NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards and indicators

Briefing paper

Quality standard topic: Autism in children, young people and adults

Output: Prioritised quality improvement areas for development.

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1 Introduction

This briefing paper presents a structured overview of potential quality improvement areas for autism in children, young people and adults. It provides the Committee with a basis for discussion and prioritising quality improvement areas for developing quality statements and measures, which will be drafted for public consultation.

Structure

The structure of this briefing paper includes a brief overview of the topic followed by a summary of each of the suggested quality improvement areas followed with supporting information.

Where relevant, guideline recommendations selected from the key development sources below are presented alongside each of the areas for quality improvement to aid the Committee when considering specific aspects for which statements and measures should be considered.

Development source

The key development sources referenced in this briefing paper are as follows:

- Autism in adults. NICE clinical guideline 142 (2012)
- Autism spectrum disorders in children and young people. NICE clinical guideline 128 (2011)
- Improving access to social care for adults with autism. Social Care Institute for Excellence (2011)
- (In progress) Autism: management of autism in children and young people. NICE clinical guideline. Publication expected August 2013.

2 Overview

2.1 Focus of quality standard

This quality standard will cover autism in children, young people and adults, including both health and social care services.

The following referrals for quality standard development in the core library will be covered by this quality standard:

- Autism (children and young people).
- Autism (adults).

The quality standard will also cover a referral from the social care work stream:

- Autism in children and adults.

2.2 Definition

Autism is a lifelong developmental disability that has a significant impact on the person and their family or carers.

Autism is a spectrum disorder, with people on a spectrum of severity. People with autism can be at different points on the spectrum for each aspect of the disorder. The term "autism" describes qualitative differences and impairments in three areas:

- difficulties with social interaction
- difficulties with social communication
- difficulties with social imagination

Autism spectrum disorders are diagnosed in children, young people and adults if these behaviours meet the criteria defined in the International Statistical Classification of Diseases and Related Health Problems (ICD-10) and the Diagnostic and Statistical Manual of Mental Disorders DSM-IV Fourth Edition (Text Revision) (DSM IV-TR) and have a significant impact on function.

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2.3 Incidence and prevalence

It is estimated that autism occurs in 1% of children and young people (approximately 120,000 children) and 1.1% of adults (approximately 450,000 adults) in the population. The prevalence rate has increased significantly in the last 2 decades. This is deemed to be due to greater awareness, increased diagnostic services and a broadening of the criteria included under the term autism to include Asperger's syndrome, atypical autism and pervasive developmental disorders.

Recent studies suggest that approximately 70% of individuals with autism also meet diagnostic criteria for at least one other (often unrecognised) mental and behavioural disorder, and 40 % meet diagnostic criteria for at least two disorders[1]

2.4 Management

Core autistic behaviours are usually present in early childhood, although features may not always be obvious until a child or young person increases their social interactions. Starting nursery or primary school, or moving to secondary school can see autistic behaviours becoming more apparent.

Average age of diagnosis of autism is in primary school (by 6 years old)[2] whereas Asperger's syndrome is often not diagnosed until secondary school (by 14 years old) or even older (early adulthood or later)[3] . Where autism isn't identified during childhood, many adults can have their condition overlooked by health, education and social care professionals. Alongside the fact that many people with autism will have a co-existing mental and or physical disorder, diagnosis can be delayed and they can find it hard to access appropriate support.

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[1] Hofvander et al., 2009; Simonoff et al., 2008

[2] Frith, 1989

[3] Attwood, 1997

There remains wide variation in access and quality of diagnostic and intervention services. There has been an increase in specific autism services in the last 10 years, with a move towards more multiagency models. However, the current estimated prevalence rates of autism have major resource implications and continue to place a considerable strain on local services.

It is important that autism is seen not just as a medical diagnosis, but recognises the social impact of autism and the potential social care needs that people with autism may have. These include areas such as education, housing and employment.

Coordination between health agencies and other key services, such as education, social care and the voluntary sector, is important. This should all happen with the full engagement and involvement of the child, young person or adult in receipt of care and services

There is a growing field of research into areas of autistic strengths[4]. This approach criticises the traditional emphasis on impairment and focuses on the strengths and potential of people with autism. This approach includes the concept of neurodiversity.

2.5 National Outcome Frameworks

The table below shows the indicators from the frameworks that the quality standard could contribute to:

NHS Outcomes Framework 2013/14	
Domain 2 Enhancing quality of life for people with long-term conditions	Overarching Indicator 2 Health related quality of life for people with long-term conditions Improvement areas 2.1 A greater proportion of people aged 18 and over suffering from a long-term condition feeling supported to manage their condition. 2.2 Employment of people with long-term conditions 2.4 Health-related quality of life for carers
Domain 4 Ensuring people have a positive experience of care	Improvement areas 4.7 Patient experience of community mental health services 4.9 (Placeholder) People’s experience of integrated care (in development).
The Adult Social Care Outcomes Framework 2013/14	
Domain 1: Enhancing quality of life for people with care and support needs	1I. Proportion of people who use services and their carers, who reported that they had as much social contact as they would like. (Public health outcomes framework 1.18)
Domain 3: Ensuring that people have a positive experience of	3A. Overall satisfaction of people who use services with their care and support 3B. Overall satisfaction of carers with social services

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[4] e.g Mottron, 2011

care	3D. The proportion of people who use services and carers who find it easy to find information about support 3E: (Placeholder) Improving people's experience of integrated care (NHS Outcomes Framework 4.9)

3 Summary of suggestions

3.1 Responses

In total 9 stakeholders responded to the 2-week engagement exercise. Suggestions were also provided by specialist committee members.

Table 1 Summary of suggested quality improvement areas

Stakeholders were asked to suggest up to 5 areas for quality improvement. These have been merged and summarised in the table below for further consideration by the Committee (incorporating stakeholder and specialist committee member suggestions). The full detail of the suggestions is provided in a separate document for information.

Suggested area for improvement	**Stakeholder**
Local pathway for recognition, referral and assessment of possible autism i) Adults ii) Children	SBS, ONHS, AAA, BNHS, RCPCH, SCM
Assessment and identification of other conditions	TA, ONHS
Services for people with autism i) Multiagency strategy group ii) Multidisciplinary team iii) Case manager / key worker	AAA, BNHS, SBS, ONHS, NAS, RCPCH, SCM,
Psychological interventions	RCPCH
Pharmacological interventions	RCPCH
Access to specialist services a) Speech and language therapy b) Sleep disorder experts c) Employment d) Befriending e) Advocacy d) Services for high functioning autism / Asperger's	NDCAMHS, SBS, SCM, NAS
Communication / access to information a) Children and young people b) Adults c) Parents / carers	RCPCH & SCM
Training a) Staff b) Making reasonable adjustments	NDCAMHS, NAS, AAA, BNHS, SBS, ONHS, SCM,

Suggested area for improvement	Stakeholder
Respite for parents / carers	SBS
Positive outlook on treatment outcomes by professionals	TA
Transition from CYP to adult services	RCN, AAA, BNHS, RCPCH, NAS, SCM,
Collection of prevalence and needs data	NAS

Table 2 Stakeholder details (abbreviations)

The details of stakeholder organisations who submitted suggestions are provided in the table below.

Abbreviation	Full name
AAA	Ambitious about autism
BNHS	Birmingham Community NHS Trust
NAS	National Autistic Society
NDCAMHS	North Durham CAMHS
ONHS	Oxford Health NHS Trust
RCN	Royal College or Nursing
RCPCH	Royal College of Paediatrics and Child Health
SBS	Step by Step School
SCM	Specialist Committee Member
TA	Treating Autism

4 Suggested improvement area: Local pathway for recognition, referral and assessment of possible autism

4.1 Summary of suggestions

Stakeholders highlighted the need for a local pathway for people who may have autism to be able to access suitably trained staff who are able to carry out an assessment and facilitate referral to appropriate support. Stakeholders raised concerns that assessment and diagnostic service provision is not consistent across the country. The pathway access points for children and young people and adults would be different. However the principles identified by stakeholders were the same, consisting of an easy single point of access to a specialist autism service where appropriate expertise is provided by a multidisciplinary team.

Suggested quality improvement area	**Source recommendations**
Access to timely diagnosis	**CG128 1.1.1 & 1.1.2** **CG142 1.2.16**
Clear local pathway for referral and diagnosis for children, young people and adults who require assessment for possible autism	**CG142 1.8.1** **CG128 1.1.1 & 1.1.2** **SCIE guide 43 p17**

4.2 Selected recommendations from the development sources

Recommendations from the development sources relating to the suggested improvement areas have been provisionally selected and are presented below to inform QSAC discussion.

Please note - four different evidence sources have been identified to inform this quality standard. To help structure the QSAC discussion where appropriate the recommendations have been split between those relevant to children and young people and those relevant to adults. The recommendations, whilst sharing the same overall principles, do differ in terms of some of the specific actions described.

i) Children and young people

Local pathway for recognition, referral and diagnostic assessment of possible autism

NICE CG128 Recommendation 1.1.1

A local autism multi-agency strategy group should be set up, with managerial, commissioner and clinical representation from child health and mental health services, education, social care, parent and carer service users, and the voluntary sector.

NICE CG128 Recommendation 1.1.2

The local autism strategy group should appoint a lead professional to be responsible for the local autism pathway for recognition, referral and diagnosis of children and young people. The aims of the group should include:

- improving early recognition of autism by raising awareness of the signs and symptoms of autism through multi-agency training (see tables 1–3 in appendix C)
- making sure the relevant professionals (healthcare, social care, education and voluntary sector) are aware of the local autism pathway and how to access diagnostic services
- supporting the smooth transition to adult services for young people going through the diagnostic pathway
- ensuring data collection and audit of the pathway takes place.

ii) Adults

Organisation and delivery of care

NICE CG142 Recommendation 1.8.1

Local care pathways should be developed to promote implementation of key principles of good care. Pathways should be:

- negotiable, workable and understandable for adults with autism, their families, partners and carers, and professionals
- accessible and acceptable to all people in need of the services served by the pathway responsive to the needs of adults with autism and their families, partners and carers
- integrated so that there are no barriers to movement between different levels of the pathway
- outcome focused (including measures of quality, service user experience and harm)

Making services accessible and acceptable

SCIE Guide 43 p 17

One approach is to provide services in a local, or regional, centre of excellence, a 'one-stop shop' for people with autism, offering:

- training and employment support
- diagnosis services
- consultancy and advice

- outreach to prevent family breakdown
- social groups and skills training
- education
- accommodation advice
- brokerage and advocacy
- support with practical tasks, paperwork and forms.

4.3 Current UK practice

The Governments strategy for adults with autism “Fulfilling and rewarding lives” (2012) included a commitment to the development of a clear and consistent pathway for the diagnosis of autism. The National Audit Office conducted a progress review[5] concerning the implementation of the strategy, 1 year after publication. The report stated that whilst progress had been made in developing guidance about diagnosis services, less progress had been made in improving access to social care assessment and diagnostic services in local authorities. Only 27 of 152 local authorities were reported to have established diagnostic pathways.

In a national survey conducted by the National Autistic Society[6] of people with autism and their parents / carers they found that whilst access to assessment and diagnosis services had improved over the last 20 years, results from the 2012 survey found that 34% of people reported that they had waited three years or more for a diagnosis after first raising concerns, with a further 30% saying that it had taken between one and two years.

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[5] The National Audit Office Progress in implementing the 2010 Adult Autism Strategy

[6] The National Autistic Society *50th survey report* 2012

5 Suggested improvement areas: Assessment and identification of other conditions

5.1 *Summary of suggestions*

Stakeholders highlighted that a number of people with autism also have co-existing conditions that can have a significant impact on their physical and mental health and wellbeing. The National Autistic Society report that these conditions are often not identified or diagnosis is delayed. This can lead to a much more complex package of care and support being required as unidentified conditions can negatively affect the success of any support or interventions a person is receiving for issues associated with their autism. Stakeholders emphasised the need for health professionals to be aware of the high prevalence of other conditions in people with autism and early identification being prioritised to enable suitable support packages and interventions to be provided.

Suggested improvement areas	**Source recommendations**
Improved investigation, diagnosis and treatment of comorbid conditions.	**CG128 1.5.7, 1.5.15** **CG142 1.1.3, 1.2.10,** **Draft CYP 1.9**
Early recognition of comorbid mental health problems in CYP and appropriate interventions offered	**CG128 1.5.7, 1.5.15** **Draft CYP 1.9**
Education of health care professionals in the presentation of challenging behaviour due to pain and discomfort caused by underlying medical problems**.**	**CG142 1.5.1** **Draft CYP 1.4.1**

5.2 *Selected recommendations from the development sources*

Recommendations from the development sources relating to the suggested improvement areas have been provisionally selected and are presented below to inform QSAC discussion

i) Children and young people

Autism diagnostic assessment for children and young people

NICE CG128 recommendation 1.5.7

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

NICE CG128 Recommendation 1.5.15

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.

Interventions for behaviour that challenges

NICE Draft CYP Guideline Recommendation 1.4.1

Include the potential for behaviour that challenges in routine assessment and care planning in children and young people with autism. Assess factors that may increase this risk, including:
- coexisting physical disorders, such as pain or gastrointestinal disorders
- coexisting mental health problems (such as anxiety or depression) and other neurodevelopmental conditions (such as ADHD)
- the physical environment, including sensory factors such as lighting and noise levels
- the social environment, including home, school and leisure activities
- changes to routines or personal circumstances

- impairments in communication that may result in difficulty understanding situations or in expressing needs and wishes
- developmental change, including puberty
- exploitation or abuse by others
- inadvertent reinforcement of behaviour that challenges.

Interventions for coexisting mental health and medical problems

NICE Draft CYP Guideline Recommendation 1.9.1

Offer psychosocial and pharmacological interventions for the management of coexisting mental health or medical problems in children and young people with autism in line with NICE guidance for children and young people, including:

- Antisocial behaviour and conduct disorders in children and young people (NICE clinical guideline 158)
- Attention deficit hyperactivity disorder (ADHD) (NICE clinical guideline 72)
- Constipation in children and young people (NICE clinical guideline 99).
- Depression in children and young people (NICE clinical guideline 28)
- Epilepsy (NICE clinical guideline 137)
- Obsessive-compulsive disorder (OCD) and body dysmorphic disorder (BDD) (NICE clinical guideline 31)
- Post-traumatic stress disorder (PTSD) (NICE clinical guideline 26).

Adults

General principles of care

NICE CG142 Recommendation 1.1.3

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

Comprehensive (diagnostic, needs and risks) assessment of suspected autism

NICE CG142 Recommendation 1.2.10

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 disabilities)
- 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- and/or hypo-sensory sensitivities

Interventions for challenging behaviour

NICE CG142 Recommendation 1.5.1

Before initiating other interventions for challenging behaviour, address any identified factors that may trigger or maintain the behaviour (see recommendation 1.2.20) 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 1.1.8).

5.3 Current UK practice

The National Autistic Society reported[7] evidence suggesting that 71% of children with autism have a co-existing mental health problem and 40% have 2 or more. Findings from a survey of parents of children receiving care from CAMHS services suggests that a number of parents had experienced staff who had little or no expertise in Autism and how to support a child with co-existing problems. Professionals reported that commissioners were not fully aware of the complex service structure required to identify and manage children with autism and co-existing conditions.

The available current practice information relating to adults in this area focuses primarily on people with learning disabilities, where other physical or mental health conditions are not identified or diagnosed. The Royal College of General Practitioners step by step guide for annual health checks for people with learning disabilities[8] highlights the need for GP’s to be aware of the potential complexity of the health needs of people with learning disabilities. The guide highlights issues concerning “diagnostic overshadowing” where the interaction of physical, behavioural and mental health issues can be difficult to interpret and can lead to illnesses not being diagnosed and treated. This has led to serious conditions being identified too late for successful prevention or cure.

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[7] The National Autistic Society “You Need to Know” 2010

[8] The RCGP, A Step by Step Guide for GP Practices: Annual Health Checks for People with a Learning Disability

6 Suggested improvement area: Services for people with autism

6.1 Summary of suggestions from stakeholders

Several stakeholders highlighted a general lack of service provision for people with autism. Stakeholders suggested there is significant variation in service provision and where services are available, service users and some professionals are not always aware of how to refer or access these. A number of stakeholders made reference to the importance of multi-disciplinary teams. The needs of people with autism vary significantly and in some cases are highly complex and multidimensional. Multidisciplinary teams were deemed to be essential if people with autism are going to have their needs accurately assessed and identified and suitable support packages put in place.

Suggested improvement areas	**Source recommendations**
Local autism multi-agency strategy groups and local specialist community-based multidisciplinary teams	**CG128 1.1.1, 1.1.2 and 1.1.3** **CG142 Adults 1.1.13, 1.1.12** **SCIE guide 43 personalising services p37** **Draft CYP 1.1.2 & 1.1.3**
Access to appropriate advice, support and interventions for individuals and their families following diagnosis	**CG128 1.1 & 1.2** **SCIE Guide 43 p11** **Draft CYP 1.1.1**
Lead professional for each local area	**CG128 1.1.2** **CG142 Adults 1.8.2**

6.2 Selected recommendations from the development sources

Recommendations from the development sources relating to the suggested improvement areas have been provisionally selected and are presented below to inform QSAC discussion.

Children

Local pathway for recognition, referral and diagnostic assessment of possible autism

NICE CG128 Recommendation 1.1.1

A local autism multi-agency strategy group should be set up, with managerial, commissioner and clinical representation from child health and mental health services, education, social care, parent and carer service users, and the voluntary sector.

NICE CG128 Recommendation 1.1.2

The local autism strategy group should appoint a lead professional to be responsible for the local autism pathway for recognition, referral and diagnosis of children and young people. The aims of the group should include:

- improving early recognition of autism by raising awareness of the signs and symptoms of autism through multi-agency training (see tables 1–3 in appendix C)
- making sure the relevant professionals (healthcare, social care, education and voluntary sector) are aware of the local autism pathway and how to access diagnostic services
- supporting the smooth transition to adult services for young people going through the diagnostic pathway
- ensuring data collection and audit of the pathway takes place.

NICE CG128 Recommendation 1.1.3

In each area a multidisciplinary group (the autism team) should be set up. The core membership should include a:

- paediatrician and/or child and adolescent psychiatrist
- speech and language therapist
- clinical and/or educational psychologist.

Organisation and delivery of services

NICE Draft CYP Guideline Recommendation 1.1.2

The overall configuration and development of local services for children and young people with autism should be coordinated by a local autism multi-agency strategy group (for people with autism of all ages) in line with Autism: recognition, referral and diagnosis of children and young people on the autism spectrum (NICE clinical guideline 128) and Autism: recognition, referral, diagnosis and management of adults on the autism spectrum (NICE clinical guideline 142).

NICE Draft CYP Guideline Recommendation 1.1.3

The assessment, management and coordination of care for children and young people with autism should be provided through local specialist community-based multidisciplinary teams ('local autism teams') in line with Autism: recognition, referral and diagnosis of children and young people on the autism spectrum (NICE clinical guideline 128) and Autism: recognition, referral, diagnosis and management of adults on the autism spectrum (NICE clinical guideline 142)

Adults

Structure for the organisation and delivery of care and interventions

NICE CG142 Recommendation 1.1.12

In order to effectively provide care and support for adults with autism, the local autism multi-agency strategy group should include representation from managers, commissioners and clinicians from adult services, including mental health, learning disability, primary healthcare, social care, housing, educational and employment services, the criminal justice system and the third sector. There should be meaningful representation from people with autism and their families, partners and carers

NICE CG142 Recommendation 1.1.13

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).

NICE CG142 Recommendation 1.8.2

Autism strategy groups should be responsible for developing, managing and evaluating local care pathways. The group should appoint a lead professional responsible for the local autism care pathway. The aims of the strategy group should include:

- developing clear policy and protocols for the operation of the pathway
- ensuring the provision of multi-agency training about signs and symptoms of autism, and training and support on the operation of the pathway
- making sure the relevant professionals (health, social care, housing, educational and employment services and the third sector) are aware of the local autism pathway and how to access services
- supporting the integrated delivery of services across all care settings
- supporting the smooth transition to adult services for young people going through the pathway
- auditing and reviewing the performance of the pathway

SCIE Guide 43 p11

Following a diagnosis of autism;

Information-sharing between NHS-based diagnostic services, and local authority/trust, private or voluntary social care providers, needs to be swift and appropriate.

People need good, prompt information about autism, and about where to get support. Who provides what information will vary from area to area, but different organisations must communicate with each other.

Personalisation

SCIE Guide 43 page 37

A personalised approach based on an understanding of the nature of the condition and individual need, sensitively supported by local specialised expertise and multi-agency collaboration, would appear to be more likely to be associated with increased satisfaction and a better outcome for adults with ASC

6.3 Current UK Practice

A national review of service provision for adults with Autism published in 2009 by the National Audit Office[9] (NAO) showed that most local organisations did not have a specific commissioning strategy for adults with autism. Seventy-four per cent of Local Authorities responding to the survey said they and their NHS partners did not have such a strategy, and only 50 per cent reported having a strategic planning group dealing with the needs of adults with autism. The NAO also reported that only 29% of local authorities and NHS bodies that responded to their survey had commissioned specialised autism diagnostic services that should include access to multidisciplinary assessment. Of the GP's that responded,

- 64% said they referred people who they thought might have high functioning autism to adult mental health services
- 19% referred to learning disability services
- 12% didn't know where to refer people
- 10% would refer to a specialist autism diagnostic service

A national survey of local child development teams (CDT's) reviewed progress in implementing the National Autism Plan for Children published in 2001[10]. The report

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[9] NAO "Supporting People with Autism Through Adulthood"

[10] Palmer, E et al (2010) Autism spectrum disorder diagnostic assessments: improvements since publication of the National Autism Plan for Children, Archives of Disabled Children

found that between 2001 and 2007 the number of CDT’s using a multidisciplinary team approach to carrying out assessments had increased from 48% to 93%. Access to different professionals as part of the multidisciplinary team has also improved, but the report did suggest that a number of professionals did not have sufficient capacity to meet the local need which affected waiting times for services.

7 Suggested improvement area: Psychological Interventions

7.1 Summary of suggestions from stakeholders

One stakeholder prioritised the general area of psychological interventions for people with autism. No further details were provided and no supporting information.

The evidence sources identified for this quality standard do include a number of recommendations relating to the use of psychological interventions for people with autism. These recommendations include specific interventions for the core symptoms of autism as well as recommendations about interventions for co-existing conditions alongside autism. The recommendations also include some references to other relevant existing NICE guidelines for co-existing conditions.

Due to the large number of recommendations, it is not appropriate to list them all in this paper. The QSAC are recommended to discuss this area with the specialist committee members to identify any specific issues that may require development into a quality statement under this heading.

8 Suggested improvement area: Pharmacological interventions

8.1 Summary of suggestion from stakeholders

One stakeholder prioritised the general area of pharmacological interventions for people with autism. No further details were provided and no supporting information. A submission from one of the SCM's highlighted the need for staff who are prescribing psychotropic drugs to have specialist training and experience in the use of medication in treating autism and linked conditions.

Suggested improvement areas	Source recommendations
Pharmacological interventions	**CG142 Adults 1.4.13, 1.4.14, 1.4.16, 1.4.21, 1.4.22** **Draft CYP 1.3.3**

8.2 Selected recommendations from evidence sources

Recommendations from the development sources relating to the suggested improvement areas have been provisionally selected and are presented below to inform QSAC discussion.

The recommendations focused on this area can be split into 2 separate themes. The recommendations concerning the use of pharmacological interventions for the core symptoms of autism are all '*do not do'* recommendations. There are some recommendations that do support the use of pharmacological interventions but these relate to treatment of co-existing conditions alongside autism rather than for autism alone. For the purposes of the briefing paper only the recommendations concerning the core symptoms of autism have been included.

Adults

NICE CG142

Recommendation 1.4.13

Do not use anticonvulsants for the management of core symptoms of autism in adults.

Recommendation 1.4.14

Do not use chelation for the management of core symptoms of autism in adults.

Recommendation 1.4.16

Do not use drugs specifically designed to improve cognitive functioning (for example, cholinesterase inhibitors) for the management of core symptoms of autism or routinely for associated cognitive or behavioural problems in adults

Recommendation 1.4.21

Do not use antipsychotic medication for the management of core symptoms of autism in adults.
Recommendation 1.4.22
Do not use antidepressant medication for the routine management of core symptoms of autism in adults

Children and young people

NICE Draft CYP guideline – Recommendation 1.3.3

Do not use the following interventions for the management of core features of autism in children and young people:

- antipsychotics
- antidepressants
- anticonvulsants
- exclusion diets (such as gluten- or casein-free diets).

8.3 Current UK Practice

The National Collaborating Centre (NCC) for Mental Health guideline on Autism in adults[11] includes reference to current practice where medication is used to manage the core symptoms of autism. However, the guideline reports that more usually drugs are used to target coexisting behavioural problems including aggression, irritability, hyperactivity and self-injury. The guideline reports findings from a UK audit of drug use for challenging behaviour in a learning disabilities sample (in which the commonest coexisting diagnosis was autism), 96% were prescribed antipsychotic medication (Marshall, 2004). In another community sample of people with a learning difficulty, Dhumad and Markar (2007) reported that autism was the reason for prescribing antipsychotic medication in 20% of people.
The NCC for Mental Health reports similar practice in the draft guideline concerning the management and support of children and young people on the autism spectrum.

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[11] NICE full guideline Autism NCC for Mental Health (2012)

9 Suggested improvement area: Access to specialist services

9.1 Summary of suggestions from stakeholders

Stakeholders suggested a number of specialist services that people with autism would benefit from being able to access, but where access was limited or unavailable. The services were related to problems many people with autism experience, that have the potential to have a significant impact on their health and wellbeing. The areas identified are listed below alongside identified recommendations from the evidence sources.

One stakeholder suggested the need for specific services to support children and young people with higher functioning autism / Asperger's syndrome. A further suggestion was made about ensuring that appropriate services were available for people no matter where they were on the spectrum and what their IQ was. This stakeholder suggested that in some instances people with higher functioning autism were unable to access services as their needs were not deemed high enough to meet service access thresholds.

Suggested improvement areas	**Source recommendations**
Access to specialist speech and language therapists	**CG128 1.1.3** **CG142 1.1.13** **Draft CYP 1.7.1**
Access to local sleep expert on request	**CG128 1.5.15** **Draft CYP 1.8** **SCIE Guide 43 p14**
Access to autism specific employment support, befriending, advocacy and travel training	**CG142 1.1.4, 1.1.11, 1.1.14, 1.4.11** **SCIE guide 43 p 17** **Draft CYP 1.1.6**
Access to emotional literacy and social interaction development for C&YP with high functioning autism/ Asperger Syndrome	No recommendations were identified
Clear pathway to support regardless of IQ	**SCIE guide 43 p24, p25, p29, p34, p35, p40**

9.2 Selected recommendations from evidence sources

Recommendations from the development sources relating to the suggested improvement areas have been provisionally selected and are presented below to inform QSAC discussion.

Speech and language therapy

Children and young people

NICE CG128 Recommendation 1.1.3

In each area a multidisciplinary group (the autism team) should be set up. The core membership should include a:
- paediatrician and/or child and adolescent psychiatrist
- speech and language therapist
- clinical and/or educational psychologist

NICE draft CYP Guideline Recommendation 1.7.1

Consult a speech and language expert in the autism team when managing receptive and expressive language problems in children and young people with autism (including when they are non-verbal).

Adults

NICE CG142 Recommendation 1.1.13

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).

Sleep disorder

Children and young people

NICE CG128 Recommendation 1.5.15

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: (long list of other conditions are also listed)

- Sleep disturbances

NICE draft CYP Guideline Recommendation 1.8.1

Consult a sleep expert in the autism team when managing sleep problems in children and young people with autism.

Adults

SCIE Guide 43 p14

There are a number of issues often connected to autism, which an assessor should consider:
- sensory issues, both in the room at the time, but also as a factor in determining need other specific learning difficulties or conditions, such as dyslexia or attention deficit hyperactivity disorder (ADHD)
- sleep issues - many people with autism have disrupted sleep patterns, which can be difficult for them and their carers dietary restrictions stresses faced by the carer;
- a separate carer's assessment should be offered - see the Carers section. The needs of siblings should be considered.

Employment support (Adults)

NICE CG142 Recommendation 1.1.11

Ensure that adults with autism who have caring responsibilities receive support to access the full range of mental and physical health and social care services, including:
- specific information, advice and support to parents about their parenting role, including parent training if needed, by professionals experienced in the care of adults and children with autism

- social support, such as childcare, to enable them to attend appointments, groups and therapy sessions, and to access education and employment.

NICE CG142 Recommendation 1.4.11

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.

Advocacy (Adults)

NICE CG142 Recommendation 1.1.4

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.

SCIE Guide 43 p 17

One approach is to provide services in a local, or regional, centre of excellence, a 'one-stop shop' for people with autism, offering:

- training and employment support
- diagnosis services
- consultancy and advice
- outreach to prevent family breakdown
- social groups and skills training
- education
- accommodation advice
- brokerage and advocacy
- support with practical tasks, paperwork and forms.

How to overcome barriers at the organisational level

SCIE Guide 43 Key recommendation for practice

Managers and commissioners of services also need to be flexible, creative and collaborative in how they meet the needs of people of autism. People with autism whose behaviour challenges services, and those with Asperger's Syndrome or high-functioning autism, in particular need better access to services.

SCIE Guide 43 p 40

Local leaders also need to set out where people with high-functioning autism or Asperger's Syndrome, who have often been denied services, get the personalised support they need under the strategy

9.3 Current UK Practice

Sleep

Research referenced by the National Autistic Society suggests that 44-83%[12] of children with autism report sleep problems. No current practice information was identified relating to the provision of sleep disorders services.

Speech and language therapy in children

The Care Quality Commission conducted a review[13] of how health care needs of disabled children and young people are currently being met. The report looked at provision commissioned by PCTs across the country and also included 158 acute Trusts. All PCTs reported that they commissioned a speech and language therapy service that was able to provide support to disabled children and young people with autism and autistic spectrum disorder. However, a national survey of local child development teams (CDT's)14 found that speech and language therapist capacity in many places was too low to meet clinical demands.

Employment services

A self- assessment of local authorities conducted in 2011 found that only 39 local authorities out of 142 that took part in the self-assessment reported providing supported employment services and 13 reported commissioning employment support providers as part of their autism service provision.

Others specialist services for adults

The NAO survey of service provision for autism[15] showed that, while some generic preventative services (such as advocacy and care management/coordination) are being commissioned in the majority of areas, these rarely include specialised autism provision. Only 19 per cent of respondent areas reported any specialised autism care management and co-ordination, only six per cent a mentoring/befriending service specifically for people with autism, and only five per cent a specialised advocacy service. Only 10 per cent of areas have commissioned ongoing support from a specialist team for people with Asperger's Syndrome.

Access to services for people with higher functioning autism / Asperger's Syndrome

Current practice information reported in SCIE guide 43 suggests that people with Asperger's Syndrome or high-functioning autism, can fall between the gaps in social care provision, and sometimes receive little or no social care support, until perhaps their needs escalate to crisis point. The report highlights problems associated with the blocking of people with high-functioning autism or Asperger's Syndrome from social care, because they do not have an IQ of 70 or below, the cut-off point for most

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[12] National Autistic Society 2008

[13] Care Quality Commission: Health care for disabled children

[14] Palmer, E et al (2010) Autism spectrum disorder diagnostic assessments: improvements since publication of the National Autism Plan for Children, Archives of Disabled Children

[15] NAO "Supporting People with Autism Through Adulthood"

learning disability services, or a severe and enduring mental illness, which excludes them from mental health services.

10 Suggested improvement area: Communication and access to information

10.1 *Summary of suggestions from stakeholders*

Three stakeholders suggested that access to information for children and young people with autism and their family or carers was a priority for inclusion in the quality standard. One suggestion referred to the need for verbal and written reports being made available to children, young people and parents or carers about their diagnosis. The other suggestions were focused more on the need for information and support being available for people after diagnosis about the implications and what services are available and how to access them

Suggested quality improvement area	**NICE guidance**
Verbal and written reports to CYP and parents and carers	**CG128 1.8.1 & 1.8.4**
Equitable access to post-diagnostic information, advice and support including liaison between agencies to fulfil their respective roles and responsibilities regarding the child or young person's diagnosis and the wider family's needs	**CG128 1.9.1**

10.2 *Selected recommendations from evidence sources*

Recommendations from the development sources relating to the suggested improvement areas have been provisionally selected and are presented below in inform QSAC discussion.

Communicating the results from the autism diagnostic assessment
NICE CG128 Recommendation 1.8.1

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.

NICE CG128 Recommendation 1.8.4

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.

Information and support for families and carers

NICE CG128 Recommendation 1.9.1

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.

10.3 Current UK Practice

The National Autism Plan for Children (NAP-C) recommended that following a diagnosis a written care plan should be provided to the families of the child. A national survey of child development teams (CDT's) reviewing the impact of the NAP-C reported that one-quarter of CDT's do not offer parents a multidisciplinary feedback discussion. The survey found that this recommendation concerning a written care plan had not been implemented by the majority of services.

The draft NICE clinical guideline on the management and support of children and young people on the autism spectrum looked at the current experience of children, young people and families. The guideline references evidence that parents and carers reported that they require more information about treatment options and the available support from social care services.

The Care Quality Commissions review[16] of how health care needs of disabled children and young people are currently being met reported that the families they spoke to reported a lack of information provision about how different services interacted with each other.

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[16] Care Quality Commission: Health care for disabled children and young people

11 Suggested improvement area: Training for health and social care staff

11.1 Summary of suggestions from stakeholders

A large number of stakeholders and 2 specialist committee members prioritised training for health and social care professionals to raise their awareness of autism and increase their ability to identify and support people who may have autism. Two stakeholders focused specifically on the need for staff working within CAMHS having a better understanding of autism due to the high number of children and young people who will have autism alongside one or more mental health problems. Two other stakeholders made specific reference to training for teachers and other education based professionals. Three suggestions were made about providing training to health, social care and education professionals in making reasonable adjustments for people with autism so services are more accessible.

Suggested quality improvement area	**NICE guidance**
ASC training for CAMHS	**CG128 1.1.2** **Draft CYP 1.1.8**
Health and social care professionals receive training in autism awareness and basic skills in managing autism	**CG128 1.1.2** **CG142 Adults 1.1.2, 1.1.3 & 1.8.2** **Draft CYP 1.1.8** **SCIE guide 43 “Raising awareness”**
Training for early years and teaching staff to identify and make reasonable adjustments for ASD	**Draft CYP 1.1.9**
Mainstream staff are trained in autism to ensure that they can make reasonable adjustments for their needs	**CG142 1.1.8** **Draft CYP 1.1.9** **SCIE guide 43 “Raising awareness” p 9, “Barriers” p 15**

11.2 Selected recommendations from evidence sources

Recommendations from the development sources relating to the suggested improvement areas have been provisionally selected and are presented below in inform QSAC discussion.

Children and young people

Local pathway for recognition, referral and diagnostic assessment of possible autism

NICE CG128 Recommendation 1.1.2

The local autism strategy group should appoint a lead professional to be responsible for the local autism pathway for recognition, referral and diagnosis of children and young people. The aims of the group should include:

- improving early recognition of autism by raising awareness of the signs and symptoms of autism through multi-agency training (see tables 1–3 in appendix C)
- making sure the relevant professionals (healthcare, social care, education and voluntary sector) are aware of the local autism pathway and how to access diagnostic services
- supporting the smooth transition to adult services for young people going through the diagnostic pathway
- ensuring data collection and audit of the pathway takes place.

Knowledge and competence of health and social care professionals

NICE Draft CYP guideline - Recommendation 1.1.8

Health and social care professionals working with children and young people with autism in any setting should receive training in autism awareness and basic skills in managing autism, which should include:

- the nature and course of autism
- the nature and course of behaviour that challenges in children and young people with autism
- recognition of common coexisting conditions, including mental health problems (such as anxiety and depression), physical health problems (such as epilepsy), sleep problems and other neurodevelopmental conditions (such as attention deficit hyperactivity disorder [ADHD])
- the importance of key transition points, such as changing schools or health or social care services
- the child or young person's experience of autism and its impact
- the impact of autism on the family (including siblings) or carers
- the impact of the social and physical environment on the child or young person
- how to assess risk (including self-harm, harm to others, self-neglect, breakdown of family or residential support, exploitation or abuse by others) and develop a risk management plan
- the changing needs that arise with puberty (including the child or young person's understanding of intimate relationships and related problems that may occur, for example, misunderstanding the behaviour of others)
- how to provide individualised care and support.

Making adjustments to the social and physical environment and processes of care

NICE Draft CYP Guideline - Recommendation 1.1.9

Take into account the physical environment in which children and young people with autism are supported and cared for and minimise any negative impact by making reasonable adjustments or adaptations to the:

- amount of personal space given
- setting, using visual supports (for example, words, pictures or symbols)
- colour of walls and furnishings
- lighting
- noise levels
- processes of health or social care (for example, arranging appointments at the beginning or end of the day to minimise waiting time, or providing single rooms for children and young people admitted to hospital).

Adults

Organisation and delivery of care

NICE CG142 Recommendation 1.8.2

Autism strategy groups should be responsible for developing, managing and evaluating local care pathways. The group should appoint a lead professional responsible for the local autism care pathway. The aims of the strategy group should include:

- developing clear policy and protocols for the operation of the pathway
- ensuring the provision of multi-agency training about signs and symptoms of autism, and training and support on the operation of the pathway
- making sure the relevant professionals (health, social care, housing, educational and employment services and the third sector) are aware of the local autism pathway and how to access services
- supporting the integrated delivery of services across all care settings
- supporting the smooth transition to adult services for young people going through the pathway
- auditing and reviewing the performance of the pathway

Principles for working with adults with autism and their families

NICE CG142 Recommendation 1.1.2

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.

NICE CG142 Recommendation 1.1.3

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.

Awareness raising and diagnosis

SCIE guide 43 p9

Training is key, and should:

- cover how to recognise autism, and how to make reasonable adjustments to accommodate people with autism
- be delivered efficiently - this could mean sharing training between organisations, or including autism in general equalities training, for some staff
- be delivered in detail for those conducting assessments, those working directly with people with autism and the managers of these people
- alter behaviour and practice among key professionals - it isn't enough to attend training but then carry on as before
- include input from people with autism and their families
- cover awareness raising about Asperger's Syndrome and high-functioning autism - the lack of support offered to people with autism of these types (**7**) means that staff may have less awareness and experience here, so more needs to be done to redress the balance.

Barriers (Making reasonable adjustments)

SCIE Guide 43 p 15

Contacting social care services, particularly for the first time, can be problematic. When offering services, information or support to people with autism, bear in mind that:

- form-filling and phone calls can be perplexing and a significant obstacle to services
- face-to-face meetings may be disconcerting, as they may involve travel to unfamiliar places to meet unfamiliar people

- some people with autism will feel overloaded with sensory impacts by the time they arrive, and will struggle to focus on the task in hand
- services should therefore be flexible, and support people to choose whatever works for them
- people might miss appointments, and should be reached out to if they do, not denied a service
- services should continuously examine their processes and language, to identify what might form a barrier to people with autism
- people may need to build up the amount of time that they can spend with a new person or build up their trust
- people may need support to identify and ask for reasonable adjustments to services
- much of what makes people with autism anxious and disconcerted about contact with bureaucracy – unhelpful telephone operators, long periods on hold, information not being shared clearly – can also annoy the general population. Getting it right for people with autism need not be an extra burden for organisations; it is something that they ought to be doing anyway.

11.3 Current UK Practice

Training and awareness raising

The NAO review of progress in implementing the National Adult Autism Strategy found that training materials and guidance have been developed on a range of areas with, for example, the aim of improving awareness and understanding among staff working with people with autism; improving the transition between, and promoting reasonable adjustments to, services; and enhancing employment support to help people with autism into work. However the report found no evidence had been collected on the impact the material has had in driving improvements in awareness of autism.

Reasonable adjustments

SCIE guide 43 references its own research that social care staff, among others, do not know enough about autism to identify when someone may have it, or to properly support someone who does. The report also suggests that too many services, when they are offered, are not suitable. Designed either for people with learning disabilities or for people with mental health problems, they lack the specialist knowledge and experience to effectively support people with autism. Learning disability day centres, for instance, will sometimes change activities for the summer months, which can cause people with autism anxiety, and in general they rely on a lot of group activities, which may not work for some people with autism.

12 Suggested improvement area: Respite for parents or carers

12.1 Summary of suggestions from stakeholders

One stakeholder prioritised the need for short breaks and respite care for families who have an autistic child. They suggested that it can be difficult for families leading to loss of quality of life, stress, burn-out and also negative impacts on siblings. The stakeholder suggests that current provision of short breaks/respite care varies across the country, and in many places there are long waiting lists

Suggested quality improvement area	NICE guidance
Short breaks/respite care to families who have an autistic child	**Draft CYP 1.1.6** **CG142 1.7.1**

12.2 Selected recommendations from evidence sources

Recommendations from the development sources relating to the suggested improvement areas have been provisionally selected and are presented below in inform QSAC discussion.

Children and young people

Organisation and delivery of service

NICE Draft CYP Guideline - Recommendation 1.1.6

Local autism teams should have a key role in the delivery and coordination of:

- Specialist care and interventions for children and young people with autism, including those living in specialist residential accommodation
- advice, training and support for other health and social care professionals and staff (including in residential and community settings) who may be involved in the care of children and young people with autism
- assessing and managing behaviour that challenges
- assessing and managing coexisting conditions in autism
- reassessing needs throughout childhood and adolescence, taking particular account of transition to adult services
- supporting access to leisure and enjoyable activities
- supporting access to and maintaining contact with educational, housing and employment services
- **providing support for families (including siblings) and carers, including offering short breaks and other respite care**
- producing local protocols for:

  - information sharing, communication and collaborative working among healthcare, education and social care services, including arrangements for transition to adult services
  - shared care arrangements with primary care providers and ensuring that clear lines of communication between primary and secondary care are maintained.

Adults

Assessment and interventions for families, partners and carers

NICE CG142 Recommendation 1.7.1

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

12.3 Current UK Practice

A survey conducted by the National Autistic Society in 2012[17] highlighted the general lack of support received by carers of people with autism. Of those that took part in the national survey 74% of carers didn't get any support for being a carer. 45% of respondents reported that they would like access to respite care or short breaks.

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[17] The National Autistic Society 'The way we are: autism in 2012.

13 Suggested improvement area: Positive outlook on treatment

13.1 Summary of suggestions from stakeholders

One stakeholder prioritised the need for professionals working with people with autism to not accept that the person has a life-long condition that needs to be managed, rather they are committed to help people “recover” or that “optimal outcomes” are achievable. They argue that the view that autism is, in all cases, a static and lifelong disorder needs to change. They refer to evidence suggesting that positive outcomes are achievable following interventions for autism and that a more accurate understanding of possible outcomes will allow more appropriate care and treatment, with the ultimate goal to give each individual diagnosed with ASD the chance of an optimal outcome.

13.2 Selected recommendations from evidence sources

No recommendations were identified that supported this stakeholder’s suggestion

13.3 Current UK Practice

No current practice information was identified for this topic.

14 Suggested improvement area: Transition

14.1 Summary of suggestions from stakeholders

Several stakeholders and a specialist committee member identified transition between services for children and young people to adult services as an important area for quality improvement. Stakeholders highlighted the need for continuation of care for people with autism and ensuring that the level of support provided to someone moving to adult services is consistent with their on-going needs. One of the suggestions also focused on the need to ensure that the young person and their family or carers are fully involved in the transition process.

Suggested quality improvement area	**NICE guidance**
Good Quality Transition between Children's and Adult services	**Draft CYP 1.10.1 – 1.10.4** **SCIE guide 43 Transitions p29 – 31**

14.2 Selected recommendations from evidence sources

Recommendations from the development sources relating to the suggested improvement areas have been provisionally selected and are presented below in inform QSAC discussion.

Transition to adult services

NICE Draft Clinical Guideline Autism: the management and support of children and young people with autism

Recommendation 1.10.1

Reassess young people with autism who are receiving treatment and care from child and adolescent mental health services (CAMHS) or paediatric services at around 14 years to establish the need for continuing treatment into adulthood. If treatment is necessary, make arrangements for a smooth transition to adult services and give information to the young person about the treatment and services they may need. The timing of transition may vary locally and individually but should usually be completed by the time the young person is 18 years. Variations should be agreed by both child and adult services.

Recommendation 1.10.2

For young people aged 16 or older whose needs are complex or severe, use the care programme approach (CPA) in England, or care and treatment plans in Wales, as an aid to transfer between services. Involve the young person in the planning and, where appropriate, their parents or carers. Provide information about adult services to the young person including their right to a social care assessment at age 18.

Recommendation 1.10.3
As part of the preparation for the transition to adult services, health and social care professionals should carry out a comprehensive assessment of the young person with autism. The assessment should make best use of existing documentation about personal, educational, occupational and social functioning, and should include assessment of any coexisting conditions, especially depression, anxiety, ADHD, OCD and global delay or intellectual disability, in line with Autism: recognition, referral, diagnosis and management of adults on the autism spectrum (NICE clinical guideline 142).

Recommendation 1.10.4
During transition to adult services, consider a formal meeting involving health and social care and other relevant professionals from child and adult services.

Getting Transition right

SCIE Guide 43 p30

During transition, there needs to be:

- full involvement of young people with autism and their families in multi-agency transition planning
- respect given to the preferences of young people with autism
- better information given to families as young people approach transition
- better communication between adults' and children's services. Some local areas are placing Children with Disabilities staff within adult teams to promote joint working; others are adopting a 'single trusted contact' model. Research is needed into whether approaches like this can be effective in improving outcomes
- an opportunity for people placed out-of-area to return home, should they wish
- training in autism for transition staff, including staff working in child and adolescent mental health services, supporting young people with autism and mental health problems to access adult mental health support
- attention paid to the needs of young people with autism who display challenging behaviour (**39**)
- autism training for Connexions workers, and better links between Connexions and social care staff
- differentiation in assessments between support needs and education needs, so that people are not put on academically limited courses due to their communication difficulties
- an underlying assumption, including in specialist schools, that young people with autism, including those with challenging behaviour, can and should lead full lives of their own choosing.

14.3 Current UK Practice

Current practice information seems to suggest that whilst there are a number of directives and policy documents in place concerning the need for transition processes, the reality is that some young people are not experiencing a smooth transition process. This can be of particular concern for young people with autism who have become comfortable with the services and support they received whilst in children and young people's services.

The NAO reported findings from a national survey[18] conducted in 2009 that despite the Special Educational Needs code of practice requiring every child with a Statement of Special Educational Need to have a transition plan prepared in year nine of compulsory education, only 45 per cent of Local Authorities responding to the survey could say they knew how many children with autism and a Statement of Special Educational Needs had a completed transition plan. Only 29 per cent knew for how many a plan was being compiled.

SCIE guide 43 states that at present, 70 per cent of children with autism identified in the special educational needs system have statements of special educational needs, and are thus entitled to transition planning from Year 9 (14 years of age). Despite this, and despite a general consensus that people need personalised, holistic and ambitious transition plans, many young people with autism need to be served better by the transition process.

They face the same problems as other groups during transition, namely:

- difficulties maintaining consistent staffing over the transition period
- lack of communication between professionals in different services
- different services switching to adult services at different ages
- fewer, less well-resourced services in adulthood
- paying for services that were free as a child
- carers feeling excluded from consultations on their now-adult family member.

In addition, some aspects of autism can make transition particularly difficult:

- School provides a structure that many people with autism like, and feel the lack of when they leave.
- Coping with change can be problematic.
- Conceiving of a range of new options can be hard.
- There is chance of falling through the gaps in adult services for people with high-functioning autism and Asperger's Syndrome.
- Adult life and expectations, including the world of personal relationships, can carry new challenges for people with autism.
- There is limited provision of further education options for people with autism, especially those who display challenging behaviour.

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[18] NAO Supporting people with autism through adulthood (2009)

15 Suggested improvement area: Collection of prevalence and service use data

15.1 Summary of suggestions from stakeholders

One stakeholder suggested that collection of standardised data on the number of adults with autism in each local area should be prioritised. They suggest that very little data is collected on adults with autism, or on the impact of services on the lives of adults with autism in local areas. The rationale for prioritising this was to support sharing of data between agencies and to have consistent data across localities to provide a baseline against which progress can be measured.

15.2 Selected recommendations from evidence sources

No recommendations were identified.

15.3 Current UK Practice

Current practice information was provided by the stakeholder that suggested this area. They state that currently, the Department of Health predominately collects social care data through four methods[19]. The data that is collected can be broken down into six demographic categories, namely Learning Disability, Mental Health, Older People, Physical Disability, Other and Carers. Autism does not easily fit into any of these categories and it is therefore impossible to identify a baseline measure to assess progress in service provision and outcomes for adults with autism.

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[19] RAP, ASC-CAR, NIS and PSSEX1 data

Appendix 1 Suggestions from stakeholder engagement exercise

See separate document