Delivering psychological services for children and young people with neurodevelopmental difficulties and their families
What do we mean by neurodevelopmental difficulties?

The term neurodevelopmental difficulties includes:

- autistic spectrum conditions;
- attention deficit conditions (AD, ADHD);
- social communication difficulties;
- foetal alcohol spectrum disorders;
- Tourette’s syndrome;
- motor co-ordination difficulties.

The term is used to mean difficulties that have onset very early in life, although their consequences are often not seen until many years later. They are not necessarily caused by something that has happened in the brain, but can be the result of other factors, such as genetics, and the environment around the child – family and early childhood experiences.

Children with formal diagnoses covering neurodevelopmental conditions are the largest group of disabled children in the UK – recent estimates are 1.7
per cent of children with autism spectrum disorders, 1.4 per cent for ADHD, and 2 to 5 per cent for foetal alcohol spectrum disorders. In addition, some children have no formal diagnostic label that would apply, and others have more than one.

The process of getting help can take some time. Typically, parents wait about a year from first noticing difficulties to seeking help and the process may be lengthy. For those children with autistic spectrum difficulties for example, the average time between seeking help and receiving a diagnosis is 3.6 years.

**Why are psychological approaches needed?**

Psychological approaches are key to understanding the difficulties of children with neurodevelopmental conditions. They are based on a detailed assessment to develop a formulation of the child’s difficulties. A psychological approach that considers behaviour in its wider context (e.g. social, cultural, gender, class and race) is important, as some children who appear on first assessment to have neurodevelopmental difficulties may, in fact, have attachment difficulties.

A diagnosis may form part of a formulation. This can be a contentious area: some families and young people do not want a diagnosis, whereas others ask for one so that the child can access other services, particularly in a school context.
The importance of psychological assessment

Assessment is not a one-off event, but an ongoing process. Diagnoses too, need to be reviewed: a child assessed as meeting the criteria for a neurodevelopmental disorder at one point in time may not fulfil those criteria later. We know that some children will be able to manage their difficulties so that they no longer cause significant problems as they get older.

The professionals involved in assessment will vary, but typically include:

- A paediatrician or child psychiatrist;
- An applied psychologist (clinical, educational or neuropsychologist);
- A speech and language therapist;
- An occupational therapist skilled in sensory assessment.

Assessment will include several different methods and situations. These should include:

- A clinical interview and developmental history through a structured discussion with parents.
- Observations of the child in various settings, such as school and in social situations with other children.
- Information gathered from other sources, such as questionnaires.

These methods allow for the following factors to be assessed:

- Mental health and behaviour.
- Communication abilities.
- Cognition or intellectual ability.
- Neuropsychological functioning.
- Achievement and adaptive functioning.

Children with neurodevelopmental difficulties are more likely to experience poor mental health than the general population. Behavioural signs of psychological distress may not be recognised when behavioural challenges (such as ADHD) are ‘core’ symptoms. A detailed assessment will help to minimise this risk.
A good assessment recognises that beliefs about the cause and course of neurodevelopmental difficulties are influenced by culture, and the reaction to diagnostic labels will also differ across cultures.
Supporting services and families

Provision for children with neurodevelopmental difficulties spans child health, CAMHS and local authority services and education. This can lead to gaps in service, which in turn create barriers in accessing help. Psychologists can support early identification of children’s difficulties by the children’s workforce by providing skilled consultation and joint working with other professionals. Clinical psychologists, used to working within and across complex systems, across the lifespan, and with expertise in child development are well placed to deliver this.

Most children with neurodevelopmental difficulties, their families and those who support them, will require interventions and management plans and strategies to support their wellbeing that are primarily psychological/behavioural in nature.

Parents report the assessment process as long and stressful and when the outcome is a ‘diagnosis’ of a neurodevelopmental condition this can be crushing. Despite this, 35 per cent of parents report being offered no help post diagnosis.

‘One of the biggest issues is that you get the diagnosis and as a parent, you are just left to deal with it.’

(Crane et al., 2015)

Parents of young children with autism report being left in the dark after being given a diagnosis for their child, and felt that professionals needed more training.

‘We need to understand the impact on families supporting a child with autism and how they can be further supported. An educated and empowered parent actually reduces the need (and then cost) on public services as they are less likely to need regular ongoing outside help.’

(Pellicano et al., 2014)
Management plans and interventions

Management plans might include:

- Support to learn new skills and strategies;
- Help to communicate effectively with people in caring and educational roles;
- Cognitive behavioural therapy and social skills training for the child to help with social skills with peers, problem-solving, self-control, listening skills and dealing and expressing feelings;
- Support for families who need help in coping with the adjustment process following diagnosis, or those families who need help coping with the child’s ongoing difficulties;
- Training for parents, carers and others.
The experience of young people

We need more research on the views of children and young people with neurodevelopmental difficulties; young people and their caregivers do not always agree about behaviours of concern or their meaning and may have different views about seeking assessment. Some researchers found that young people with Asperger’s syndrome argued against a medical diagnosis, whereas parents had sought assessment to provide a medical definition, help and, in some cases a cure. One young person commented:

‘Autistics don’t “suffer”. There is nothing bad at all with being autistic. We’re not “disordered”; we’re just different. That’s all.’ *(Clarke & van Ameron, 2008)*

Not all young people feel engaged in the process of neurodevelopmental assessment and once a ‘diagnosis’ has been given, young people’s responses will vary and change over time. Initial feelings of anger or denial may change to more positive feelings, including an understanding of previous life events, and an enhanced awareness of why some situations give rise to difficulties, leading to more informed future choices. New opportunities may open, there may be access to literature and sources of advice enabling the development of new strategies and an awareness that others have similar difficulties.

‘… One of my strongest defences against all my disabilities is the awareness of exactly where my problems lie.’ *(Hale, 1998, p.130, cited in Jones, 2001)*
Service issues

There are additional potential problems in the system:

- Services ordered around specific disorders may mean that there is limited access to clinicians with skills outside of that specific area. This is a problem particularly for children with co-occurring difficulties, such as a child with ADHD and severe anxiety.

- Children with neurodevelopmental difficulties who do not also have intellectual difficulties are unable to access Child and Adolescent Mental Health Services for learning disability.

- Some children are excluded by mainstream services because their anxiety is wrongly seen as part of their autistic difficulties.

- Sometimes, the child’s difficulties may be framed in terms of mental health difficulties, or even more distressingly, as a ‘mental illness’ to meet service criteria. This is clearly a problem for children whose difficulties are neurodevelopmental.
What can you expect from a good service for children and young people with neurodevelopmental difficulties and their families?

A good service will:

■ Understand the contribution of neurodevelopmental difficulties when children/young people are experiencing difficulties in their lives, and also that children can need the help of services at any age.

■ Recognise that having more than one neurodevelopmental difficulty is the norm and organise care so that children and their families can access clinicians with expertise and knowledge in a range of areas, not just for specifically defined and labelled ‘disorders’.

■ Minimise gaps in service provision and work in a joined up and family-focused way across organisations and specialisms, such as paediatrics, speech and language therapy, schools, and so on.

■ Deliver inclusive services for children experiencing the distress associated with poor mental health regardless of whether they have neurodevelopmental difficulties.

■ Provide assessments that are comprehensive and multi-disciplinary, and which proactively work to minimise the length of the assessment process and the stress associated with it for children and their families.

■ Understand the contributions of contextual factors (including culture) to family and clinician views throughout the process, and recognise that over time the needs of the children and their parents will change.

■ Ensure that any ‘diagnosis’ is seen within the context of a wider psychological formulation of the child and family’s difficulties and strengths to promote a shared understanding of the child.

■ Support the child and the parents after the assessment has finished.

■ Offer interventions and management plans which help the child, their family and other support networks in the child’s various environments: home, social and school.
References


We would recommend that this leaflet is read in conjunction with other leaflets in the series and in particular with Clinical and applied psychologists in child and adolescent mental health.

This leaflet summarises a chapter in What Good Looks Like in Psychological Services for Children, Young People and their Families. Electronic copies can be downloaded for free from: http://shop.bps.org.uk/publications/child-and-family-clinical-psychology-review-no-3-summer-2015.html

**Hard copies** can be requested for free from Helen Barnett, British Psychological Society: Helen.Barnett@bps.org.uk

If you would like to discuss any of the information in this brochure further, please contact: dcpchildlead@bps.org.uk