

# ASD Assessment and Diagnosis

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## I think my child may have a dual diagnosis, what should I do?

As a parent, you are the one who knows your child best. It is important to start thinking why you believe your child may have dual diagnosis.

What evidence do you have? Talk to other people in your child's life about your concerns (e.g. family, speech and language therapist, teacher, SENCo/ALNCo); it may be that other people are thinking along the same lines as you. Make a note of the behaviours you believe indicate that your child may have a dual diagnosis (keeping a diary over a period of time can be useful as evidence).

The next step is to show your evidence to the GP or paediatrician. You should expect to have your concerns and observations taken seriously.

If the professional agrees with your concerns, they will make a referral to the appropriate service for an Autism assessment.

If there is uncertainty about making a referral, ask the professional to explain their thinking. You have the right to ask for a second opinion.

You may want to look at the NICE guidelines which you can find at [nice.org.uk/](https://www.nice.org.uk/)

## Good practice guidelines for assessment of Autism

There are no specific tools or questionnaires for the assessment of Autism in people who have Down's syndrome. So, the diagnostic process will involve a qualitative clinical judgment, based on information collected using tools appropriate for the child's developmental stage.

The following are standards for ASD assessment for professionals as outlined in the NICE guidelines.

Included in every autism diagnostic assessment should be:

- Detailed questions about parent's or carer's concerns and, if appropriate, the child's or young person's concerns
- Details of the child's or young person's experiences of home life, education and social care
- A developmental history, focusing on developmental and behavioural features consistent with ICD-11 or DSM-5 criteria (consider using an autism-specific tool to gather this information)
- Assessment (through interaction with and observation of the child or young person) of social and communication skills and behaviours, focusing on features consistent with ICD-11 or DSM-5 criteria (consider using an autism-specific tool to gather this information)
- A medical history, including prenatal, perinatal and family history, and past and current health conditions
- A physical examination
- Consideration of the differential diagnosis (see recommendation 1.5.7)
- Systematic assessment for conditions that may coexist with autism (see recommendation 1.5.15)
- Development of a profile of the child's or young person's strengths, skills, impairments and needs that can be used to create a needs-based management plan, taking into account family and educational context.
- Communication of assessment findings to the parent or carer and, if appropriate, the child or young person. [2011, amended 2017]

**Prof. Pat Howlin, a Professor of Clinical Child Psychology at the Institute of Psychiatry, London, and a researcher in ASD and Developmental Disability, produced the following standards for ASD assessment of a child/adult who has a learning disability in 2000.**

- **Detailed assessment of cognitive level (verbal and non-verbal) and of expressive and receptive language abilities.**
- **A developmental history covering progress from infancy onwards preferably obtained with a standardised interview (ADI-R, DISCO)**
- **Observations of the child in both structured and non-structured settings (use of standardised instrument such as ADOS can be very informative)**
- **Routine screening for medical/genetic conditions**
- **Consideration of other psycho-social factors**

## Autism in Down's syndrome

This is a relatively new area of research, with a small but developing evidence base. Studies in the past 10-20 years have shown that anywhere between 5% and 39% of people who have Down's syndrome will also have ASD. This large differentiation reflects the subjectivity of Autism assessment as there can be a variability of the assessment tools used and the criteria for diagnosis. It is also important to note the overlap of symptoms with those of intellectual disability (Froehike ref).

Our knowledge of the profile of people who have a dual diagnosis continues to change as we gain a greater understanding of the two conditions co-existing.

It is always important to bear in mind that people who have single or dual diagnosis are all individuals and therefore any generalisations made may not apply to your child.

In 2014 the DSA supported a study looking at Autism characteristics in children who have Down's syndrome. They found several characteristics (including offering comfort, social smiling and eye gaze) that are better developed in children with Down's syndrome who screen positive for ASD compared with people with ASD only. On the other hand, the children with Down's syndrome and ASD tended to have more compulsions and rituals.

The parents in the study also reported that their children with Down's syndrome and ASD tended to have more communication and social relating difficulties (although they often had good eye contact), as well as being more self-absorbed than children without the additional diagnosis.

When the behaviour of the children with Down's syndrome who met the threshold for ASD was compared with that of other children with Down's syndrome, there were higher rates of emotional symptoms, conduct problems, hyperactivity and peer problems. Levels of behaviour problems and hyperactivity in the Down's syndrome and ASD group were just as high as in an ASD only group. In contrast, they showed fewer emotional problems than the ASD only group

You can read the full summary of this study on our webpage.

## Receiving a diagnosis of ASD

Even when a diagnosis is suspected, receiving the confirmation may provoke strong emotions. It can take time to process, and it may be difficult to take in a lot of information initially.

According to the NICE guidelines where a diagnosis has been received the family should be provided with individual information on support available locally for parents, carers and autistic children and young people, according to the family's needs.

### This may include details of:

- **Local and national support organisations and courses on offer for parents and carers**
- **Organisations that can provide advice on welfare benefits if required**
- **Organisations that can provide information on educational support and social care if required**
- **Information to help prepare for the future, for example transition to adult services.**

## What else to do

It may be that a report is sent to your child's school to make them aware of the new diagnosis and you can talk to them about any additional services available (for example: An Autism Outreach Service) to support your child. At your child's next annual review ask for the diagnosis to be written into their Education, Health and Care Plan (EHCP).

If you feel that, because of the new diagnosis, there need to be immediate and significant changes to the level of support your child receives, you can ask for an early statutory review of their EHCP or a reassessment of your child's needs (as appropriate).

Information about EHCPs and education can be found on our website.

If your child receives social care support from the local authority, you may like to consider asking them for a review of your child's care plan.

## Other support from the DSA

There are regular Down's syndrome with complex needs support meetings for parent carers online approximately every six weeks. These meetings offer an opportunity to meet other parents and to share information. If you would like to attend one of these meetings, you can book your place on our website training page. We also have a closed Complex Needs Facebook group where parents can post questions and offer advice.

Our information team are happy to talk with you and answer general questions around process however they are not able to comment on the diagnosis of individuals.

## References and further reading

Froehle, M & Zaborek, R (2013) When Down Syndrome and Autism Intersect: A Guide to DS-ASD for Parents and Professionals Woodbine House

Warner G., Moss J., Smith P., Howlin P. (2014) Autism Characteristics and Behavioural Disturbances in ~ 500 Children with Down's Syndrome in England and Wales. Autism Research, Vol 7, Issue 4, 433-441

Warner G and Howlin, P (2015) Autism Characteristics in Children with Down's Syndrome in England and Wales DSA Journal; 132 Autumn/Winter 2015

Reilly, C. (2009) Autism spectrum disorders in Down syndrome: A review: Research in Autism Spectrum Disorders Volume 3, Issue 4, October–December 2009, Pages 829–839

Gray, L., Ansell, P., Baird, G. & Parr, J.R. (2011). The continuing challenge of diagnosing autism spectrum disorder in children with Down syndrome. Child: Care, Health and Development, 37(4), 459–461.

Moss, J., Richards, C., Nelson, L. and Oliver, C. (2012). Prevalence of autism spectrum disorder symptomatology and related behavioural characteristics of autism spectrum disorder in Down syndrome. Autism: International Journal of Research and Practice, 17 (4) 390-404

Lambert, K (2020) Parents' experience of having a child with the dual-diagnosis of Down's syndrome and Autism Spectrum Condition: A Narrative Analysis, DSA journal 141

Mental Wellness in Adults with Down Syndrome Dennis McGuire and Brian Chicoine

NICE guidelines - <https://www.nice.org.uk/guidance/cg128>

National Autistic Society website - <https://www.autism.org.uk/>

# CONTACT US

## Down's Syndrome Association

Langdon Down Centre,  
2a Langdon Park, Teddington,  
Middlesex, TW11 9PS

t. 0333 1212 300

f. 020 8614 5127

e. [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk)

e. [training@downs-syndrome.org.uk](mailto:training@downs-syndrome.org.uk)

w. [downs-syndrome.org.uk](http://downs-syndrome.org.uk)

### Wales

e. [wales@downs-syndrome.org.uk](mailto:wales@downs-syndrome.org.uk)

### Northern Ireland

e. [enquiriesni@downs-syndrome.org.uk](mailto:enquiriesni@downs-syndrome.org.uk)



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