

Autism: recognition referral and
diagnosis of children and young
people on the autism spectrum

Clinical case scenarios for professionals working with children and young people

September 2011

These clinical case scenarios accompany the clinical guideline: 'Autism: recognition, referral and diagnosis of children and young people on the autism spectrum' (available at www.nice.org.uk/guidance/CG128).

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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 on the next page.

These eight clinical case scenarios have been compiled to improve and assess users' knowledge of the recognition, referral and diagnosis of autism in children and young people. They illustrate how the recommendations from 'Autism: recognition, referral and diagnosis of children and young people on the autism spectrum', (NICE clinical guideline 128, www.nice.org.uk/CG128) can be applied in practice for those working with and caring for children and young people.

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. Slides from the clinical case scenario slide set can be added to the standard NICE slide set produced for this guideline.

You will need to refer to the NICE clinical guideline to help you decide what steps you would need to follow with each case, so make sure that users have access to a copy (either online at www.nice.org.uk/guidance/CG128 or as a print out). You may also want to refer to the autism NICE pathway that will be published in October 2011 (<http://pathways.nice.org.uk/>), and the specialist library page on NHS Evidence (www.evidence.nhs.uk/topic/autism).

Each case scenario includes details of the child or young person's initial presentation. The clinical decisions about assessment and diagnosis 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.

Clinical case scenarios for professionals working with children and young people

Case scenario 1: Howard – recognition, referral and diagnosis

Presentation

Howard is 7 years old and presents at his GP with his mother as she is concerned about his challenging behaviour in school. He is very noncompliant and has hit staff and pupils. Howard had early language delay but now uses fluent sentences. His school reports indicate that he has moderately impaired intellectual ability with above average reading skills and a marked failure to develop any peer relationships. His parents report that his language is stereotyped and repetitive and that he repeats videos and DVDs. He is very limited in terms initiating social communication and has a restricted pattern of interests, currently an over-focus on DVDs.

He has stereotyped repetitive motor mannerisms and seeks to feel people's clothes. Howard does use eye gaze, facial expression and gesture but is an infrequent initiator of communication.

Howard shows some appropriate responses to other people's emotions but also often shows an odd response, for example smiles if distress shown. He is unconcerned about modulating behaviour according to the social context and has some fixed routines, for example reading through all the notices at the swimming pool every time.

Recognising possible autism

1.1 Question

Howard's GP is unsure about the possibility of autism. What should he consider and take into account?

1.1 Answer

Howard's GP should consider the possibility of autism because his parents have raised concerns regarding early development and behaviour. Because the GP is unsure about the possibility of autism, he or she should speak to a colleague to confirm the suspicions. The GP could also speak to a member of the autism team to gain advice about whether to refer Howard to the team for assessment.

Howard's GP may use the primary school age signs and symptoms table (in appendix C of the NICE guideline) to help further identify whether autism should be considered.

The GP should discuss Howard's behaviour with his mother and sensitively explain the possible causes, which may include autism. The GP should also emphasise that there may be many explanations for Howard's behaviour.

The GP should not rule out autism because Howard uses eye gaze, facial expressions and gestures of affection.

Relevant recommendations

Consider the possibility of autism if there are concerns about development or behaviour, but be aware that there may be other explanations for individual signs and symptoms. [1.2.1]

Always take parents' or carers' concerns and, if appropriate, the child's or young person's concerns, about behaviour or development seriously, even if these are not shared by others. [1.2.2]

When considering the possibility of autism and whether to refer a child or young person to the autism team, be critical about your professional competence and seek advice from a colleague if in doubt about the next step. [1.2.3]

Autism team members should:

- provide advice to professionals about whether to refer children and young people for autism diagnostic assessments
- decide on the assessment needs of those referred or when referral to another service will be needed
- carry out the autism diagnostic assessment
- share the outcome of the autism diagnostic assessment with parents and carers, and with children and young people if appropriate
- with parent or carer consent and, if appropriate, the consent of the child or young person, share information from the autism diagnostic assessment directly with relevant services, for example through a school visit by an autism team member
- offer information to children, young people and parents and carers about appropriate services and support. [1.1.7]

If you have concerns about development or behaviour but are not sure whether the signs and/or symptoms suggest autism, consider:

- consulting a member of the autism team who can provide advice to help you decide if a referral to the autism team is necessary
- referring to another service. That service can then refer to the autism team if necessary. [1.3.4]

To help identify the signs and symptoms of possible autism, use tables 1–3 (see appendix C of the NICE guideline). Do not rule out autism if the exact features described in the tables are not evident; they should be used for guidance, but do not include all possible manifestations of autism. [1.2.4]

Discuss developmental or behavioural concerns about a child or young person with parents or carers, and the child or young person themselves if appropriate. Discuss sensitively the possible causes, which may include autism, emphasising that there may be many explanations for the child's or young person's behaviour. [1.2.8]

Do not rule out autism because of:

- good eye contact, smiling and showing affection to family members
- reported pretend play or normal language milestones
- difficulties appearing to resolve after a needs-based intervention (such as a supportive structured learning environment)
- a previous assessment that concluded that there was no autism, if new information becomes available. [1.2.7]

Referring to the autism team

1.2 Question

Howard's GP has decided that Howard displays enough of the signs and symptoms for autism in order for him to refer Howard to the area's autism team.

This was confirmed after discussion with a member of the autism team who advised the GP to refer Howard. What should the referral letter include and what information should the GP give to Howard and his mother?

1.2 Answer

Howard's GP should ensure that the information he has gained from Howard's mother and from cross referencing Howard's signs and symptoms to those within the primary school age signs and symptoms table, are included in the referral letter. They should also include antenatal and perinatal history, developmental milestones, and relevant medical history and investigations if these are available.

The GP should arrange another appointment with Howard and his mother to explain what will happen on referral to the autism team.

Related recommendations

When referring children and young people to the autism team, include in the referral letter the following information:

- reported information from parents, carers and professionals about signs and/or symptoms of concern
- your own observations of the signs and/or symptoms. [1.3.6]

When referring children and young people to the autism team, include in the referral letter the following information, if available:

- antenatal and perinatal history
- developmental milestones
- factors associated with an increased prevalence of autism (see box 1 in the NICE guideline)
- relevant medical history and investigations
- information from previous assessments. [1.3.7]

Explain to parents or carers and, if appropriate, the child or young person, what will happen on referral to the autism team or another service. [1.3.8]

After referral to the autism team

1.3 Question

The autism team has received Howard's referral from his GP. What should the autism team consider when deciding whether to carry out an autism diagnostic assessment?

1.3 Answer

The severity and duration of Howard's signs symptoms should be considered, as well as how persistent they are across different settings. The impact of Howard's signs and symptoms on family life and the level of his mother's concerns should also be taken into account. The likelihood of an alternative diagnosis should also be considered.

The autism team decide to carry out an autistic diagnostic assessment for Howard and therefore his case coordinator seeks a report from his school and gathers additional health and social care information including results from hearing and vision tests. The case coordinator also informs Howard's mother about the diagnostic assessment process and the likely timings and tests associated with this process.

Related recommendations

When deciding whether to carry out an autism diagnostic assessment, take account of the following (unless the child is under 3 years and has regression in language or social skills – see recommendation 1.4.2 in NICE guideline):

- the severity and duration of the signs and/or symptoms
- the extent to which the signs and/or symptoms are present across different settings (for example, home and school)
- the impact of the signs and/or symptoms on the child or young person and on their family or carer
- the level of parental or carer concern, and if appropriate the concerns of the child or young person
- factors associated with an increased prevalence of autism (see box 1 on page 4 of the NICE guideline)
- the likelihood of an alternative diagnosis. [1.4.4]

Once it has been decided to carry out an autism diagnostic assessment, with consent from parents or carers (and the child or young person if appropriate):

- seek a report from the pre-school or school if one has not already been made available
- gather any additional health or social care information, including results from hearing and vision assessments. [1.4.7]

A case coordinator in the autism team should be identified for every child or young person who is to have an autism diagnostic assessment. [1.5.2]

The autism case coordinator should:

- act as a single point of contact for the parents or carers and, if appropriate, the child or young person being assessed, through whom they can communicate with the rest of the autism team
- keep parents or carers and, if appropriate, the child or young person, up-to-date about the likely time and sequence of assessments
- arrange the provision of information and support for parents, carers, children and young people as directed by the autism team
- gather information relevant to the autism diagnostic assessment (see recommendation 1.4.7). [1.5.3]

Autism diagnostic assessment

1.4 Question

How should members of the autism team carry out Howard's diagnostic assessment and what should be included?

1.4 Answer

Howard's diagnostic assessment should begin within 3 months of the referral. Members of the autism team should discuss with Howard and his mother how information should be shared among healthcare professionals throughout the diagnostic assessment. Efficient communication between professionals is important to prevent repeat requests for information throughout the assessment process.

The assessment should include:

- Howard's home life experience
- detailed questions about his mother's concerns
- a developmental history focusing on developmental and behavioural features consistent with ICD-10 or DSM-IV criteria
- assessment of social and communication skills
- a medical history
- a physical examination
- a systematic assessment for conditions that may coexist with autism
- development of a profile that can be used to create a needs based management plan.

The profile should illustrate Howard's strengths, skills, impairments and needs and should take into account Howard's family and educational context.

Related recommendations

Start the autism diagnostic assessment within 3 months of the referral to the autism team. [1.5.1]

Discuss with the parents or carers and, if appropriate, the child or young person, how information should be shared throughout the autism diagnostic assessment, including communicating the outcome of the assessment. Take into account, for example, the child or young person's age and ability to understand. [1.5.4]

Include in every autism diagnostic assessment:

- detailed questions about parent's or carer's concerns and, if appropriate, the child's or young person's concerns
- details of the child's or young person's experiences of home life, education and social care
- a developmental history, focusing on developmental and behavioural features consistent with ICD-10 or DSM-IV criteria (consider using an autism-specific tool to gather this information)
- assessment (through interaction with and observation of the child or young person) of social and communication skills and behaviours, focusing on features consistent with ICD-10 or DSM-IV criteria (consider using an autism-specific tool to gather this information)
- a medical history, including prenatal, perinatal and family history, and past and current health conditions
- a physical examination
- consideration of the differential diagnosis (see recommendation 1.5.7 in the NICE guideline)
- systematic assessment for conditions that may coexist with autism (see recommendation 1.5.15 in the NICE guideline)
- development of a profile of the child's or young person's strengths, skills, impairments and needs that can be used to create a needs-based management plan, taking into account family and educational context
- communication of assessment findings to the parent or carer and, if appropriate, the child or young person. [1.5.5]

Avoid repeated information gathering and assessments by efficient communication between professionals and agencies. [1.4.8]

Communicating the results of the diagnostic assessment

1.5 Question

The diagnostic assessment confirms that Howard does have autism and therefore a diagnosis is made. What should Howard's case coordinator in the autism team do to ensure the results of the diagnostic assessment are communicated effectively and to all those who need to receive this information?

1.5 Answer

The findings should be discussed immediately and sensitively with Howard and his mother. The conclusions drawn and why a diagnosis of autism has been made should be discussed and a written report of the assessment provided. Howard's case coordinator should deliver this information in person and sensitively, bearing in mind that the news of a diagnosis may evoke positive or negative feelings within Howard and his mother.

A written report of the diagnostic assessment should be sent to Howard's GP and shared with relevant professionals involved in Howard's care if his mother gives consent.

Howard should be offered a follow up appointment within 6 weeks for further discussion and the autism team should discuss with Howard's mother the risk of autism occurring in siblings.

Related recommendations

After the autism diagnostic assessment discuss the findings, including the profile, sensitively, in person and without delay with the parents or carers and, if appropriate, the child or young person. Explain the basis of conclusions even if the diagnosis of autism was not reached. [1.8.1]

Use recognised good practice when sharing a diagnosis with parents, carers, children and young people. [1.8.2]

Provide parents or carers and, if appropriate, the child or young person, with a written report of the autism diagnostic assessment. This should explain the findings of the assessment and the reasons for the conclusions drawn. [1.8.4]

Share information, including the written report of the diagnostic assessment, with the GP. [1.8.5]

With parental or carer consent and, if appropriate, the consent of the child or young person, share information with key professionals involved in the child's or young person's care, including those in education and social care. [1.8.6]

With parental or carer consent and, if appropriate, the consent of the child or young person, make the profile available to professionals in education (for example, through a school visit by a member of the autism team) and, if appropriate, social care. This is so it can contribute to the child or young person's individual education plan and needs-based management plan. [1.8.7]

For children and young people with a diagnosis of autism, offer a follow-up appointment with an appropriate member of the autism team within 6 weeks of the end of the autism assessment for further discussion (for example about the conclusions of the assessment and the implications for the child or young person). [1.8.8]

Case scenario 2: Ellie – recognition and referral

Presentation

Ellie, who is 3, has come to clinic with a suspected ear infection. Ellie's mum says that her daughter has been rocking rhythmically and clutching her ear at the same time. There has been some moisture on her pillow in the morning and Ellie is reluctant to let her mum investigate what is wrong. Ellie is attempting to rock while she is seated on her mother's knee and uses the same repetitive vocalisation "Don't wanna go to the shops" over and over again. She feels hot to touch and will not let healthcare practitioners approach her with any equipment. Her vocalisation becomes louder and more insistent when you attempt examination.

Recognising possible autism

2.1 Question

How should you approach examining Ellie?

2.1 Answer

You should examine Ellie taking into account her needs and preferences. These are some of the strategies you could use to help overcome Ellie's reluctance to being examined:

- Show Ellie the equipment you need to use.
- Let Ellie feel and hold the equipment.
- Demonstrate on Ellie's mum what you are going to do.
- Take Ellie's temperature using a temperature strip that will not hurt her.
- Encourage Ellie to use equipment on her mum.
- If Ellie is resistant to examination, make a second appointment for later in the day. Discuss with Ellie's mum whether stickers or other incentives or distractions might help.
- See Ellie in a non-threatening environment such as the nurse's office or if possible at home.

You should speak to Ellie's mum about Ellie's development and behaviour and consider her concerns seriously. Ask about Ellie's use and understanding of language. You could use the preschool signs and symptoms table to help identify the possibility of autism (appendix C of the NICE guideline).

You could also use a tool to help gather information about the signs and symptoms for autism in a structured way. However please be aware that tools are not essential and should not be used to make or rule out a diagnosis of autism.

Be aware that Ellie's mum may not have recognised Ellie's symptoms and that autism may be under-diagnosed in girls. You should discuss sensitively the possible causes of Ellie's behaviour and the fact that this may include autism. Be aware when discussing this that Ellie's mum may not have suspected a developmental or behavioural condition and that it may take her time to come to terms with receiving this news.

Related recommendations

Consider the possibility of autism if there are concerns about development or behaviour, but be aware that there may be other explanations for individual signs and symptoms. [1.2.1]

Always take parents' or carers' concerns and, if appropriate, the child's or young person's concerns, about behaviour or development seriously, even if these are not shared by others. [1.2.2]

To help identify the signs and symptoms of possible autism, use tables 1–3 (see appendix C of the NICE guideline). Do not rule out autism if the exact features described in the tables are not evident; they should be used for guidance, but do not include all possible manifestations of autism. [1.2.4]

When considering the possibility of autism, be aware that:

- signs and symptoms should be seen in the context of the child's or young person's overall development
- signs and symptoms will not always have been recognised by parents, carers, children or young people themselves or by other professionals
- when older children or young people present for the first time with possible autism, signs or symptoms may have previously been masked by the child or young person's coping mechanisms and/or a supportive environment
- it is necessary to take account of cultural variation, but do not assume that language delay is accounted for because English is not the family's first language or by early hearing difficulties
- autism may be missed in children or young people with an intellectual disability
- autism may be missed in children or young people who are verbally able
- autism may be under-diagnosed in girls
- important information about early development may not be readily available for some children and young people, for example looked-after children and those in the criminal justice system
- signs and symptoms may not be accounted for by disruptive home experiences or parental or carer mental or physical illness. [1.2.5]

When considering the possibility of autism, ask about the child or young person's use and understanding of their first language. [1.2.6]

Discuss developmental or behavioural concerns about a child or young person with parents or carers, and the child or young person themselves if appropriate. Discuss sensitively the possible causes, which may include autism, emphasising that there may be many explanations for the child's or young person's behaviour. [1.2.8]

Be aware that if parents or carers or the child or young person themselves have not suspected a developmental or behavioural condition, raising the possibility may cause distress, and that:

- it may take time for them to come to terms with the concern
- they may not share the concern. [1.2.9]

Be aware that tools to identify children and young people with an increased likelihood of autism may be useful in gathering information about signs and symptoms of autism in a structured way but are not essential and should not be used to make or rule out a diagnosis of autism. Also be aware that:

- a positive score on tools to identify an increased likelihood of autism may support a decision to refer but can also be for reasons other than autism
- a negative score does not rule out autism. [1.3.5]

Referring to the autism team

2.2 Question

You suspect that autism may be a possibility. What should you do to ensure that your suspicions are correct and how should you go about referring Ellie to the local autism team?

2.2 Answer

You should discuss Ellie's case and your concerns with a colleague to see if they agree with your suspicions of autism. If they share your concerns you should contact a member of the autism team to discuss whether referral is necessary and if so how to go about referring Ellie.

The autism team member agrees that Ellie should be referred. You should include in the referral letter the information you have gathered about Ellie's signs and symptoms in addition to the information you have gathered from Ellie's mum. If available you should also include Ellie's antenatal and perinatal history and relevant medical history and investigations.

You should explain to Ellie's mum what will happen on referral, using information you received from the autism team when you discussed referring Ellie with them.

Related recommendations

When considering the possibility of autism and whether to refer a child or young person to the autism team, be critical about your professional competence and seek advice from a colleague if in doubt about the next step. [1.2.3]

If you have concerns about development or behaviour but are not sure whether the signs and/or symptoms suggest autism, consider:

- consulting a member of the autism team who can provide advice to help you decide if a referral to the autism team is necessary
- referring to another service. That service can then refer to the autism team if necessary. [1.3.4]

When referring children and young people to the autism team, include in the referral letter the following information:

- reported information from parents, carers and professionals about signs and/or symptoms of concern
- your own observations of the signs and/or symptoms. [1.3.6]

When referring children and young people to the autism team, include in the referral letter the following information, if available:

- antenatal and perinatal history
- developmental milestones
- factors associated with an increased prevalence of autism (see box 1 in NICE guideline)
- relevant medical history and investigations
- information from previous assessments. [1.3.7]

Explain to parents or carers and, if appropriate, the child or young person, what will happen on referral to the autism team or another service. [1.3.8]

Case scenario 3: Arjinder – recognition and referral

Presentation

Arjinder is 27 months old and comes to the clinic with his grandmother. Arjinder's family are concerned because he does not turn towards members of his family when they come into the room and despite them calling his name, he does not seem to show any recognition of his name nor of the significant people in his life. Arjinder has had a hearing test and all appears to be normal.

While Arjinder is sitting on his grandmother's lap during the consultation he seems to be hearing the whir of the computer fan on your desk and occasionally turns towards the ticking of the clock on the wall. Arjinder does not respond to his grandmother's voice and does not show any particular reaction when you call him by name. You wind up a toy in front of him and he immediately pays attention to the winding noise and the subsequent actions of the toy.

Recognising possible autism

3.1 Question

How should you work with Arjinder and his grandmother to examine Arjinder and what should be considered?

3.1 Answer

You should consider the possibility of autism because of Arjinder's suspected hearing impairment and lack of response to family members. These are two alerting signs and symptoms for possible autism.

You should take time to discuss Arjinder's development, understanding of his first language, and signs and symptoms with his grandmother and agree on a series of actions to follow, which will include a referral to the autism team for a multidisciplinary assessment.

Arjinder's grandmother informs you that he seemed to understand his first language better a couple of months ago and seems to have gone 'backwards' in terms of language development. Arjinder should be referred to the autism team because he is younger than 3 years and has regression in language

Related recommendations

Consider the possibility of autism if there are concerns about development or behaviour, but be aware that there may be other explanations for individual signs and symptoms. [1.2.1]

Take time to listen to parents or carers and, if appropriate, the child or young person, to discuss concerns and agree any actions to follow including referral.[1.2.10]

Refer children younger than 3 years to the autism team if there is regression in language or social skills. [1.3.1]

Referring to the local autism team

3.2 Question

How should you refer Arjinder to the local autism team and what should be included in the referral letter?

3.2 Answer

There should be only one point of referral into the autism team. If you do not know this, speak to a member of the autism team who may help by going through the referral process with you.

Include in the referral letter reported information and your own observations about Arjinder's signs and symptoms. Include details about the severity and the extent to which these signs and symptoms are present across different settings. Also include the likelihood of an alternative diagnosis.

Antenatal and perinatal history, developmental milestones and relevant medical history and investigations should also be included in the referral letter if available.

Related recommendations

Provide a single point of referral for access to the autism team. [1.1.8]

Autism team members should:

- provide advice to professionals about whether to refer children and young people for autism diagnostic assessments
- decide on the assessment needs of those referred or when referral to another service will be needed
- carry out the autism diagnostic assessment
- share the outcome of the autism diagnostic assessment with parents and carers, and with children and young people if appropriate
- with parent or carer consent and, if appropriate, the consent of the child or young person, share information from the autism diagnostic assessment directly with relevant services, for example through a school visit by an autism team member
- offer information to children, young people and parents and carers about appropriate services and support. [1.1.7]

Consider referring children and young people to the autism team if you are concerned about possible autism on the basis of reported or observed signs and/or symptoms (see tables 1–3 in appendix C of the NICE guideline). Take account of:

- the severity and duration of the signs and/or symptoms
- the extent to which the signs and/or symptoms are present across different settings (for example, home and school)
- the impact of the signs and/or symptoms on the child or young person and on their family
- the level of parental or carer concern and, if appropriate, the concerns of the child or young person
- factors associated with an increased prevalence of autism (see box 1 on page 20 of the NICE guideline)
- the likelihood of an alternative diagnosis. [1.3.3]

When referring children and young people to the autism team, include in the referral letter the following information:

- reported information from parents, carers and professionals about signs and/or symptoms of concern
- your own observations of the signs and/or symptoms. [1.3.6]

When referring children and young people to the autism team, include in the referral letter the following information, if available:

- antenatal and perinatal history
- developmental milestones
- factors associated with an increased prevalence of autism (see box 1 in the NICE guideline)
- relevant medical history and investigations
- information from previous assessments. [1.3.7]

Case scenario 4: Natasha – recognition

Presentation

Natasha is 13 years old and presents with her parents at her GP with physical symptoms and friendship problems. She has a well above average IQ, all early milestones were reached but in retrospect, Natasha's parents report that there were always problems with social interaction with peers.

Natasha has a liking for routines, and a tendency to literal understanding of what people say and do. Her parents think that Natasha is naive and immature compared with her peers.

Natasha's teacher identified a need for some extra support for learning and she was well supported in primary school, but since secondary transfer Natasha began to complain more frequently of headaches and stomach aches, and does not wish to go to school.

Natasha has never displayed any behavioural difficulties but her parents have long-standing concerns about friendship difficulties with peers. In school, Natasha frequently fails to understand task instructions but does not ask for help because she does not wish to draw attention to herself.

Next steps for recognition

4.1 Question

What should Natasha's GP consider and discuss with her parents?

4.1 Answer

Natasha's GP should take her parents' concerns seriously and may use the secondary school signs and symptoms tables to help identify signs and symptoms for autism. Because Natasha is presenting at a later age, the fact that signs and symptoms may be masked by coping mechanisms should be considered.

Related recommendations

Always take parents' or carers' concerns and, if appropriate, the child's or young person's concerns, about behaviour or development seriously, even if these are not shared by others. [1.2.2]

When considering the possibility of autism, be aware that:

- signs and symptoms should be seen in the context of the child's or young person's overall development
- signs and symptoms will not always have been recognised by parents, carers, children or young people themselves or by other professionals
- when older children or young people present for the first time with possible autism, signs or symptoms may have previously been masked by the child or young person's coping mechanisms and/or a supportive environment
- it is necessary to take account of cultural variation, but do not assume that language delay is accounted for because English is not the family's first language or by early hearing difficulties
- autism may be missed in children or young people with an intellectual disability
- autism may be missed in children or young people who are verbally able
- autism may be under-diagnosed in girls
- important information about early development may not be readily available for some children and young people, for example looked-after children and those in the criminal justice system
- signs and symptoms may not be accounted for by disruptive home experiences or parental or carer mental or physical illness. [1.2.5]

Next steps for considering referral

4.2 Question

Natasha's GP has concerns about Natasha but is unsure whether the signs and symptoms suggest autism. What should the GP do?

4.2 Answer

The GP should consult a member of the autism team to discuss Natasha's case. They could also consider referring Natasha to another service because that service can then refer Natasha on to the autism team if necessary.

If Natasha's GP is still unsure whether their concerns warrant a referral, they should consider a period of watchful waiting and reconsider referral if concerns remain after a period of time.

Related recommendations

If you have concerns about development or behaviour but are not sure whether the signs and/or symptoms suggest autism, consider:

- consulting a member of the autism team who can provide advice to help you decide if a referral to the autism team is necessary
- referring to another service. That service can then refer to the autism team if necessary. [1.3.4]

If you do not think concerns are sufficient to prompt a referral, consider a period of watchful waiting. If you remain concerned about autism, reconsider your referral decision. [1.3.9]

Case scenario 5: Simon – assessment and diagnosis

Presentation

Simon is 7 years old. His school was concerned because Simon was not able to focus on class instruction and tasks. This prompted referral to the autism team. Simon was not attaining despite having an above average IQ and language ability. Simon had particular problems with writing and became very frustrated if he made mistakes.

He was not interested in making friends, and seemed to be 'in his own world'. Parents report that Simon becomes frustrated if things are 'not right', and that he has an insistence on perfectionism and routine. He has a focus of interest on the Second World War – this is the most recent of several intense interests. Simon talks at people about this and does not tolerate interruption.

He is not responsive to his name being called, seldom chats, responds without looking at people and he spends 1–2 hours daily in his own world re-enacting fantasy with actions.

Simon has a warm relationship with parents and is kind to his sibling but is anxious that the sibling does not break rules.

Next steps for assessment

5.1 Question

Simon has been referred to his local autism team. What should happen next?

5.1 Answer

One or more members of the autism team should consider whether to carry out an autism diagnostic assessment. When deciding on this, autism team members should consider Simon's reported signs and symptoms and the impact these are having on Simon and his family's lives.

Related recommendations

When a child or young person is referred to the autism team, at least one member of the autism team should consider whether to carry out:

- an autism diagnostic assessment **and/or**
- an alternative assessment. [1.4.1]

When deciding whether to carry out an autism diagnostic assessment, take account of the following (unless the child is under 3 years and has regression in language or social skills – see recommendation 1.4.2 in the NICE guideline):

- the severity and duration of the signs and/or symptoms
- the extent to which the signs and/or symptoms are present across different settings (for example, home and school)
- the impact of the signs and/or symptoms on the child or young person and on their family or carer
- the level of parental or carer concern, and if appropriate the concerns of the child or young person
- factors associated with an increased prevalence of autism (see box 1 on page 20 of the NICE guideline)
- the likelihood of an alternative diagnosis. [1.4.4]

5.2 Question

The autism team has decided that Simon's signs and symptoms are sufficient to need an autism diagnostic assessment. What should the team do next?

5.2 Answer

With consent from Simon's parents, the autism team should seek a report from Simon's school and should gather additional health or social care information, including results from hearing and vision assessments.

The autism team should avoid repeated requests for information by effectively communicating between themselves and involved agencies.

Simon should be assigned a case coordinator and the assessment should start within 3 months of being referred.

Simon's case coordinator should act as a point of contact for Simon's parents and should arrange for the provision of information and support.

The autism team should discuss with Simon's parents how best to share information throughout the diagnostic assessment.

Related recommendations

Once it has been decided to carry out an autism diagnostic assessment, with consent from parents or carers (and the child or young person if appropriate):

- seek a report from the pre-school or school if one has not already been made available
- gather any additional health or social care information, including results from hearing and vision assessments. [1.4.7]

Avoid repeated information gathering and assessments by efficient communication between professionals and agencies. [1.4.8]

Start the autism diagnostic assessment within 3 months of the referral to the autism team. [1.5.1]

A case coordinator in the autism team should be identified for every child or young person who is to have an autism diagnostic assessment. [1.5.2]

The autism case coordinator should:

- act as a single point of contact for the parents or carers and, if appropriate, the child or young person being assessed, through whom they can communicate with the rest of the autism team
- keep parents or carers and, if appropriate, the child or young person, up-to-date about the likely time and sequence of assessments
- arrange the provision of information and support for parents, carers, children and young people as directed by the autism team
- gather information relevant to the autism diagnostic assessment (see recommendation 1.4.7). [1.5.3]

Discuss with the parents or carers and, if appropriate, the child or young person, how information should be shared throughout the autism diagnostic assessment, including communicating the outcome of the assessment. Take into account, for example, the child or young person's age and ability to understand. [1.5.4]

5.3 Question

What should be included in Simon's autism diagnostic assessment?

5.3 Answer

Detailed questions about Simon's parents concerns and experiences of home life, education and social care should be documented. A developmental history should be included which focuses on behavioural features consistent with ICD-10 or DSM-IV criteria. To gather this information, autism team members could consider using an autism-specific tool.

A medical history, including prenatal, perinatal and family history, and past and current health conditions should also be included. A physical examination and consideration of the differential diagnosis should be noted.

There should be a systematic assessment for conditions that may coexist with autism. A profile of Simons' strengths, skills, impairments and needs should be put together.

Related recommendations

Include in every autism diagnostic assessment:

- detailed questions about parent's or carer's concerns and, if appropriate, the child's or young person's concerns
- details of the child's or young person's experiences of home life, education and social care
- a developmental history, focusing on developmental and behavioural features consistent with ICD-10 or DSM-IV criteria (consider using an autism-specific tool to gather this information)
- assessment (through interaction with and observation of the child or young person) of social and communication skills and behaviours, focusing on features consistent with ICD-10 or DSM-IV criteria (consider using an autism-specific tool to gather this information)
- a medical history, including prenatal, perinatal and family history, and past and current health conditions
- a physical examination
- consideration of the differential diagnosis (see recommendation 1.5.7 in the NICE guideline)
- systematic assessment for conditions that may coexist with autism (see recommendation 1.5.15 in the NICE guideline)
- development of a profile of the child's or young person's strengths, skills, impairments and needs that can be used to create a needs-based management plan, taking into account family and educational context
- communication of assessment findings to the parent or carer and, if appropriate, the child or young person. [1.5.5]

5.4 Question

A general physical examination should be performed. What should the autism team member carrying this out look for?

5.4 Answer

You should look for skin stigmata, neurofibromatosis or tuberous sclerosis using a Wood's light. Signs of injury, for example self-harm or child maltreatment, should be documented and congenital anomalies and dysmorphic features noted.

Related recommendations

Perform a general physical examination and look specifically for:

- skin stigmata of neurofibromatosis or tuberous sclerosis using a Wood's light
- signs of injury, for example self-harm¹ or child maltreatment²
- congenital anomalies and dysmorphic features including macrocephaly or microcephaly. [1.5.6]

¹ See 'Self-harm: the short-term physical and psychological management and secondary prevention of self-harm in primary and secondary care' (NICE clinical guideline 16). Available from www.nice.org.uk/guidance/CG16

² See 'When to suspect child maltreatment' (NICE clinical guideline 89). Available from www.nice.org.uk/guidance/CG89

5.5 Question

What differential diagnoses should be considered?

5.5 Answer

The following differential diagnoses for autism should be considered, as should whether specific assessments are needed to help interpret Simon's autism history and observations:

- Neurodevelopmental disorders:
 - specific language delay or disorder
 - intellectual disability or global developmental delay
 - developmental coordination disorder (DCD).
- Mental and behavioural disorders:
 - attention deficit hyperactivity disorder (ADHD)
 - mood disorder
 - anxiety disorder
 - attachment disorders
 - oppositional defiant disorder (ODD)
 - conduct disorder
 - obsessive compulsive disorder (OCD)
 - psychosis.
- Conditions in which there is developmental regression:
 - Rett syndrome
 - epileptic encephalopathy.
- Other conditions:
 - severe hearing impairment
 - severe visual impairment
 - maltreatment
 - selective mutism.

Related recommendations

Consider the following differential diagnoses for autism and whether specific assessments are needed to help interpret the autism history and observations:

- Neurodevelopmental disorders:
 - specific language delay or disorder
 - intellectual disability or global developmental delay
 - developmental coordination disorder (DCD).
- Mental and behavioural disorders:
 - attention deficit hyperactivity disorder (ADHD)
 - mood disorder
 - anxiety disorder
 - attachment disorders
 - oppositional defiant disorder (ODD)
 - conduct disorder
 - obsessive compulsive disorder (OCD)
 - psychosis.
- Conditions in which there is developmental regression:
 - Rett syndrome
 - epileptic encephalopathy.
- Other conditions:
 - severe hearing impairment
 - severe visual impairment
 - maltreatment
 - selective mutism. [1.5.7]

Question 5.6

Which assessments are needed to construct a profile for Simon? This profile may be used to create a needs based management plan, taking into account family and educational context.

Answer 5.6

The following assessments should be performed to construct Simon's personal profile:

- intellectual ability and learning style
- academic skills
- speech, language and communication
- fine and gross motor skills
- adaptive behaviour (including self-help skills)
- mental and emotional health (including self-esteem)
- physical health and nutrition
- sensory sensitivities
- behaviour likely to affect day-to-day functioning and social participation
- socialisation skills.

Related recommendations

Consider which assessments are needed to construct a profile for each child or young person, for example:

- intellectual ability and learning style
- academic skills
- speech, language and communication
- fine and gross motor skills
- adaptive behaviour (including self-help skills)
- mental and emotional health (including self-esteem)
- physical health and nutrition
- sensory sensitivities
- behaviour likely to affect day-to-day functioning and social participation
- socialisation skills. [1.5.8]

The results of Simon's autism diagnostic assessment confirmed that Simon does have autism and thus a diagnosis was made. Simon's case coordinator discussed the findings of the assessment, including the profile, with Simon's parents. A written report of the assessment was given to Simon's parents and this was also shared with Simon's GP.

With parental consent this information should be shared with key professionals involved with Simon's care and education. This could be achieved by a member of the autism team visiting Simon's school.

The autism team should provide Simon's parents with information on support available locally.

Related recommendations

After the autism diagnostic assessment discuss the findings, including the profile, sensitively, in person and without delay with the parents or carers and, if appropriate, the child or young person. Explain the basis of conclusions even if the diagnosis of autism was not reached. [1.8.1]

Provide parents or carers and, if appropriate, the child or young person, with a written report of the autism diagnostic assessment. This should explain the findings of the assessment and the reasons for the conclusions drawn. [1.8.4]

Share information, including the written report of the diagnostic assessment, with the GP. [1.8.5]

With parental or carer consent and, if appropriate, the consent of the child or young person, share information with key professionals involved in the child's or young person's care, including those in education and social care. [1.8.6]

With parental or carer consent and, if appropriate, the consent of the child or young person, make the profile available to professionals in education (for example, through a school visit by a member of the autism team) and, if appropriate, social care. This is so it can contribute to the child or young person's individual education plan and needs-based management plan. [1.8.7]

Provide individual information on support available locally for parents, carers, children and young people with autism, according to the family's needs. This may include:

- contact details for:
 - local and national support organisations (who may provide, for example, an opportunity to meet other families with experience of autism, or information about specific courses for parents and carers and/or young people)
 - organisations that can provide advice on welfare benefits
 - organisations that can provide information on educational support and social care
- information to help prepare for the future, for example transition to adult services. [1.9.1]

Case scenario 6: Lenny – coexisting condition

History

Lenny reached all of his developmental milestones at quite an early stage. As a baby and toddler he never seemed to get full up when he was eating, the limits had to be set by how much he was given to eat. He has now become fussier and will 'steal' food that he likes from the kitchen and will eat it all as rapidly as he can.

Lenny quite rapidly picked up words and has always been considered clever by his family. Lenny had no problems with toilet training, but did have 'accidents' when he was totally absorbed in activities. This can still happen when Lenny is involved in Pokemon games on his Nintendo DS.

Lenny had no real difficulties at pre-school, but the groups rarely exceeded eight children. Lenny became unsettled and distressed when he started in the reception class of his primary school. Lenny found it difficult to socialise; often played alone and developed solitary interests, particularly in the Pokemon cartoon character. Lenny wanted to be dressed up as Pokemon and wanted his Pokemon toy beside him all of the time. School used to get him to do his work initially by using the opportunity to play with Pokemon as an incentive. However, this simply resulted in Pokemon telling teachers that Lenny was too busy to work. Staff became frustrated with Lenny's fixation on the Pokemon character. At home and school life revolved around Pokemon for lengthy periods of the day Lenny would speak about Pokemon. Lenny would use his Pokemon toy as a way to talk during activities at home and at school. Lenny demonstrated a limited interest in playing with peers and would not play games others suggested. He was interested in playing only with children who were prepared to do things and play games that Lenny wanted to do.

Diagnosis

At the age of 6 Lenny was referred to the local autism team because of concerns that he might have autism. The outcome of the referral was a diagnosis of autism. As a result, Lenny was also assessed as having special

educational needs and additional resources were provided, including training input for staff working with Lenny at his school.

By the time he was 7, Lenny was interested in playing only with younger children, because they tended to do what he wanted them to and often enjoyed playing his Pokemon role-play games. If the children became bored or started to drift away from the game, Lenny's playing became rougher. This pattern of behaviour was repeated at home with his younger siblings. If adults addressed Lenny's behaviour he 'shut down' and would become mute for days at a time.

Lenny was very sensitive to any changes occurring at home or at school. He would hide away under tables, retreat into doorways and refuse to sit with other children. When Lenny became stressed he punched his head and pulled out hair.

Presentation

Lenny is now 8 years old and has presented to his family GP with his mother because she feels his 'naughtiness' is beyond adult control

6.1 Question

What should the GP consider and advise?

6.1 Answer

Lenny's GP should consider that there may be a differential diagnosis to explain Lenny's presenting behaviour and that it may be more than just 'plain naughtiness'.

The GP should advise Lenny's mother to ask for a Special Education Needs assessment at school and they should re-refer Lenny to the autism team to carry out further assessments for possible coexisting conditions.

Related recommendations

Consider the following differential diagnoses for autism and whether specific assessments are needed to help interpret the autism history and observations:

- Neurodevelopmental disorders:
 - specific language delay or disorder
 - intellectual disability or global developmental delay
 - developmental coordination disorder (DCD).
- Mental and behavioural disorders:
 - attention deficit hyperactivity disorder (ADHD)
 - mood disorder
 - anxiety disorder
 - attachment disorders
 - oppositional defiant disorder (ODD)
 - conduct disorder
 - obsessive compulsive disorder (OCD)
 - psychosis.
- Conditions in which there is developmental regression:
 - Rett syndrome
 - epileptic encephalopathy.
- Other conditions:
 - severe hearing impairment
 - severe visual impairment
 - maltreatment
 - selective mutism [1.5.7]

Consider whether the child or young person may have any of the following as a coexisting condition, and if suspected carry out appropriate assessments and referrals:

- Mental and behaviour problems and disorders:
 - ADHD
 - anxiety disorders and phobias
 - mood disorders
 - oppositional defiant behaviour
 - tics or Tourette syndrome
 - OCD
 - self-injurious behaviour.
- Neurodevelopmental problems and disorders:
 - global delay or intellectual disability
 - motor coordination problems or DCD
 - academic learning problems, for example in literacy or numeracy
 - speech and language disorder.
- Medical or genetic problems and disorders:
 - epilepsy and epileptic encephalopathy
 - chromosome disorders
 - genetic abnormalities, including fragile X
 - tuberous sclerosis
 - muscular dystrophy
 - neurofibromatosis.
- Functional problems and disorders:
 - feeding problems, including restricted diets
 - urinary incontinence or enuresis
 - constipation, altered bowel habit, faecal incontinence or encopresis
 - sleep disturbances
 - vision or hearing impairment. [1.5.15]

Next steps

Lenny was seen by a consultant paediatrician in the autism team and by an educational psychologist. After a number of meetings that also involved staff from the school, a reassessment was undertaken.

A meeting was held to go through the assessment findings and it was agreed by Lenny's parents and the professionals involved that referral should be made for a specialist assessment, if Lenny agreed to this. Lenny discussed the referral with his parents and said he wanted to go ahead with it.

Given the outcomes of the re-assessment, a referral for differential diagnosis was appropriate. Lenny was seen by a specialist consultant and a specialist primary mental healthcare worker from the child and adolescent mental health service (CAMHS) in clinics, at home and at school. A number of assessment techniques were used, including Strengths and Difficulties questionnaires and diagnostic interviews.

The findings suggested that alongside his autism spectrum disorder, Lenny had developed an oppositional defiant disorder (ODD). The ODD behaviour seemed to have initially developed as a coping mechanism to manage Lenny's anxieties and external stressors. This had proven to be successful and Lenny had started to use it to 'control' things, rather than just cope, and at this point the disorder started.

Case scenario 7: John – differential diagnosis

Presentation

John is a 7 year old boy referred because of problems in peer relationships, having never had a friend, and difficulties at school, where he does not integrate with other children and does not engage in schoolwork.

7.1 Question

How should the autism team deal with this referral?

7.1 Answer

The autism team should identify a case coordinator to take John's case forward. John's case coordinator should gather the information they can for the diagnostic assessment and keep John's parents informed. John's assessment should start within 3 months of referral.

Related recommendations

A case coordinator in the autism team should be identified for every child or young person who is to have an autism diagnostic assessment. [1.5.2]

The autism case coordinator should:

- act as a single point of contact for the parents or carers and, if appropriate, the child or young person being assessed, through whom they can communicate with the rest of the autism team
- keep parents or carers and, if appropriate, the child or young person, up-to-date about the likely time and sequence of assessments
- arrange the provision of information and support for parents, carers, children and young people as directed by the autism team
- gather information relevant to the autism diagnostic assessment (see recommendation 1.4.7 in the NICE guideline). [1.5.3]

Start the autism diagnostic assessment within 3 months of the referral to the autism team. [1.5.1]

John is assessed with his parents and the following is established. John has never had friends and has never understood how to play with other children. He is rough with them and always likes to be in control. He is intrusive and 'gets in children's faces'. He does not seem to understand that other children do not like that. He has no sense of stranger danger and will speak to strangers in the street and the park. He likes routines for his days at home and school and has a temper outburst if something happens that is different from the normal routine. He has had facial tics since the age of 4. He was late talking, with first words at

30 months and putting words together at 40 months. John is very different from his 5 year old brother, who is popular and does well at school.

John is sad about the fact that he has never had friends. He is able to be loving and caring towards his family members and will cuddle his younger brother if he is hurt. He is helpful and will share his toys. He has never had unusual nor obsessive interests. Although language development was late, there were never any qualitative abnormalities. Tone variation and non-verbal communication have always been good. Grammar and use of words have always been normal for a child at that level of language development. In the clinic room, eye contact is good and language structure and tone variation are normal. In the Autism Diagnostic Observation Schedule, John shows good imaginative play and plays nicely and interactively with the assessor.

John has always been very active, running around lots and climbing whatever he can. He is very energetic and intrusive when playing with other children. The most he sits down to watch television for is 10 minutes, and even then, he wriggles in the seat a lot. John has never sat down for more than 5 minutes to play with a toy or do craft. He gets very easily distracted, loses things a lot and is very forgetful. John usually does things without thinking and this gets him into trouble. He has very little sense of danger and his parents have to hold his hand if he is by a road. The family cannot play games with him because he will not wait his turn. The family avoid taking him shopping because he runs off a lot and cannot wait in queues without having a temper outburst. These problems have always occurred at home and at school.

7.2 Question

When assessing John's signs and symptoms what should the autism team consider?

7.2 Answer

The team should be aware that John may display some of the signs and symptoms seen in the autism spectrum but may not reach the diagnostic criteria. The team should also consider the possibility of a differential diagnosis.

Related recommendations

Be aware that some children and young people will have features of behaviour that are seen in the autism spectrum but do not reach the ICD-10 or DSM-IV diagnostic criteria for definitive diagnosis. Based on their profile, consider referring to appropriate services. [1.5.13]

Consider the following differential diagnoses for autism and whether specific assessments are needed to help interpret the autism history and observations:

- Neurodevelopmental disorders:
 - specific language delay or disorder
 - intellectual disability or global developmental delay
 - developmental coordination disorder (DCD).
- Mental and behavioural disorders:
 - attention deficit hyperactivity disorder (ADHD)
 - mood disorder
 - anxiety disorder
 - attachment disorders
 - oppositional defiant disorder (ODD)
 - conduct disorder
 - obsessive compulsive disorder (OCD)
 - psychosis.
- Conditions in which there is developmental regression:
 - Rett syndrome
 - epileptic encephalopathy.
- Other conditions:
 - severe hearing impairment
 - severe visual impairment
 - maltreatment
 - selective mutism [1.5.7]

Although John has some symptoms seen on the autism spectrum, he does not have many symptoms: he is able to understand others' feelings; there have been no unusual or obsessive interests; although language was delayed, there were no qualitative abnormalities. The Autism Diagnostic Observation Schedule is within normal limits, making a diagnosis of autism very unlikely.

It is more likely that John has attention-deficit/hyperactivity disorder (ADHD); he has a lifetime history of pervasive poor attention, over activity and impulsivity in all situations. Some children with ADHD may superficially appear to have symptoms of autism. In particular, they can be intrusive and want to be in control of peer interactions. They may have a strong wish for routines because they find life easier with predictable structure and find it hard to organise themselves. Children with ADHD are more likely to have other neurodevelopmental disorders, including tic disorders and language delay. If a presentation suggests autism, it is important to carry out a full assessment of all symptom areas, considering all areas of development, and thoroughly examine the child.

Case scenario 8: Susan – coexisting condition

Presentation

Susan is a 15 year old girl referred by the GP because of poor school attendance and low mood.

At assessment, Susan says that she has been feeling sad most of the time for 6 months. It takes her 4 hours to get to sleep and she feels tired all day. Her appetite has gone down and she has lost about a stone. She thinks she is stupid and ugly. She is finding it hard to concentrate on her schoolwork. She does not want to go to school because she is worried other students will make fun of her. However, she manages to go shopping without problems. She does not want to be dead, and hopes that life will get better.

Susan says that she has always been bullied at school and that people have always called her 'Oddball'. People at school laugh at the way she speaks and make fun of what she says. They tease her because she has a big collection of dolls and dolls houses and likes to talk about it a lot. She has never had a true friend. She would like to have friends but never knows how to act around people.

Susan's parents confirm that Susan has never had friends. She did not have any interest in other children before she started school and just wanted to play dolls. There was no imaginative play with the dolls – she just liked collecting them and lining them up. When she started at school she was happy to just wander around on her own. From the age of 10 she started saying that she wished she had friends, but never talked about friends she had and never wanted to invite other children round. She has always spent a lot of time doing her schoolwork and has always been top of her year, which her parents are very proud of. Susan has always liked to keep to herself at home and has never been that bothered by what other family members have wanted to do, and has never shown concern towards other family members. Susan started talking before her 1st birthday. Her speech has always been flat without variation. She would sometimes speak at length about her dolls, which she has always been

obsessed with. She has never shown good eye contact and would never point, wave or clap as a child.

Next steps for diagnosis

8.1 Question

What should the autism team consider before considering a diagnosis for Susan?

8.1 Answer

The possibility of differential diagnoses should be considered, paying particular attention to the reasons for Susan's poor school attendance.

Related recommendations

Consider the following differential diagnoses for autism and whether specific assessments are needed to help interpret the autism history and observations:

- Neurodevelopmental disorders:
 - specific language delay or disorder
 - intellectual disability or global developmental delay
 - developmental coordination disorder (DCD).
- Mental and behavioural disorders:
 - attention deficit hyperactivity disorder (ADHD)
 - mood disorder
 - anxiety disorder
 - attachment disorders
 - oppositional defiant disorder (ODD)
 - conduct disorder
 - obsessive compulsive disorder (OCD)
 - psychosis.
- Conditions in which there is developmental regression:
 - Rett syndrome
 - epileptic encephalopathy.
- Other conditions:
 - severe hearing impairment
 - severe visual impairment
 - maltreatment
 - selective mutism [1.5.7]

Susan currently has moderate depression, which explains her poor school attendance.

NICE will be publishing a Clinical Guideline on the management of Autism in 2013 and these cases do not include recommendations for ongoing treatment.

In Susan's case the depression should be treated in line with the NICE Guideline for Depression in Children and Young People (CG28). Alongside this, clinicians should liaise with school about the importance of stopping the bullying.

8.2 Question

What is Susan's likely diagnosis?

8.2 Answer

Susan has Asperger's syndrome, with lifelong difficulties in social interaction, obsessive interests and qualitative abnormalities in language (without language delay). This has led to difficulties in socialising at school, leading to bullying. The persistent bullying has led to depressed mood and reluctance to go to school.

It is important to fully assess the likely causal factors in all cases presenting with emotional disorders. Cases of autism (especially in academically high-functioning young people) may not be picked up until adolescence, when young people become aware that they are different and want to have friends and to 'fit in'.

8.3 Question

What information and support should the autism team provide for Susan and her family?

8.3 Answer

Susan should be given the contact details for local and national support organisations. This may provide Susan with the opportunity to meet other young people who have Asperger's syndrome. Organisations may also be able to help with welfare benefits and educational support.

Information should be provided about transferring to adult services for when Susan reached her 19th birthday.

Related recommendations

Provide individual information on support available locally for parents, carers, children and young people with autism, according to the family's needs. This may include:

- contact details for:
 - local and national support organisations (who may provide, for example, an opportunity to meet other families with experience of autism, or information about specific courses for parents and carers and/or young people)
 - organisations that can provide advice on welfare benefits
 - organisations that can provide information on educational support and social care
- information to help prepare for the future, for example transition to adult services. [1.9.1]

Other implementation tools

NICE has developed tools to help organisations implement the clinical guideline on autism: recognition referral and diagnosis of children and young people on the autism spectrum (listed below). These are available on the NICE website (www.nice.org.uk/guidance/CG128).

- Costing statement.
- Awareness raising slide set.
- Audit support.
- Signs and symptoms tables.

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).

Related NICE guidance

Published

- Looked-after children and young people. NICE public health guidance 28 (2010). Available from www.nice.org.uk/guidance/PH28
- When to suspect child maltreatment. NICE clinical guideline 89 (2009). Available from www.nice.org.uk/guidance/CG89
- Attention deficit hyperactivity disorder. NICE clinical guideline 72 (2008). Available from www.nice.org.uk/guidance/CG72
- Depression in children and young people. NICE clinical guideline 28 (2005). Available from www.nice.org.uk/guidance/CG28
- The epilepsies. NICE clinical guideline 20 (2004). Available from www.nice.org.uk/guidance/CG20
- Self-harm. NICE clinical guideline 16 (2004). Available from www.nice.org.uk/guidance/CG16

Under development

NICE is developing the following guidance (details available from www.nice.org.uk):

- Autism: recognition, referral, diagnosis and management of adults on the autism spectrum. NICE clinical guideline (publication date to be confirmed).
- Autism: the management and support of children and young people on the autism spectrum. NICE clinical guideline (publication date to be confirmed).

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