive–compulsive disorder)
- neurological disorders (for example, epilepsy)
- physical disorders
- communication difficulties (for example, speech and language problems, and selective mutism)
- hyper- or hypo-sensory sensitivities. **[1.2.10]**

¹² Baron-Cohen S, Wheelwright S, Robinson J et al. (2005) The Adult Asperger Assessment (AAA): a diagnostic method. *Journal of Autism and Developmental Disorders* 35: 807–19

¹³ Lord C, Pickles A, McLennan J et al. (1997) Diagnosing autism: analyses of data from the Autism Diagnostic Interview. *Journal of Autism and Developmental Disorders* 27: 501–17.

¹⁴ Lord C, Risi S, Lambrecht L et al. (2000) The Autism Diagnostic Observation Schedule – Generic: a standard measure of social and communication deficits associated with the spectrum of autism. *Journal of Autism and Developmental Disorders* 30: 205–23.

¹⁵ Gillberg C, Gillberg C, Rastam M et al. (2001) The Asperger Syndrome (and high-functioning autism) Diagnostic Interview (ASDI): a preliminary study of a new structured clinical interview. *Autism* 5: 57–66.

¹⁶ Ritvo RA, Ritvo ER, Guthrie D et al. (2011) The Ritvo Autism Asperger Diagnostic Scale – Revised (RAADS-R): a scale used to assist the diagnosis of autism spectrum disorders in adults: an international validation study. *Journal of Autism and Developmental Disorders* 41: 1076–89.

During a comprehensive assessment, assess the following risks:

- self-harm (in particular in people with depression or moderate or severe learning disability)
- rapid escalation of problems
- harm to others
- self-neglect
- breakdown of family or residential support
- exploitation or abuse by others.

Develop a risk management plan if needed. **[1.2.12]**

Develop a care plan based on the comprehensive assessment, incorporating the risk management plan and including any particular needs (such as adaptations to the social or physical environment), and also taking into account the needs of the family, partner or carer(s). **[1.2.13]**

Do not use biological tests, genetic tests or neuroimaging for diagnostic purposes routinely as part of a comprehensive assessment. **[1.2.11]**

Next steps

The assessment establishes that Sue, who presents as a well functioning woman with some language problems, has Asperger's syndrome. She demonstrates the following signs and symptoms: difficulties in social interaction and resistance to change.

At the assessment Sue's mother reveals that Sue was good at school but she had no clear friends other than one girl with whom she went out a lot. Sue is interested in history and maths and has a good head for dates and figures. Sue can add up columns of numbers mentally very quickly. She has a limited social life and tends to be home all the time. She is rather wooden in her non-verbal communication and has lots of routines and problems with change. Sue talks a lot, but is rather concrete and tangential. She interprets many colloquialisms literally and her mother says Sue is not good at sarcasm.

4.3 Question

What should happen next?

4.3 Answer

Offer Sue a follow-up appointment to discuss the implications of this diagnosis and the further care and support required.

The specialist autism team should work with Sue to identify the correct treatment and care. When considering this, the autism team should take into account the nature of Sue's autism and the presence of social or personal factors. Consider that Sue may be anxious about decision making and may have altered sensitivity to drugs or interventions.

Give Sue information about the nature, content and duration of any proposed intervention.

Relevant recommendations

Offer all adults who have received a diagnosis of autism (irrespective of whether they need or have refused further care and support) a follow-up appointment to discuss the implications of the diagnosis, any concerns they have about the diagnosis, and any future care and support they may require. **[1.2.18]**

When discussing and deciding on interventions with adults with autism, consider:

- experience of, and response to, previous interventions
- the nature and severity of autism
- the extent of any associated functional impairment arising from the autism, a learning disability or mental or physical disorder
- the presence of any social or personal factors that may have a role in the development or maintenance of any identified problem(s)
- the presence, and nature, severity and duration, of any coexisting disorders
- the identification of predisposing and possible precipitating factors that could lead to crises if not addressed¹⁷. **[1.3.1]**

When discussing and deciding on care and interventions with adults with

¹⁷ Adapted from 'Common mental health disorders: identification and pathways to care' (NICE clinical guideline 123). Available from www.nice.org.uk/guidance/CG123

autism, take into account the:

- increased propensity for elevated anxiety about decision-making in people with autism
- greater risk of altered sensitivity and unpredictable responses to medication or other physical interventions
- environment, for example whether it is suitably adapted for people with autism, in particular those with hyper- or hypo-sensory sensitivities (see recommendation 1.1.8 in the NICE guideline)
- presence and nature of hyper- or hypo-sensory sensitivities and how these might impact on the delivery of the intervention
- importance of predictability, clarity, structure and routine for people with autism
- nature of support needed to access interventions. **[1.3.2]**

When discussing and deciding on interventions with adults with autism, provide information about:

- the nature, content and duration of any proposed intervention
 - the acceptability and tolerability of any proposed intervention
 - possible interactions with any current interventions and possible side effects
 - the implications for the continuing provision of any current interventions¹⁸.
- [1.3.3]**

4.4 Question

What further assessment is necessary, taking into account Sue's caring responsibilities for her son Barry?

¹⁸ Adapted from 'Common mental health disorders: identification and pathways to care' (NICE clinical guideline 123). Available from www.nice.org.uk/guidance/CG123

4.4 Answer

Having autism does not mean that Sue is a bad or unsafe mother. In this case there are no concerns about the development of Barry, who is doing well. If there were concerns about Sue's parenting of Barry then a parenting assessment would be necessary. An autism assessment is not an assessment of parenting skills.

Case scenario 5: Brian

This case is relevant to primary, secondary and tertiary care settings.

Presentation

Mrs Porter approaches her GP about her son Brian, who is 25. She recently separated from her husband and they are currently in divorce proceedings. Mrs Porter feels that Brian, who still lives with her, could not live independently even though he has several A-levels and appears to be of 'normal' intelligence. Since leaving school Brian has tried to get work but has failed and for the past 6 years has spent most of his time in his bedroom on his computer.

Brian does not go out often, and only buy things for his computer using money that he 'borrows' from his mother. He has not signed on for benefits and any attempts to persuade him to do so are met with verbal resistance and inactivity.

Mrs Porter describes Brian as a loner who is uninterested in visitors. Brian retires to his room as soon as visitors arrive. She does not know what he does in his room but describes him as 'obsessed' with the paranormal. He watches TV alone in his room and not with his mother. He has not spoken to his father for the past 4 years, although she is unclear why.

Mrs Porter worries that Brian cannot look after himself because when she is out he does not come down to eat, even if food is left out for him, and will not spontaneously do things around the house using his initiative, unless she hands him a set of instructions saying he must complete them. When she cut herself cooking and had to go to A&E Brian's reaction was 'who is cooking my dinner?'

She feels Brian should be classified as a dependant in the divorce proceedings. Her husband is arguing he should not be seen as a dependant but as a self centred wilful young man. Her solicitor has asked her to seek a medical view.

5.1 Question

What should the GP suggest to Mrs Porter and how should they go about initially assessing Brian?

5.1 Answer

Explain to Mrs Porter that Brian needs to be seen in person to be assessed. A home visit may be needed if Brian is reluctant to come into the surgery.

Consider referring him for assessment of possible autism because he appears to lack empathy and social interaction. He is also struggling to obtain employment. These indications highlight possible autism.

Consider using the AQ-10 to help determine whether Brian should be referred to the specialist autism team for a comprehensive autism assessment.

Relevant recommendations

Consider assessment for possible autism when a person has:

- one or more of the following:
 - persistent difficulties in social interaction
 - persistent difficulties in social communication
 - stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests, **and**
- one or more of the following:
 - problems in obtaining or sustaining employment or education
 - difficulties in initiating or sustaining social relationships
 - previous or current contact with mental health or learning disability services
 - history of a neurodevelopmental condition (including learning disabilities and attention deficit hyperactivity disorder) or mental disorder. **[1.2.2]**

For adults with possible autism who do not have a moderate or severe learning disability, consider using the Autism-Spectrum Quotient – 10 items (AQ-10)¹⁹ (If a person has reading difficulties, read out the AQ-10.) If a person scores above six on the AQ-10, or autism is suspected based on clinical judgement (taking into account any past history provided by an informant), offer a comprehensive assessment for autism. **[1.2.3]**

¹⁹ Allison C, Auyeung B, Baron-Cohen S 20120 Towards brief 'red flags' for autism screening: the short Autism Spectrum Quotient and the short Quantitative Checklist in 1000 cases and 3000 controls. *Journal of the American Academy of Child and Adolescent Psychiatry* 51: 202–12.

Next steps

After assessing Brian and conducting the AQ-10, for which he had a positive score, the GP refers Brian to the specialist autism team.

5.2 Question

How should the comprehensive autism assessment be conducted?

5.2 Answer

Conduct the assessment in a multidisciplinary manner with the specialist autism team and draw on a range of professionals. Discuss with Brian the content of each section of the assessment.

Review Brian's signs and symptoms, developmental history, his functioning at home and other neurodevelopment conditions.

Assess possible coexisting disorders or conditions. Do not routinely use biological tests, genetic tests or diagnostic neuroimaging as part of the assessment.

Also assess Brian's risks. There is evidence of self-neglect because Brian will not come down to eat unless he is told to do so.

Relevant recommendations

A comprehensive assessment should:

- be undertaken by professionals who are trained and competent
- be team-based and draw on a range of professions and skills
- where possible involve a family member, partner, carer or other informant or use documentary evidence (such as school reports) of current and past behaviour and early development. **[1.2.5]**

At the beginning of a comprehensive assessment, discuss with the person the purpose of the assessment and how the outcome of the assessment will be fed back to them. Feedback should be individualised, and consider involving a family member, partner, carer or advocate, where appropriate, to support the person and help explain the feedback. **[1.2.6]**

During a comprehensive assessment, enquire about and assess the following:

- core autism signs and symptoms (difficulties in social interaction and communication and the presence of stereotypic behaviour, resistance to change or restricted interests) that have been present in childhood and continuing into adulthood
- early developmental history, where possible

- behavioural problems
- functioning at home, in education or in employment
- past and current physical and mental disorders
- other neurodevelopmental conditions
- hyper- and hypo-sensory sensitivities and attention to detail.

Carry out direct observation of core autism signs and symptoms especially in social situations. **[1.2.7]**

During a comprehensive assessment, take into account and assess for possible differential diagnoses and coexisting disorders or conditions, such as:

- other neurodevelopmental conditions (use formal assessment tools for learning disability)
- mental disorders (for example, schizophrenia, depression or other mood disorders, and anxiety disorders, in particular, social anxiety disorder and obsessive–compulsive disorder)
- neurological disorders (for example, epilepsy)
- physical disorders
- communication difficulties (for example, speech and language problems, and selective mutism)
- hyper- or hypo-sensory sensitivities. **[1.2.10]**

Do not use biological tests, genetic tests or neuroimaging for diagnostic purposes routinely as part of a comprehensive assessment. **[1.2.11]**

During a comprehensive assessment, assess the following risks:

- self-harm (in particular in people with depression or moderate or severe learning disability)
- rapid escalation of problems
- harm to others
- self-neglect
- breakdown of family or residential support
- exploitation or abuse by others.

Develop a risk management plan if needed. [1.2.12]

Next steps

Brian's assessment reveals that he has continued to be sheltered in the family into adulthood. This could be seen by others as Brian being mentally ill or idle. He has a preoccupation, rather than fixed routines, which is also a symptom of autism.

Brian is the only son in the family. His sister is healthy and is working as a nursery nurse and living with her boyfriend. Brian was teased at school and has always been shy with few friends. Teachers said he was a 'model pupil' and very polite. He did well in maths and science, but hated sport.

Brian is a silent man, who tends to answer questions in monosyllables and to stare. He looks angry but when asked how he feels he says 'OK'. When you ask him about his paranormal interests he talks at length.

Brian's main issue is his social needs. Because he is a vulnerable adult, he is likely to be defined as a dependent in any court case.

5.3 Question

What interventions should be considered for Brian?

5.3 Answer

Consider a group-based social learning programme focused on improving social interaction. If Brian finds the group-based activity difficult, consider an individually delivered programme.

The social programme should include modelling, peer feedback, discussion and decision making, explicit rules and suggested strategies for dealing with socially difficult situations. Because Brian has had restricted social contacts consider a group or individual leisure activity programme.

Consider a structured and predictable training programme based on behavioural principles to help Brian with activities of daily living.

Offer Brian an individually supported employment programme to help him obtain employment. As part of this programme Brian could visit the disability advisor at the local job centre and apply for benefits. Someone else can fill out the forms for Brian or his mother could be made an appointee by the Department for Work and Pensions to apply on his behalf. The disability advisor will be aware of support in the local area and can offer advice. There may be many organisations where Brian could apply to do voluntary work and there are charities conducting courses for the disabled. As Brian is computer literate he could do a course in IT and possibly get some work experience or work related skills. He could be referred to Remploy, The Shaw Trust or similar by the disability advisor at the job centre with a view to looking for employment. Employment would mean Brian would be less isolated.

Relevant recommendations

For adults with autism without a learning disability or with a mild to moderate learning disability, who have identified problems with social interaction, consider:

- a group-based social learning programme focused on improving social interaction
- an individually delivered social learning programme for people who find group-based activities difficult. **[1.4.1]**

Social learning programmes to improve social interaction should typically include:

- modelling
- peer feedback (for group-based programmes) or individual feedback (for individually delivered programmes)
- discussion and decision-making
- explicit rules
- suggested strategies for dealing with socially difficult situations. **[1.4.2]**

For adults with autism of all ranges of intellectual ability, who need help with activities of daily living, consider a structured and predictable training programme based on behavioural principles. **[1.4.4]**

For adults with autism without a learning disability or with a mild to moderate learning disability, who are socially isolated or have restricted social contact, consider:

- a group-based structured leisure activity programme
- an individually delivered structured leisure activity programme for people who find group-based activities difficult. **[1.4.5]**

A structured leisure activity programme should typically include:

- a focus on the interests and abilities of the participant(s)
- regular meetings for a valued leisure activity
- for group-based programmes, a facilitator with a broad understanding of autism to help integrate the participants
- the provision of structure and support. **[1.4.6]**

For adults with autism without a learning disability or with a mild learning disability, who are having difficulty obtaining or maintaining employment, consider an individual supported employment programme. **[1.4.11]**

An individual supported employment programme should typically include:

- help with writing CVs and job applications and preparing for interviews

- training for the identified work role and work-related behaviours
- carefully matching the person with autism with the job
- advice to employers about making reasonable adjustments to the workplace
- continuing support for the person after they start work
- support for the employer before and after the person starts work, including autism awareness training. **[1.4.12]**

Question 5.4

How should healthcare professionals involve Brian's mother?

Answer 5.4

Ask Brian if he would like to involve his mother in his care. If he would like his mother's involvement, encourage this and discuss confidentiality with both Brian and his mother. Explain to Brian's mother how she can support him. Ensure that services are not withdrawn because of Brian's mother's involvement.

Provide Brian's mother with information about autism, local support groups and her right to a formal carer's assessment.

Relevant recommendations

Discuss with adults with autism if and how they want their families, partners or carers to be involved in their care. During discussions, take into account any implications of the Mental Capacity Act (2005) and any communication needs the person may have (see recommendation 1.1.5 in the NICE guideline).

[1.1.15]

If the person with autism wants their family, partner or carer(s) to be involved, encourage this involvement and:

- negotiate between the person with autism and their family, partner or carer(s) about confidentiality and sharing of information on an ongoing basis
- explain how families, partners or carers can help support the person with autism and help with care plans
- make sure that no services are withdrawn because of involvement of the family, partner or carer(s), unless this has been clearly agreed with both the person with autism and their family, partner or carer(s). **[1.1.16]**

Give all families, partners and carer(s) (whether or not the person wants them to be involved in their care) verbal and written information about:

- autism and its management
- local support groups and services specifically for families, partners and carers
- their right to a formal carer's assessment of their own physical and mental health needs, and how to access this. **[1.1.17]**

Question 5.5

What should be included in the assessment of needs for Brian's mother?

Answer 5.5

Include an assessment of personal, social and emotional support, support in her caring role, advice on and support in obtaining practical support and the planning of Brian's future care.

Provide Brian's mother with information about support groups, specifically those designed to address the needs of carers of those with autism.

Relevant recommendations

Offer families, partners and carers of adults with autism an assessment of their own needs including:

- personal, social and emotional support
- support in their caring role, including respite care and emergency plans
- advice on and support in obtaining practical support
- planning of future care for the person with autism. **[1.7.1]**

When the needs of families, partners and carers have been identified, provide information about, and facilitate contact with, a range of support groups including those specifically designed to address the needs of families, partners and carers of people with autism. **[1.7.2]**

Case scenario 6: Andrew

This case is relevant to primary, secondary and tertiary care settings.

History

Andrew is 30 years old; he is his parents' second son and has been registered with the same GP practice from birth. He had an apparently normal childhood with very few visits to the surgery and attended mainstream education.

He had an episode of depression when he was 22 years old and was seen by mental health services. He had a prescription for venlafaxine and some counselling.

Presentation

He presents to his GP saying that his ex-girlfriend thought he might have Asperger's syndrome. He is persuaded to do an on-line screening tool and goes for a private assessment. Both of these indicate the possibility of Asperger's.

The GP notes that he is uncomfortable in social situations and struggles with meeting people, is rigid and repetitive in his daily routines, including with his food, and that his major interest is in cars and their number plates.

6.1 Question

What should the GP suspect, where may they obtain advice and what further information should they have gathered from Andrew?

6.1 Answer

Begin to suspect and consider assessment for possible autism, because Andrew struggles in social situations and is rigid in his daily routines.

Advice could be obtained from the specialist autism team or a fellow GP within the practice.

The GP should have gathered further information from Andrew about his social relationship history, his development history and his employment background.

Relevant recommendations

Consider assessment for possible autism when a person has:

- one or more of the following:
 - persistent difficulties in social interaction
 - persistent difficulties in social communication
 - stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests, **and**
- one or more of the following:
 - problems in obtaining or sustaining employment or education
 - difficulties in initiating or sustaining social relationships
 - previous or current contact with mental health or learning disability services
 - history of a neurodevelopmental condition (including learning disabilities and attention deficit hyperactivity disorder) or mental disorder. **[1.2.2]**

The specialist autism team should have a key role in the delivery and coordination of:

- specialist diagnostic and assessment services
- specialist care and interventions
- advice and training to other health and social care professionals on the diagnosis, assessment, care and interventions for adults with autism (as not all may be in the care of a specialist team)
- support in accessing and maintaining housing, educational and employment services

- support to families, partners and carers where appropriate
- care and interventions for adults with autism living in specialist residential accommodation
- training, support and consultation for staff who care for adults with autism in residential and community settings. **[1.1.15]**

Next steps

The GP discusses the case with a colleague in secondary care who has an interest in Asperger's, and a referral to the secondary care specialist autism team is made.

Andrew waits 18 months for his initial assessment, he had no extra input during this long wait and is given no advice.

6.2 Question

What could have ensured that Andrew had a better experience of access to the service for assessment?

6.2 Answer

A single point of referral for primary care to refer individuals into the specialist autism service. Systems to provide overall coordination of assessment services. Designating one professional to oversee each referred person's care may also aid efficient access to care.

Relevant recommendations

There should be a single point of referral (including self-referral) to specialist services for adults with autism. [1.8.8]

Support access to services and increase the uptake of interventions by:

- ensuring systems (for example, care coordination or case management) are in place to provide for the overall coordination and continuity of care for adults with autism
- designating a professional to oversee the whole period of care (usually a member of the primary healthcare team for those not in the care of a specialist autism team or mental health or learning disability service)²⁰.

[1.8.10]

Next steps

Andrew is assessed by the specialist service and is given a diagnosis of Asperger's syndrome 4 months after his assessment. The assessment establishes Andrew's difficulty sustaining relationships and that he still lives at home. He had moved out once for 3 weeks to be with his girlfriend but this had not worked out. He has had a succession of jobs; he currently works in finance but had left a number of jobs because of difficulties in relationships with colleagues. He was not bullied at school, but describes himself as having been different. The counselling he had 8 years ago for his bout of depression has not been helpful because Andrew felt that "words were just repeated back to him".

6.3 Question

What intervention should be offered to Andrew and what should it include?

²⁰ Adapted from 'Common mental health disorders: identification and pathways to care' (NICE clinical guideline 123). Available from www.nice.org.uk/guidance/CG123

6.3 Answer

A group-based social learning programme focused on improving social interaction. This should typically include: modelling, peer feedback, discussion and decision making, explicit rules and suggested strategies for dealing with difficult social situations.

Also offer help with daily living activities.

Relevant recommendations

For adults with autism without a learning disability or with a mild to moderate learning disability, who have identified problems with social interaction, consider:

- a group-based social learning programme focused on improving social interaction
- an individually delivered social learning programme for people who find group-based activities difficult. **[1.4.1]**

Social learning programmes to improve social interaction should typically include:

- modelling
- peer feedback (for group-based programmes) or individual feedback (for individually delivered programmes)
- discussion and decision-making
- explicit rules
- suggested strategies for dealing with socially difficult situations. **[1.4.2]**

For adults with autism of all ranges of intellectual ability, who need help with activities of daily living, consider a structured and predictable training programme based on behavioural principles. **[1.4.4]**

Next steps

Andrew is offered, and accepts, six sessions of post-diagnostic psychoeducational group work. He also has an assessment by a specialist social worker for help with budgeting, housing and employment. His mother is

offered a carers assessment. His father, who is described as being “just like Andrew” turns down help.

Relevant recommendation

Give all families, partners and carer(s) (whether or not the person wants them to be involved in their care) verbal and written information about:

- autism and its management
- local support groups and services specifically for families, partners and carers
- their right to a formal carer's assessment of their own physical and mental health needs, and how to access this. [1.1.17]

Next steps

Shortly after being given his diagnosis Andrew sees another doctor at the GP practice, and is diagnosed with anxiety.

Question 6.4

What intervention should Andrew be offered for his anxiety?

Answer 6.4

Psychosocial interventions informed by the NICE anxiety guideline (available from <http://guidance.nice.org.uk/CG113>). Andrew should be offered a comprehensive assessment for his anxiety to identify an appropriate intervention.

Relevant recommendations

For adults with autism and coexisting mental disorders, offer psychosocial interventions informed by existing NICE guidance for the specific disorder.

[1.6.2]

For people who may have GAD, conduct a comprehensive assessment that does not rely solely on the number, severity and duration of symptoms, but also considers the degree of distress and functional impairment. **[1.2.5]** of CG113 Anxiety from <http://guidance.nice.org.uk/CG113>

Next steps

Andrew is off work for an initial period of 2 weeks and then has a phased return over a further 2-week period.

He returns to the original GP 4 months later with ongoing problems of anxiety and is referred for cognitive behavioural therapy (CBT). It is a generic service because there is no specialist service for CBT in autism spectrum conditions (ASC) locally.

Case scenario 7: Henry

This case is relevant to primary care settings.

Presentation

Joan seeks advice from her GP about her husband Henry, a 48 year old accountant. Their children are going to college, and with the changes in their lives she is starting to realise that there are unsolvable problems with their relationship and is wondering if he has Asperger's syndrome. She feels that either Henry does not care about her or that he does not notice how she is feeling.

The GP advises Joan that Henry would need to come in and be seen before he could give her any advice. Henry agrees to visit the GP at the insistence of his wife.

7.1 Question

What information should the GP obtain from Henry during his first appointment?

7.1 Answer

Ask about Henry's:

- family background
- education
- employment
- social life and interests.

The GP should also ask Henry whether he would like his wife involved in the initial assessment. If he agrees, then the GP should ask Joan about the same aspects of Henry's life.

Next steps

Henry agrees to involve Joan. The GP completes the AQ-10 with Henry and also asks Joan to answer the same questions about him. Henry scores himself well within the normal range, however Joan's answers place him well within the autism spectrum range.

Joan's views are clearly very important because the AQ-10 shows such discrepancy between her and Henry's views on Henry's attributes.

The assessment establishes the following:

- Henry is an accountant. He is the son of a general surgeon and was a high performer at school and at university. He is the author of several books on accountancy. He feels he is well regarded and respected within his department and he likes his work. He rates himself as generally very happy, but recognises that things are not going well with his wife. He is unsure why and stresses that he loves her.
- Joan feels that he is not good at informal social events, or at picking up social nuances, and that his friends are organised by her as his 'social secretary'. However, she accepts that at work he is well regarded by his colleagues although she feels he is taken advantage of and is 'used' by them. "He cannot cope with the politics of work."

- They have two sons and one daughter. Joan says that Henry left her to do most of the childcare. The younger son, Philip, was referred by his school to the child and adolescent mental health service after he presented with severe anxiety following bullying at school when he was 12. He was diagnosed with Asperger's. After a move to another school Philip did well and is now at university studying mathematics with support from the local Asperger's service. The other two children did well at college and are in relationships and working.
- Joan met Henry at university where she was studying English and was attracted to Henry because he was such a kind and gentle man and they both shared an interest in music. However, she felt he was socially naive. She was his first serious girlfriend. After they had been married for a while she felt he was finding it an effort to think about her. Sometimes he would arrive at home and go straight to his study and not say hello to her or to their children. She had to organise Sunday as a 'family day'. Now they are alone together at home because the children have left. Recently she had distressing news that her mother was ill – that day he had gone straight to his study, and when he did come down an hour later for tea he failed to pick up that she was upset. She told him of her mother's diagnosis of breast cancer and he responded by telling her the prognosis. This event brought to the fore for her that she was feeling unsupported by him, and made her realise how much he had failed to support her in bringing up their children and the emotional stress of Philip's diagnosis.
- She describes him as a man who dislikes change but copes with it reasonably well. He spends his spare time at home either listening to music or composing alone or reading accountancy books and articles.
- The GP notices that Henry shows little emotional facial expression other than smiling through the assessment, even when Joan is talking of her distress. He also has little body expression as he talks or responds to others. He does not mirror how others are sitting in the room. His speech is highly intelligent in content but rather flat in delivery. When asked about how he feels about his wife and her concerns, he talks in a formal style rather than an emotional one.

7.2 Question

Should the GP refer Henry for further assessment?

7.2 Answer

Henry has many features of autism but may not meet the formal criteria for diagnosis.

Consider what the value would be to Henry of obtaining diagnosis. He does not see himself as having difficulties. He is successful at work, and the main difficulty he is having is in his marital relationship. Exploration of their relationship difficulties may be of greater value than a formal diagnosis at this stage.

If Henry were having difficulties at work a diagnosis of autism might be to his advantage in terms of employment rights. However, given that at present he is apparently successful at work, getting a diagnosis may just damage his self-esteem.

Be clear with Henry about what he wants. If it is decided to refer for formal diagnosis then be clear with the specialist autism team about the reasons for referral.

In this case it may be more appropriate to explore the marital disharmony. The GP should have a sensitive discussion with Henry to see what he feels about the whole situation. How does he feel about the fact that his wife may think he has Asperger's, and how did he feel about filling in the AQ-10? If he says that the most important thing is to sort out his relationship with his wife, as he does say that he loves her – then that is where expert input is most likely to be productive. A similar discussion could then be had with his wife and if agreed a referral for marital counselling.

Case scenario 8: Jusna

This case is relevant to secondary and tertiary care settings.

History

Jusna is 30 years old and has a diagnosis of high functioning autism. She has been using mental health services since her mid-20s because of depression. Jusna lives with her mother. The mother also cares for Jusna's grandmother, who recently moved into the family home, Jusna has experienced high levels of anxiety since her grandmother moved in. She has been demanding regular reassurance from her mother.

Presentation

Jusna has begun self-harming (head banging and picking at her arms). These behaviours have not occurred since adolescence. Jusna's mother is under a lot of pressure, but she cannot ask her mother to move because that would be criticised by other people in their family and religious community.

8.1 Question

How should the specialist autism team identify the correct treatment for Jusna and how should they approach caring for her?

8.1 Answer

When discussing and deciding on interventions, consider Jusna's experience and response to previous interventions. Take into account the nature and severity of her autism and the extent of any functional impairment. Also consider the nature and severity of Jusna's depression and anxiety to ensure that the intervention is appropriate.

Be culturally sensitive in delivering care and advice, and seek to establish factors specific to Jusna's culture and religious community.

Provide information about the nature, content and duration of any proposed intervention in addition to the implications for continuing the provision of any current interventions.

Work in partnership with Jusna and her mother (if Jusna has agreed to her mother's involvement) and offer care respectfully. Take time to build a supportive and empathic relationship with Jusna. Aim to foster her autonomy and promote her active participation in decisions about her care.

Provide Jusna's mother and grandmother with information about autism and its management. Concentrate on explaining autism to Jusna's grandmother who is new to living with someone with autism. It may be that Jusna's grandmother can adapt her behaviour and reduce the impact her moving in is having on Jusna.

Relevant recommendations

When discussing and deciding on interventions with adults with autism, consider:

- experience of, and response to, previous interventions
- the nature and severity of autism
- the extent of any associated functional impairment arising from the autism, a learning disability or mental or physical disorder
- the presence of any social or personal factors that may have a role in the development or maintenance of any identified problem(s)
- the presence, and nature, severity and duration, of any coexisting disorders

- the identification of predisposing and possible precipitating factors that could lead to crises if not addressed²¹. **[1.3.1]**

When discussing and deciding on interventions with adults with autism, provide information about:

- the nature, content and duration of any proposed intervention
- the acceptability and tolerability of any proposed intervention
- possible interactions with any current interventions and possible side effects
- the implications for the continuing provision of any current interventions²². **[1.3.3]**

All staff working with adults with autism should:

- work in partnership with adults with autism and, where appropriate, with their families, partners or carers
- offer support and care respectfully
- take time to build a trusting, supportive, empathic and non-judgemental relationship as an essential part of care. **[1.1.1]**

All health and social care professionals providing care and support for adults with autism should:

- aim to foster the person's autonomy, promote active participation in decisions about care and support self-management
- maintain continuity of individual relationships wherever possible
- ensure that comprehensive information about the nature of, and interventions and services for, their difficulties is available in an appropriate language or format (including various visual, verbal and aural, easy-read and different colour and font formats)
- consider whether the person may benefit from access to a trained advocate. **[1.1.4]**

²¹ Adapted from 'Common mental health disorders: identification and pathways to care' (NICE clinical guideline 123). Available from www.nice.org.uk/guidance/CG123

²² Adapted from 'Common mental health disorders: identification and pathways to care' (NICE clinical guideline 123). Available from www.nice.org.uk/guidance/CG123

If a person with autism does not want their family, partners or carer(s) to be involved in their care:

- give the family, partner or carer(s) verbal and written information about who they can contact if they are concerned about the person's care
- bear in mind that people with autism may be ambivalent or negative towards their family or partner. This may be for many different reasons, including a coexisting mental disorder or prior experience of violence or abuse. **[1.1.18]**

8.2 Question

What interventions should be considered for Jusna?

8.2 Answer

Because Jusna demonstrates problems with social interaction with her grandmother, consider a group-based social learning programme.

Treat Jusna's depression, anxiety and self-harm in accordance with existing NICE guidelines. Those treating Jusna for her coexisting conditions should have an understanding of the core symptoms of autism and consider adapting interventions to meet Jusna's needs. Jusna's recent change in behaviour is a result of her grandmother moving in to her home; give Jusna's mother advice about this and discuss possible options to change this.

Provide a psychosocial intervention that is based on behavioural principles as initial management of Jusna's change and challenging behaviour.

Relevant recommendations

For adults with autism with no or a mild to moderate learning disability, who have identified problems with social interaction, consider a group-based social learning programme focused on improving social interaction. **[1.4.1]**

Staff delivering interventions for coexisting mental disorders for adults with autism should:

- have an understanding of the core symptoms of autism and their possible impact on the treatment of coexisting mental disorders
- consider seeking advice from a specialist autism team regarding delivering and adapting these interventions for people with autism. **[1.6.1]**

Address any identified factors that may trigger or maintain challenging behaviour (see recommendation 1.2.20 in the NICE guideline) before initiating other interventions. Such factors should be addressed by offering:

- the appropriate care for physical disorders (for example, gastrointestinal problems or chronic pain)
- treatment for any coexisting mental disorders, including psychological and pharmacological interventions (for example, anxiolytic, antidepressant or antipsychotic medication), informed by existing NICE guidance

- interventions aimed at changing the physical or social environment environment (for example, who the person lives with) when problems are identified, such as:
 - advice to the family, partner or carer(s)
 - changes or accommodations to the physical environment (see recommendation 1.1.8 in the NICE guideline). **[1.5.1]**

Offer a psychosocial intervention for the challenging behaviour first if no coexisting mental or physical disorder, or problem related to the physical or social environment, has been identified as triggering or maintaining challenging behaviour. **[1.5.2]**

Provide psychosocial interventions for challenging behaviour based on behavioural principles, and informed by a functional analysis of behaviour (see recommendation 1.5.3 of the NICE guideline) and a rationale for offering the intervention for the initial management of challenging behaviour. **[1.5.5]**

8.3 Question

What else should the specialist autism team do, considering Jusna's change in behaviour?

8.3 Answer

Consider repeating the comprehensive assessment that Jusna should have received before diagnosis. Include a risk assessment and develop a new risk management plan.

Relevant recommendations

During a comprehensive assessment, take into account and assess for possible differential diagnoses and coexisting disorders or conditions, such as:

- other neurodevelopmental conditions (use formal assessment tools for learning disability)
- mental disorders (for example, schizophrenia, depression or other mood disorders, and anxiety disorders, in particular, social anxiety disorder and obsessive–compulsive disorder)
- neurological disorders (for example, epilepsy)
- physical disorders
- communication difficulties (for example, speech and language problems, and selective mutism)
- hyper- or hypo-sensory sensitivities. **[1.2.10]**

During a comprehensive assessment, assess the following risks:

- self-harm (in particular in people with depression or moderate or severe learning disability)
- rapid escalation of problems
- harm to others
- self-neglect
- breakdown of family or residential support
- exploitation or abuse by others.

Develop a risk management plan if needed. **[1.2.12]**

Case scenario 9: Patrick

This case is relevant to secondary and tertiary care settings.

History

Patrick is a 52 year old man employed in repetitive non-demanding work. He came to the attention of psychiatric services 10 years ago when he was diagnosed with depressive disorder and obsessive compulsive disorder (OCD). He was prescribed a selective serotonin reuptake inhibitor and clomipramine.

Presentation

Patrick is referred for Mental Health Act assessment because of severe self-neglect. He is admitted to hospital and diagnosed as having schizophrenia.

Psychological assessment reveals a mild learning disability. He has started having problems at work, making multiple errors and needing intense supervision. He has been unable to cope with technical modernisation and he prefers to carry out his tasks in traditional methods. He has problems in budgeting, and has been buying and hoarding expensive domestic appliances that he never uses.

Patrick has poor social communication and exhibits gaze avoidance. He has obsessive symptoms but no psychotic symptoms.

A diagnosis of autism spectrum disorder is suspected and he is referred to a specialist centre for autism assessment where a diagnosis of atypical autism is confirmed.

9.1 Question

How should health and social care professionals approach caring for Patrick?

9.1 Answer

Take time to adopt a trusting, supportive and non-judgemental relationship with Patrick. Be aware of the nature of Patrick's autism and the fact that he has only recently received a diagnosis. Aim to foster Patrick's autonomy and promote his active participation in treatment decisions.

Relevant recommendations

All staff working with adults with autism should:

- work in partnership with adults with autism and, where appropriate, with their families, partners and carers
- offer support and care respectfully
- take time to build a trusting, supportive, empathic and non-judgemental relationship as an essential part of care. **[1.1.1]**

All staff working with adults with autism should have an understanding of the:

- nature, development and course of autism
- impact on personal, social, educational and occupational functioning
- impact of the social and physical environment. **[1.1.2]**

All health and social care professionals providing care and support for adults with autism should:

- aim to foster the person's autonomy, promote active participation in decisions about care and support self-management
- maintain continuity of individual relationships wherever possible
- ensure that comprehensive information about the nature of, and interventions and services for, their difficulties is available in an appropriate language or format (including various visual, verbal and aural, easy-read and different colour and font formats)
- consider whether the person may benefit from access to a trained advocate. **[1.1.4]**

9.2 Question

How should health and social care professionals go about identifying the correct intervention for Patrick?

9.2 Answer

Discuss possible interventions with Patrick. Consider his experience of previous treatments and responses to those treatments. Take into account the nature and severity of Patrick's autism and coexisting conditions.

Assess the environment within which interventions will take place to ensure it is suitably adapted for people with autism.

Give Patrick information about the nature and duration of possible interventions.

Relevant recommendations

When discussing and deciding on interventions with adults with autism, consider:

- their experience of, and response to, previous interventions
- the nature and severity of their autism
- the extent of any associated functional impairment arising from the autism, a learning disability or a mental or physical disorder
- the presence of any social or personal factors that may have a role in the development or maintenance of any identified problem(s)
- the presence, nature, severity and duration of any coexisting disorders
- the identification of predisposing and possible precipitating factors that could lead to crises if not addressed²³. **[1.3.1]**

When discussing and deciding on care and interventions with adults with autism, take into account the:

- increased propensity for elevated anxiety about decision-making in people with autism
- greater risk of altered sensitivity and unpredictable responses to medication
- environment, for example whether it is suitably adapted for people with autism, in particular those with hyper- or hypo-sensory sensitivities (see recommendation 1.1.8 in the NICE clinical guideline)
- presence and nature of hyper- or hypo-sensory sensitivities and how these

²³ Adapted from '[Common mental health disorders: identification and pathways to care](#)' (NICE clinical guideline 123).

might impact on the delivery of the intervention

- importance of predictability, clarity, structure and routine for people with autism
- nature of support needed to access interventions. **[1.3.2]**

When discussing and deciding on interventions with adults with autism, provide information about:

- the nature, content and duration of any proposed intervention
- the acceptability and tolerability of any proposed intervention
- possible interactions with any current interventions and possible side effects
- the implications for the continuing provision of any current interventions²⁴.

[1.3.3]

9.3 Question

What intervention should be considered for Patrick's autism?

²⁴ Adapted from '[Common mental health disorders: identification and pathways to care](#)' (NICE clinical guideline 123).

9.3 Answer

Consider a group based social learning programme that focuses on social interaction, and includes peer feedback, discussion and decision making and suggested strategies for dealing with socially difficult situations.

Patrick struggles with budgeting, so consider a structured training program to help with daily living activities, in addition to a leisure activity program which may help with his social life as he currently has little social contact.

Also consider an individual supported employment program. As part of this, give Patrick's employer advice and support about making reasonable adjustments.

Relevant recommendations

For adults with autism without a learning disability or with a mild to moderate learning disability, who have identified problems with social interaction, consider:

- a group-based social learning programme focused on improving social interaction
- an individually delivered social learning programme for people who find group-based activities difficult. **[1.4.1]**

Social learning programmes to improve social interaction should typically include:

- modelling
- peer feedback (for group-based programmes) or individual feedback (for individually delivered programmes)
- discussion and decision-making
- explicit rules
- suggested strategies for dealing with socially difficult situations. **[1.4.2]**

For adults with autism of all ranges of intellectual ability, who need help with activities of daily living, consider a structured and predictable training programme based on behavioural principles. **[1.4.4]**

For adults with autism without a learning disability or with a mild to moderate

learning disability, who are socially isolated or have restricted social contact, consider:

- a group-based structured leisure activity programme
- an individually delivered structured leisure activity programme for people who find group-based activities difficult. **[1.4.5]**

A structured leisure activity programme should typically include:

- a focus on the interests and abilities of the participant(s)
- regular meetings for a valued leisure activity
- for group-based programmes, a facilitator with a broad understanding of autism to help integrate the participants
- the provision of structure and support. **[1.4.6]**

For adults with autism without a learning disability or with a mild learning disability, who are having difficulty obtaining or maintaining employment, consider an individual supported employment programme. **[1.4.11]**

An individual supported employment programme should typically include:

- help with writing CVs and job applications and preparing for interviews
- training for the identified work role and work-related behaviours
- carefully matching the person with autism with the job
- advice to employers about making reasonable adjustments to the workplace
- continuing support for the person after they start work
- support for the employer before and after the person starts work, including autism awareness training. **[1.4.12]**

9.4 Question

What intervention should be offered for Patrick's depressive disorder and OCD?

Answer 9.4

Offer interventions and pharmacological interventions in line with the NICE clinical guideline on depression (<http://guidance.nice.org.uk/CG90>) and OCD (<http://guidance.nice.org.uk/CG31>). Consider adapting the method of delivery.

Relevant recommendations

For adults with autism and coexisting mental disorders, offer psychosocial interventions informed by existing NICE guidance for the specific disorder.

[1.6.2]

Adaptations to the method of delivery of cognitive and behavioural interventions for adults with autism and coexisting common mental disorders should include:

- a more concrete and structured approach with a greater use of written and visual information (which may include worksheets, thought bubbles, images and 'tool boxes')
- placing greater emphasis on changing behaviour, rather than cognitions, and using the behaviour as the starting point for intervention
- making rules explicit and explaining their context
- using plain English and avoiding excessive use of metaphor, ambiguity and hypothetical situations
- involving a family member, partner, carer or professional (if the person with autism agrees) to support the implementation of an intervention
- maintaining the person's attention by offering regular breaks and incorporating their special interests into therapy if possible (such as using computers to present information). **[1.6.3]**

For adults with autism and coexisting mental disorders, offer pharmacological interventions informed by existing NICE guidance for the specific disorder.

[1.6.4]

Other implementation tools

NICE has developed tools to help organisations implement the clinical guideline on autism: recognition, referral. Diagnosis and management of adults on the autism spectrum (listed below). These are available on the NICE website (www.nice.org.uk/guidance/CG142).

- Costing report – details of the likely costs and savings when the cost impact of the guideline is not considered to be significant.
- Audit support – for monitoring local practice.
- Link to the Royal College of General Practitioners (RCGP) free online educational tool: the ‘Autism in General Practice’ course enables GPs and the primary healthcare team to improve the care they and their practice provide for patients with autism spectrum conditions.
- Link to the AQ-10 diagnostic tool.

A practical guide to implementation, ‘How to put NICE guidance into practice: a guide to implementation for organisations’, is also available (www.nice.org.uk/usingguidance/implementationtools).

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