HSC Health and Social Care Board

Autism
Adult Care Pathway

Regional Autistic Spectrum Disorder Network
(RASDN)

Revised September 2013

Acknowledgements

Alternative Formats

This report can also be made available in alternative formats such as; large print, computer disk, Braille, audio tape or translation for anyone not fluent in English.

Please contact the Communications Office at the Health and Social Care Board on (028) 9055 3740.

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1.0   Overview

The Regional Autistic Spectrum Disorder Network (RASDN) was established to take forward the Department of Health, Social Services and Public Safety's (DHSSPS) Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/09 –2010/11 (June 2009). The Action Plan was developed in response to the recommendations outlined in the Independent Review of Autism Services (2007) across Northern Ireland set up by the then Minister for Health, Social Services and Public Safety.

1.1   Regional Autistic Spectrum Disorder Network (RASDN)

The objectives of RASDN were to implement the DHSSPS's three year ASD Strategic Action Plan 2008/09 – 2010/11. This Action Plan includes specific recommendations in relation to:

- ➢ service design/redesign to improve autism care;
- ➢ performance improvement;
- ➢ training and awareness raising;
- ➢ communication and information; and
- ➢ effective engagement of partnership working.

RASDN comprises representatives from the Health and Social Care Board (HSCB), Public Health Agency (PHA), five Health and Social Care (HSC) Trusts, Regional Reference Group members including parents/carers and service users, and voluntary organisations working with children, young individuals and adults with autism and their families/carers), DHSSPS and the Department of Education/Education and Library Boards.

This Adult Care pathway document has been developed as part of the service redesign to improve autism care.

1.2   Purpose of the Adult Care Pathway Document

The Adult Care Pathway provides guidance to professionals, adults and families on autism. It aims to cover the identification and diagnosis of autism, on-going assessment and access to support and services for adults of all ages with autism.

The document applies to all adults from 18 years of age, and takes account of the period of transition from childhood to adult services. It

follows on from the children's pathway Six Steps of Autism Care (for children and young individuals in Northern Ireland) HSCB October 2011. The care pathway takes account of the equality categories in particular age, gender, cultural issues, disability, sexual orientation and family relationships. The Care Pathway recognises that adults with autism from black and minority ethnic communities groups may face difficulty in accessing services.

1.3   Definition

This definition is taken from NICE Guidance 2012

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

In this Care Pathway 'autism' refers to 'autism spectrum disorders' encompassing autism, Asperger's syndrome and atypical autism (or pervasive developmental disorder not otherwise specified)

Autism prevalence in the adult population is estimated to be 1.1%, Dr Terry Brugha, Professor of Psychiatry at the University of Leicester in Estimating the Prevalence of Autism Spectrum Conditions: Extending the 2007 Adult Psychiatric Morbidity Survey (2012).

There is an increasing number of adults not previously known to services, who have features of autism, but these do not cause significant clinical difficulties or impairments. Referral to specialist diagnostic services will only be accepted for those individuals who have clinically significant challenges. Individuals who do not meet the set threshold will be signposted to other supportive services.

1.4 Individuals Presenting in Adulthood

A range of individuals who may present for an autism assessment in adulthood:-

a) Individuals who were in receipt of services in childhood but for whom an assessment for autism was not completed. This may have been for a number of reasons including 'diagnostic overshadowing' whereby difficulties displayed were attributed to an individual's learning disability or mental health or behavioural condition.

b) Individuals whose difficulties first present in adulthood.

c) Individuals who may have been 'coping' due to their family support or their own capabilities, those masking difficulties who have struggled through but find that in adulthood, without the structured environment of school, they are unable to cope.

1.5 Key Strategic Drivers

The Adult Care Pathway incorporates local and regional policies, and reflects the principles as noted within the following publications:

- ➢ Autism Act (Northern Ireland) 2011

- ➢ Bamford Review of Mental Health and Learning Disability (Northern Ireland)

- ➢ HSCB Transforming Your Care – A Review of Health and Social Care in Northern Ireland, (2011);

- ➢ DHSSPS, Service Framework for Mental Health and Wellbeing (2010-11);

- ➢ DHSSPS, Learning Disability Service Framework (2011-12) Draft;

- ➢ National Institute for Health and Clinical Excellence(NICE) Guidance: Autism Recognition, Referral, Diagnosis and Management of Adults on the autistic spectrum. CG 142 June 2012.

It is acknowledged that this Care Pathway is being implemented in circumstances that are challenging in terms of the overall financial position within HSC Trusts and general deficits in terms of dedicated autism provision within adult services.

While significant investment would be required to support full implementation of the Pathway it is nevertheless important to identify in each local Trust area the 'initial steps' that will be taken towards realisation of the Pathway. The HSCB will regularly monitor progress towards full implementation of the Pathway and endeavour to secure new resources where possible.

1.6　Guiding Principles

The development and implementation of this pathway is based on a number of agreed guiding principles, including the following:

- **Person centred approach:(** Appendix 1**)** any care and support – as well as the diagnostic process - will take into account individuals'' needs and preferences. Individuals with autism should have the opportunity to make informed decisions about their care and identified support needs, in partnership with their health and social care professionals;

- Practice should be guided by the **recovery concept** (Appendix 2) where recovery is about building a meaningful and satisfying life, as defined by the person themselves, whether or not there are on-going or recurring symptoms or problems;

- The establishment and promotion of clear**, consistent pathways**, which focus on improving specialist diagnostic assessment for adults and includes effective transition into adult services/life;

- Access **to specialist assessment** for adults with possible autism who experience significant distress impairment in social-communication skills with repetitive/restricted behaviour and interests;

- The **regional standardisation** of models, referrals, best practice protocols　　and　processes

- A **multi-disciplinary/cross agency approach** to provide post diagnostic support;

➢ Working **in partnership with adults with autism** and their families/carers;

➢ Supporting the continuous professional development of relevant HSC professionals, including, where appropriate, workforce redesign.

1.7   Outcomes

The following key outcomes are sought:

➢ Improved access to information about autism and available services;
➢ Access to a multi-disciplinary and integrated assessment,
➢ Involvement of individuals and their families in all stages of the assessment and care planning process;
➢ Holistic assessment of need which is translated into person centred plans
➢ Support for carers in their caring role (including young carers);

Outcomes for Service Users:

➢ Improved quality of life, as identified by the service user;
➢ Inclusion as a valued and respected member of society;
➢ Improved functioning in social/educational/employment settings;
➢ Improved experience of care, support arrangements and of community life;
➢ Higher levels of individual satisfaction;
➢ Identified individual needs are met;
➢ Greater control over one's own life.

Outcomes will be measured through existing measurement tools used within Trusts including the CORE and Recovery Star and will include the service user's perspective of achievement of their own identified goals.

1.8　The Proposed Model

- ➢ Pre-referral:
- ➢ Referral and screening*;*
- ➢ Assessment and Diagnosis: *specialist diagnostic teams;*
- ➢ Post diagnosis support;
- ➢ Review as required;
- ➢ Discharge

Each of these will be discussed in full in the following sections.

Autism Adult Care Pathway Flow Chart

Person has difficulties which suggest possible Autism – difficulties which significantly impair daily functioning
Standard ASD Referral Form Completed

Screening Assessment Completed

N → **Discharge** from ASD Service and signpost to alternative services

Y

Referral accepted by Specialist Autism Multi-Disciplinary Team/Teams
Assessment completed

Inconclusive evidence about diagnosis

ASD not confirmed as present

Further targeted assessment completed

ASD confirmed as present

Discharge from ASD Service and signpost to alternative services

ASD confirmed as not present

Person-Centred Plan
- Support
- Interventions

Discharge from ASD Service and signpost to

2.0 Making a Referral

Individuals who have social and personal characteristics indicative of autism have different experiences of how these features impact on their everyday life; they may allied difficulties - learning disability, mental health or behavioural difficulties.

2.1 Pre-Referral

If an individual has a concern about their condition they should meet with their General Practitioner (GP) or health professional, in the first instance.

At the pre-referral stage, health and social care professionals should identify
 (i)   those concerns that specifically suggest the possibility that the individual may have autism, and

 (ii)   (ii) the degree to which the person's daily functioning is impaired. They may also sign post to appropriate support offered by voluntary and community sector agencies.

Individuals being referred for an autism assessment must provide their consent , where they have the capacity to do.

The individual and their families/ carers, will be provided with information regarding the assessment and diagnostic processes within the HSC Trust and, where possible, the person(s) who will be involved in any planned assessments.

Individuals with autism will be involved in decisions about their care and support in partnership with their health and social care professionals. If adults with autism do not have the capacity to make decisions, health and social care professionals should follow the Department of Health and Social Services Guide on Seeking Consent www.dhsspsni.gov.uk/**consent**-guidepart

2.2 Referral and screening

A referral should be made in accordance with standardised referral criteria as follows:

1. Adults must be resident in the HSC Trust's geographical area and registered with a GP.

2. Where the individual is able to give valid and informed consent, this must be obtained prior to referral.

3. The individual must be over 18 years of age on receipt of referral.

4. Referrals must state that there is a concern about autism. They should include supporting evidence/examples in keeping with diagnostic criteria as to the reasons for requesting specialist assessment. The assessment process will be delayed if sufficient relevant information is not provided when making a referral.

5. Adults who have significant levels of difficulty in daily functioning are suitable for specialist diagnostic assessment.

6. All HSC Trusts should have referral pathways to the specialist diagnostic team. Depending upon HSC Trust structures, initial referral should be forwarded to one of the following:

    ➢ Learning Disability Service – when the individual has a known or suspected diagnosis of learning disability;
    ➢ Mental Health Service Single Point of Access – whether the individual has a mental health condition or not;
    ➢ One point of access, where available.

7. Referrals must be made on the standardised Referral Form (Please see **Appendix 4** for a copy).

3.0 Integrated Multi-Disciplinary Assessment

3.1   The Multi-disciplinary Team

An autism assessment must be team- based and draw upon a range of professionals who have specialist autism training and skills to provide a holistic opinion.

The core assessment team should include at least two of the following professionals to allow for effective multidisciplinary working:

- ➢ Clinical Psychology;
- ➢ Psychiatry;
- ➢ Speech and Language Therapy;
- ➢ Nursing (Learning Disability/ Mental Health);
- ➢ Occupational Therapy;
- ➢ Other appropriately trained professionals with relevant knowledge and expertise.

It is imperative that at least one professional involved has considerable experience of co-occurring conditions and/ or differential diagnoses. Clinical Psychology is a core element of the multi-disciplinary team with psychiatry consultation being required in more complex cases. Each multidisciplinary team member should understand in full the profession-specific roles and responsibilities of the overall team.

3.2   Diagnostic Assessment

The purpose of diagnostic assessment is to determine if difficulties meet the criteria for a diagnosis of autism, as outlined within NICE guidance CG 142 (2012).

It is agreed that there should generally be four core elements within the diagnostic process:-

1. A neuro-developmental history, obtained via corroborating interview with family/relative.
2. A direct, autism-specific assessment with the individual, including consideration of possible differential diagnoses.
3. Observational recording of assessment session(s), specifically detailing any indicatives of autism.
4. The exercise of clinical judgement in respect of the sum of the information collected.

As an absolute minimum, elements 2,3 and 4 *must* be included in the assessment**.** Whilst important and desirable, it is accepted that element 1 (a corroborating interview) may not be obtainable in some exceptional cases.

Diagnostic assessment may also be gathered from the following:

- Standardised measure of adaptive functioning - this will include assessment of the individuals' functioning in different environments (home environment, education and work setting);
- Assessment of communication and language skills;
- Comprehensive functional assessment of any problematic behaviour

The above information may be obtained from the diagnostic assessment process or may require onward referral for further assessment. Where further assessment information is required, the individual and his/her carers (where relevant) and the referral agent will be advised as to the nature of further assessment and the relevant timeframes.

This period of further assessment will be time-limited and will focus upon individual need and may include:

- Seeking further information to contribute to the autism assessment or intervention.
- Seeking further information to rule-out other possible diagnosis (for example, management of psychotic symptoms to facilitate a clearer presentation).

3.3   Full Needs Assessment

A full needs assessment for the individual with autism should be strengths based and include assessment of differential diagnosis and/or co-existing conditions such as:

- Other neuro-developmental disorders such as learning disability or attention deficit hyperactivity disorder, developmental co-ordination difficulty;
- Mental health conditions such as schizophrenia, depression, anxiety disorders, particularly social anxiety disorder, personality disorder and obsessive compulsive disorder;
- Neurological disorders such as epilepsy or Tourette's Syndrome;
- Physical health problems;

- Communication difficulties, for example, specific speech and language disorders, such as selective mutism ;
- Sensory processing difficulties, such as hyper or hypo-sensory sensitivities;
- Behaviours which are challenging;
- Dependence on alcohol or other substances;

Upon collation of the available evidence, and where a definite diagnostic opinion cannot be given, the autism diagnosis may be put on hold to allow further intervention (for example, management of psychotic symptoms). This period should be time-limited.

All individuals are entitled to a community care assessment regardless of age, disability, ethnicity, gender (including transgender), religion or belief or, sexual orientation.

Assessment should include the assessment of risks which may include
- self-harm (in particular, in individuals with depression or moderate or severe intellectual disability);
- harm to others;
- self-neglect;
- breakdown of family or residential support;
- deterioration of situation;
- exploitation or abuse by others.

HSC Trusts will develop a risk management plan, if needed. Please see the Promoting Quality Care Guidelines at
http://www.dhsspsni.gov.uk/mhld-good-practice-guidance-2010.pdf

3.4   Outcomes of Specialist Autism Assessment

The diagnostic team, will finalise their opinion and develop a recommendation as to whether or not the adult meets the diagnostic criteria for autism.

3.5   Independent sector diagnosis

Where a person presents with a diagnosis from **an independent sector diagnostician** or has a historic diagnosis, the diagnosis should be in keeping with the regional pathway diagnostic standards set out in this document.   Where this is not the case, a referral to the specialist diagnostic team will follow. (It is important that any potential delay/

waiting time associated with accessing Trust assessment services, does not become a barrier to addressing individual needs which may require immediate attention).

4.0 Diagnostic Outcomes

Assessment may result in three possible outcomes:

1. A diagnosis is confirmed as present.

2. The diagnosis is confirmed as not present. In this instance, the individual, his/her GP, and (with the appropriate agreement and consent) any relevant others should be notified accordingly. The individual may be referred on to other services, depending upon his/her particular needs and presentation.

3. A diagnosis of autism is uncertain or inconclusive. A recommendation may be made to access a second opinion or to complete a re-assessment following a period of time (at which point it may be possible to arrive at a conclusive finding).

4.1 Post Diagnostic Meeting and Person Centred Plan

Following diagnosis, the individual (and their carer, if appropriate) will be invited to attend a meeting with the diagnostic team. The specialist diagnostic team will discuss the diagnosis. A report will be produced which will contain recommendations – including, where appropriate, a referral to, or information about, the availability of other relevant statutory, voluntary or community services.

A copy of the final report will be provided to the individual and the individual's carers (subject to the individual's consent) and all relevant professionals within six weeks of the assessment.

A Person-centred Plan will be drawn up with those individuals who are identified as being on the spectrum, and carer (if involved) and a named worker from core services. This should address the individual's needs and identify immediate priorities for support, and map out a process to bring together the input of relevant agencies and services.

Where autism diagnosis is not evident the clinicians will meet with the individual and their carer to explain the basis for their conclusions and discuss possible referral to other services/agencies.

Occasionally, an individual may clinically fulfil the criteria for a diagnosis of autism. They may however feel reluctance or decide not to accept the 'diagnostic label'. In such situations, the individual should still be offered support –depending on their identified needs and preferences.

4.3   Involving Families and Carers

The multi-disciplinary team should discuss with the adult who has autism if and how they want their families or carers to be involved in their care. If the person with autism wants their family or carer(s) to be involved, this should be supported. The team should negotiate between the person with autism and their family or carer(s) about confidentiality and sharing of information on an on-going basis.

Families/carers should also be provided with information about local support groups and services specifically for carers, and be advised about how to access these. They should also be advised of their right to a formal Carer's Assessment.

If a person with autism does not want their family or carer(s) to be involved in their care, the family or carers should be given verbal and written information about autism, and advised about who they can contact if they are concerned about the person's care and support.

5.0   Post Diagnostic Follow-Up Support

5.1   Support to individuals and their families

Individuals with autism often require support across a range of areas including education and training, employment, housing and benefits. This requires effective interagency working across a range of statutory and third sector organisations.

Information on support services should be made available to each individual with autism and to their Carers. Based on the assessed and expressed support needs of the individual, support needs will be identified, targets will be set including provision to be made as part of Person Centred Plan. Discussion about support should be carried out in partnership with the individual and their families (where relevant) through a process of a two-way engagement. Support should be incorporated into the individual's Person Centred Plan and should set out the key elements required to meet the support needs of the individual.

A separate guidance document entitled 'HSCB Autism Support Across the Lifespan'(updated February 2013 offers more detailed information in this area.

5.2 Support Options

These may include:

- ➤ Access to Training and employment
- ➤ Advocacy;
- ➤ Condition-specific information;
- ➤ Communication strategies;
- ➤ Education based interventions;
- ➤ Environmental adaptations and sensory processing strategies;
- ➤ Family support programme;
- ➤ Financial signposting;
- ➤ Life coaching
- ➤ Mental health and well-being promotion based on Recovery;
- ➤ Psychological and behavioural support ;
- ➤ Personalisation/self-directed support;
- ➤ Support to live independently in the community;
- ➤ Suitable housing;
- ➤ Voluntary and community sector support

5.3 Specific or Targeted Interventions

Within the field of autism there are a broad range of interventions and treatments promoted to address the key symptoms of the condition. It is noted however, that for many such interventions the evidence base for adults is still emerging and conclusive findings regarding the efficacy of specific interventions is sparse.

The intervention(s) that may potentially be of benefit to an individual will vary from person to person and be dependent upon the individual's assessed need and the presence of any co-occurring difficulties. The range of possible interventions to be considered can include:

- Autism information and literature will be made available for adults and their family/carers in order to enhance understanding of autism and empower individuals to optimise their development and life choices.

- Cognitive Behaviour Interventions which are often used to treat co-existing mental health problems such as social anxiety, depression and obsessive compulsive disorder; or to enhance skills development for example, teaching decision making skills and problem solving skills.

- Social skills programmes designed to enhance skills such as conversational skills, understanding social roles and relationships and developing self-confidence.

- Integrated programmes combining several of the above interventions.

- Support for developing Independent living skills

Finally, it is recommended that individuals with autism should be made aware of the benefits of using a 'Health Passport' (self-advocacy booklet). The health passport should be part of the individual's Person-Centred Plan, and provide information regarding the individual's care needs and agreed intervention/support plan.

5.4   Review and On-going Support

Once the Person Centred Plan is agreed, the named contact person/key-worker within the HSC Trust will facilitate reviews with the individual and their carer(s), as required and remain a central point of contact for future enquiries or concerns.

It is important that the Review process will involve the service user, the carer(s) and the service providers / other agency staff as appropriate;

The purpose of the Review is to:

- Share information on progress towards identified goals and support needs;

- Consider the level of the individual's needs and risks

- Review the goals achieved and further needs

- Update the Person Centred Care Plan based on the review

- Arrange/facilitate appropriate support.

As indicated in 5.1 above, individuals with autism often require support across a range of areas including; education and training, employment, housing and benefits. This requires effective interagency working across a range of statutory, voluntary and community sector

6.0 Transitions – From Children's To Adult Services In
Health and Social Care

Families frequently report the considerable difficulties experienced during the transition between children's and adult services. The meaningful involvement of young individuals and parents or carers is the key to successful transition planning. Parents require good and timely information, advice and guidance about how to plan for their young person's transition to adulthood.

Care of young individuals in transition between paediatric services/child and adolescent mental health services (CAMHS) and adult services should be planned and managed according to the best practice guidance described in Northern Ireland Children and Young People's Plan Transition to Adulthood of Young People with Disabilities Action Plan 2011-2014 Regional Sub Group Transition to Adulthood of Young People with Disabilities DRAFT (April 2013)

Review of Document

This Adult Care Pathway document will be reviewed and re-issued in June 2015.

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8.0 Appendices

➤ Appendix 1 – Person Centred Approaches

➤ Appendix 2 - Recovery Principle

➤ Appendix 3 – DSM-5 Criteria and Severity-Levels for ASD (Proposal)

➤ Appendix 4 – Standardised Referral Form

➤ Appendix 5 – Commonly Used Assessment Measures for Adults with Possible Autism

Appendix 1: Person Centred Approaches

Person centred approaches are ways of commissioning, providing and organising services rooted in listening to what individuals want, to help them live in their communities as they choose. These approaches work to use resources flexibly, designed around what is important to a person from their *own* perspective and work to remove any cultural and organisational barriers to this. Individuals are not simply placed in pre-existing services and expected to adjust, rather the service strives to adjust to the person. Person centred approaches look to mainstream services and community resources for assistance and do not limit themselves to what is available within specialist learning disability services. They strive to build a person centred organisational culture, where each organisation:

➢ Considers it as essential to listen and respect the views of the person;

➢ Focuses on action that will change individuals' lives;

➢ Encourages creative thinking;

➢ Supports active problem solving and a "we can do it" approach;

➢ Encourages and values everyone's contribution;

➢ Encourages staff to use their initiative and make decisions;

➢ Promotes partnership working;

➢ Looks beyond the organisation to create new opportunities;

➢ Welcomes ideas and new developments;

➢ Encourages flexible use of resources to make things happen;

➢ Has a clear commitment to equal opportunities;

➢ Fosters a sense of "ownership" in relation to the quality of support provided.

Person Centred Planning

Definition:

"We all think about, and plan our lives in different ways. Some people have very clear ideas about what they want and how to achieve it; others take opportunities as they arise. Some people plan and then see how they can match their plans to reality.

Sometimes it is useful to plan in a structured way, and person centred planning provides a family of styles that can help do this. Person centred planning is not just about services, or disability, it is something that everyone can use to plan their lives."

O' Brien and Lovett (1992) reported in Sanderson (2000)

Person centred planning is a process for continual listening and learning, focussing on what is important to someone now and in the future, and acting upon this in alliance with their family and friends. This listening is used to understand a person's capacities and choices. Person centred planning is the basis for problem solving and negotiation to mobilise the necessary resources to pursue a person's aspirations. These resources may be obtained from someone's own network, service providers or from non-specialist and non-service sources.

There are five key features of person centred planning that help to distinguish it from other forms of planning and assessment:

1.	The person is at the centre.

2.	Family members and friends are full partners.

3.	Person centred planning reflects the person's capacities, what is important to the person (now and for their future) and specifies the support they require to make a valued contribution to their community.

4.	Person centred planning builds a shared commitment to action that will uphold the person's rights.

5.	Person centred planning leads to continual listening, learning and action, and helps the person to get what they want out of life.

Appendix 2: Recovery Principle

Definition:

"Recovery is about building a meaningful and satisfying life, as defined by the person themselves, whether or not there are ongoing or recurring symptoms or problems" (Shepherd, Boardman and Slade 2008).

Principles

> ➢ Recovery focuses on a person's right to build a meaningful life for themselves with or without the continuing presence of mental ill health.
> ➢ Recovery is about a person's self-determination and self-management.

Recovery is a philosophical concept which recognises the strengths of each individual and acknowledges that with empowerment and support they can live full and meaningful lives, despite symptoms and characteristics which may continue to be difficult to manage.

The recovery ethos should enable users to understand and cope with their mental health problems, build on their inherent strengths and resourcefulness, establish supportive networks and pursue dreams and goals that are important to them and to which they are entitled as citizens (Vision for Change 2006). It is essential for those who use services to be active participants in their own recovery rather than passive recipients of 'expert' care.

In Northern Ireland, the Reform and Modernisation of Mental Health and Learning Disability Services Review recommended that the recovery approach should be at the centre of all mental health services.

http://www.dhsspsni.gov.uk/service_framework_for_mental_health_and_wellbeing_-_

Appendix 3:

Proposed DSM-5 criteria for autism spectrum disorders
https://sfari.org/news-and-opinion/news/2012/proposed-dsm-5-criteria-for-autism-spectrum-disorders

An individual must meet criteria A, B, C and D:

A. Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and manifest by all 3 of the following:
1. Deficits in social-emotional reciprocity; ranging from abnormal social approach and failure of normal back and forth conversation through reduced sharing of interests, emotions, and affect and response to total lack of initiation of social interaction.
2. Deficits in nonverbal communicative behaviours used for social interaction; ranging from poorly integrated- verbal and nonverbal communication, through abnormalities in eye contact and body-language, or deficits in understanding and use of nonverbal communication, to total lack of facial expression or gestures.
3. Deficits in developing and maintaining relationships, appropriate to developmental level (beyond those with caregivers); ranging from difficulties adjusting behaviour to suit different social contexts through difficulties in sharing imaginative play and in making friends to an apparent absence of interest in people.

B. Restricted, repetitive patterns of behaviour, interests, or activities as manifested by at least two of the following:
1. Stereotyped or repetitive speech, motor movements, or use of objects; (such as simple motor stereotypies, echolalia, repetitive use of objects, or idiosyncratic phrases).
2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behaviour, or excessive resistance to change; (such as motoric rituals, insistence on same route or food, repetitive questioning or extreme distress at small changes).
3. Highly restricted, fixated interests that are abnormal in intensity or focus; (such as strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
4. Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment; (such as apparent indifference to pain/heat/cold, adverse response to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects).

C. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities)
D. Symptoms together limit and impair everyday functioning

Severity-Levels

Severity level	Social communication	Restricted interests and repetitive behaviours
Level 3 'Requiring very substantial support'	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning; very limited initiation of social interactions and minimal response to social overtures from others.	Preoccupations, fixated rituals and/or repetitive behaviours markedly interfere with functioning in all spheres. Marked distress when rituals or routines are interrupted; very difficult to redirect from fixated interest or returns to it quickly.
Level 2 'Requiring substantial support'	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions and reduced or abnormal response to social overtures from others.	RRBs and/or preoccupations or fixated interests appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress or frustration is apparent when RRB's are interrupted; difficult to redirect from fixated interest.
Level 1 'Requiring support'	Without supports in place, deficits in social communication cause noticeable impairments. Has difficulty initiating social interactions and demonstrates clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions.	Rituals and repetitive behaviours (RRB's) cause significant interference with functioning in one or more contexts. Resists attempts by others to interrupt RRB's or to be redirected from fixated interest.

ICD-10 Criteria for "Childhood Autism"<superscript>*</superscript>

A. Abnormal or impaired development is evident before the age of 3 years in at least one of the following areas:
1. receptive or expressive language as used in social communication;
2. the development of selective social attachments or of reciprocal social interaction;
3. functional or symbolic play.

B. A total of at least six symptoms from (1), (2) and (3) must be present, with at least two from (1) and at least one from each of (2) and (3)

1. Qualitative impairment in social interaction are manifest in at least two of the following areas:
a. failure adequately to use eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction;
b. failure to develop (in a manner appropriate to mental age, and despite ample opportunities) peer relationships that involve a mutual sharing of interests, activities and emotions;
c. lack of socio-emotional reciprocity as shown by an impaired or deviant response to other people's emotions; or lack of modulation of behaviour according to social context; or a weak integration of social, emotional, and communicative behaviours;
d. lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g. a lack of showing, bringing, or pointing out to other people objects of interest to the individual).

2. Qualitative abnormalities in communication as manifest in at least one of the following areas:
a. delay in or total lack of, development of spoken language that is not accompanied by an attempt to compensate through the use of gestures or mime as an alternative mode of communication (often preceded by a lack of communicative babbling);
b. relative failure to initiate or sustain conversational interchange (at whatever level of language skill is present), in which there is reciprocal responsiveness to the communications of the other person;
c. stereotyped and repetitive use of language or idiosyncratic use of words or phrases;
d. lack of varied spontaneous make-believe play or (when young) social imitative play

3. Restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities are manifested in at least one of the following:
a. An encompassing preoccupation with one or more stereotyped and restricted patterns of interest that are abnormal in content or focus; or one or more interests that are abnormal in their intensity and circumscribed nature though not in their content or focus;
b. Apparently compulsive adherence to specific, non-functional routines or rituals;
c. Stereotyped and repetitive motor mannerisms that involve either hand or finger flapping or twisting or complex whole body movements;
d. Preoccupations with part-objects of non-functional elements of play materials (such as their odour, the feel of their surface, or the noise or vibration they generate).

C. The clinical picture is not attributable to the other varieties of pervasive developmental disorders; specific development disorder of receptive language (F80.2) with secondary socio-emotional problems, reactive attachment disorder (F94.1) or disinhibited attachment disorder (F94.2); mental retardation (F70-F72) with some associated emotional or behavioural disorders; schizophrenia (F20.-) of unusually early onset; and Rett's Syndrome (F84.12).

***World Health Organization. (1992).** *International classification of diseases: Diagnostic criteria for research* **(10th edition). Geneva, Switzerland:**

http://www.iancommunity.org/cs/autism/icd10_criteria_for_autism

Appendix 4: Standardised Referral Form

Referral to the Adult Autism Spectrum Disorder Diagnostic Service

The Adult Autism Spectrum Disorder Diagnostic Service accepts referrals of individuals from the age of 18 years who present with signs which suggest that they may fall within the Autism Spectrum and have difficulties functioning. Referrals which fail to meet the specified criteria will be declined.

Please note that referrals for assessment can be accepted only where the purpose of the referral (i.e. assessment for Autism Spectrum Disorder) has been fully discussed with the client and consent has been agreed. Please √ to confirm this has been done

Confirm if known to Trust Services   Yes ☐   No ☐   Service _____

Personal Information

Name:	**D.O.B:**
Age:	**Gender:**
Language(s) spoken at home:	
Full Address (With Postcode):	**Telephone number:**
Contact Person(s) and Relationship to Client: (if applicable)	**Telephone number:**
General Practitioner: **Surgery Address:** **Postcode:**	**Telephone number:**

Reason for Referral (specific concerns to be provided overleaf: (Note any reasons why clarification of a possible ASD Diagnosis is likely to be helpful)

Professionals / Agencies Involved

Professionals/Agencies CURRENTLY Involved	Professionals/Agencies PREVIOUSLY Involved
Daycare/School/Education/Work/Training CURRENTLY Involved	**Previous School/ Educational Attainments Any Statement of Special Educational Needs?**

Risk Assessment:

	Past	Current		Past	Current	Additional comment on risk:
Self Harm			**Alcohol abuse**			
Suicidal Ideation			**Forensic**			
Neglect			**Aggression**			
Drug Abuse			**Violence**			

Please state specific concerns/possible indications of ASD:

Development: Was there evidence of any developmental delay? Were all developmental milestones achieved? Please provide details if available:

Communication ability: (e.g. Level of understanding/expressive language; non verbal communication; unusual characteristics of communication)

Quality of social functioning / social interaction with family / peers / strangers:

Concerns re: restricted interests/leisure activities:

Activities of daily living: (e.g. degree of independence, awareness of danger)

Behavioural concerns: (e.g. poor sleep; dietary concerns; aggression/self harm; obsessive behaviours; coping with change)

Psychological / Medical / additional needs: (to include co-morbid concerns and medication)

Other information e.g. (list any issues or concerns that might potentially influence the assessment:

Referred by:

Name: **Profession:**
Address: **Telephone number:**

Signature: _____   **Date:** _____

Please return completed form to:

Date Received: _____   **System Logged:** _____

Health and Care Number: _____

Appendix 5: Commonly Used Assessment Measures for Adults with Possible Autism

Area of Assessment	Commonly Used Measures	Comments
Screening – to be conducted by referral agent	Gilliam Asperger's Disorder Scale (2001) Gilliam Autism Rating Scale-2 (2006) Adult Autism Spectrum Quotient (2001) *Australian Scale for Asperger's Syndrome (Modified Meyer, 2000) *Screening measure for autism in adults (NAS) Autism Spectrum Questionnaire (AQ-10, British version)+	Many screening tools have been developed for children presenting with possible autism, but may be helpful with adults if appropriately adapted by the interviewer. A number of scales (those marked with an *) are available for downloading, whilst others are copyrighted and must be purchased before use.

ASD-specific assessment: 1 - History	Neuro-developmental history ADI-R DISCO Asperger's Syndrome Diagnostic Interview (ASDI) – Gillberg, 2001+ Ritvo Autism Asperger Diagnostic Scale – Revised (RAADS-R) – Ritvo, 2011+	Historical information is important to obtain when possible, but it may not always be available. Information from other sources, including school reports, may be helpful. There is no firm evidence-base in favour of any particular framework for history taking. The headings within either diagnostic system provide a framework for the ASD- specific developmental history.
2.-Direct assessment	*Standardised assessment* Cognitive and neuro-psychological assessment The Awareness of Social Inference Test *Non-standardised and qualitative assessment* Happe Strange Stories Test	For adults confirmed or suspected of having a Learning Disability, assessment of intellectual functioning will be essential. In other cases, such assessment may provide valuable information about the individual's cognitive profile and executive functioning. Specific underlying cognitive deficits are often postulated to be at the core of observed symptoms of ASD – theory of mind, executive functioning deficit, weak central coherence, etc. A range of qualitative assessments may be used to elicit such information Self-rating scales on friendship, stress, empathy, feelings, self-esteem, social skills, anger management and

		emotional regulation may also be useful to complete
	Social Stories Questionnaire Sequencing Idioms and humour	
3 - Observation	Autism Diagnostic Observation Schedule – Generic (ADOS-G) – Lord, 2000 Observation in the clinic setting by an ASD-experienced professional (or one in training)	Contemporaneous observational recording *must* take place in a clinic setting, and *may* be useful in other structured and/or unstructured settings as well (for example, in the person's place of work, day placement or hospital)

+ Endorsed by NICE Guidelines