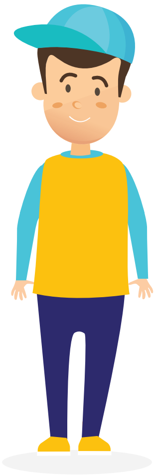
# Diagnostic Changes in Child & Adolescent Mental Health

## Parent Information Leaflet

If you're reading this, you may have just found out that your child's mental health or neurodevelopmental diagnosis has changed - that is, an existing diagnosis has been removed, replaced or supplemented with a different diagnosis. This may be confusing for both yourself and your child. This leaflet is intended to help you understand why diagnostic changes happen and how you can support your child during this time of transition. The information provided is based on research undertaken as part of the Prevalence and Experience of Diagnostic Shifts (PAEDS) research project led by researchers in University College Dublin.

### How are diagnoses made in child and adolescent mental healthcare?

The process of making a mental health and/or neurodevelopmental diagnosis is usually guided by diagnostic manuals. The two main diagnostic manuals are the **Diagnostic and Statistical Manual of Mental Disorders (DSM)** and the **International Classification of Diseases (ICD)**. These manuals draw on scientific and clinical knowledge to set out the range of diagnoses that are possible and the criteria (symptoms) necessary to diagnose each condition. Clinicians assess whether a young person meets diagnostic criteria through a range of methods, including completing validated questionnaires or checklists, observing the young person's behavior in different settings, collecting information from the child's school, and listening to the young person and family's accounts of the difficulties they have been experiencing and their family history.



### What is a diagnostic change?

A diagnostic change happens when clinicians decide it is appropriate to **change the diagnosis** that a young person was previously given. This may involve withdrawing the previous diagnosis, replacing it with a different diagnosis, and/or supplementing the original diagnosis with an additional (comorbid) diagnosis.

### How frequently do diagnostic changes occur in Child & Adolescent Mental Health Services (CAMHS)?

The PAEDS research project examined the clinical records of over 12,500 children attending CAMHS in the UK. This study found that a diagnostic change occurred in approximately **one in five** cases. The most common diagnostic shifts involved crossover between (a) mood disorders and anxiety disorders, (b) Attention Deficit Hyperactivity Disorder (ADHD) and conduct disorders, and (c) ADHD and Autism Spectrum Disorders (ASD). However, many other variations and combinations were observed and are possible.

### Why might a diagnosis change?

There are numerous different reasons why a diagnosis might change.

**First**, a young person's symptoms may change as they mature and have different life experiences, with the result that they no longer meet criteria for the initial diagnosis they received. Alternatively, behaviours that were age-appropriate in early life may become concerning and warrant a diagnosis as the child ages.

**Second**, the process of diagnosing mental health or neurodevelopmental conditions is complex: there are no precise biological tests that can conclusively diagnose a particular disorder. Diagnostic errors can sometimes occur and later need correction.

**Third,** the reliance on clinical judgement means that individual health professionals can sometimes have genuine differences in clinical opinion about the appropriateness of particular diagnoses.

**Fourth**, the diagnostic manuals mentioned above are regularly updated to reflect advances in scientific and clinical knowledge; this can mean that the criteria for diagnoses change over time.

## How can a diagnostic change affect a young person's life?

The PAEDS researchers spoke to parents and young people across Ireland who had direct experience of diagnostic changes. These interviews revealed a range of clinical, emotional, social and practical repercussions that diagnostic changes may have.

- **Clinical implications** could include a revised prognosis and change of the therapeutic options that were available or recommended. Depending on the context, the diagnostic change could also affect the relationship between the young person/family and their clinical team.
- **Emotional implications** could be both positive or negative, depending on the circumstances. Some families felt a sense of relief that the revised diagnosis improved their understanding of the young person's difficulties. Others felt confused or frustrated by the change. Young people could experience the new diagnosis as challenging their existing self-identity, but could also value the sense of explanation the new diagnosis provided.
- **Social implications** were also both positive and negative. Some parents reported that a revised diagnosis made them readjust their parenting strategies or the parent-child relationship. Children could find it challenging to get used to such changes in the home environment, even if they were ultimately beneficial. Also, because different diagnoses can have different stereotypes or stigma attached to them, some families believed that a change in diagnosis affected how the young person was treated in school or the wider community.
- **Practical implications** could be significant when access to services was linked to diagnostic classifications. In particular, young people who moved between mental health and ASD diagnoses could fall between the cracks of CAMHS (specialised for mental healthcare) and disability services (responsible for ASD services). Some parents also reported that the addition/removal of certain diagnoses affected the educational supports offered to their child.

## How can young people be best supported during a diagnostic change?

Every young person's situation is completely unique, depending on factors such as maturity, personality and the reasons for the diagnostic change. As the greatest expert on their particular child, the parent should be supported by their clinical team in judging how best to communicate the diagnostic change to their child and help them through any challenges they may experience. Some strategies that other parents have found helpful include:

- Taking the time to **research** the new diagnosis through trusted websites and recommended resources. These will help parents have a better understanding of their child's new diagnosis and how it may affect them. Parents can ask their clinical team to recommend any child-friendly books or websites that could help explain the new diagnosis to your child.
- Seeking advice from the clinical team regarding the **extent of information** to share with the young person. Some parents prefer a fully open communication approach, whereas others feel that communication of the diagnostic change to their child should be limited or delayed. It is helpful to discuss the pros and cons of telling your child with the team before making a definitive decision.
- Collaborating with the clinical team to develop a **strategy** for telling the young person about the diagnostic change. The person who will deliver the information, the words that will be used, and responses to likely questions from the young person can be prepared in advance.
- Ensuring that communicating the diagnostic change to the young person occurs in a safe and comfortable **environment**. It may take some time for the information to sink in and questions to arise, so the parent should ensure they are nearby and available for a few hours afterwards.
- Asking the clinical team's advice on whether and how information about the new diagnosis should be **shared with schools** or other important organisations/persons in the young person's life.
- Emphasising that the young person's core **identity**, including all of their unique strengths and challenges, remains the same despite the change in diagnosis. This is also important for the rest of the family to bear in mind.
- Focusing on the young person's distinctive **talents and abilities**, and emphasising that the challenges they may face do not take away from their positive attributes.

- Using **metaphors** to aid communication. For example, synonyms (e.g. chair/seat, biscuit/cookie) can convey the idea that calling something by a different name does not change it; and different versions of the same object (e.g. brands of cars/phones/chocolate) can help convey that individuals can work in different ways but be equally valued.
- Avoiding making any **abrupt changes** in the home as the young person adjusts to the revised diagnosis. New environments or parenting strategies can be phased in gradually, and the rationale for these can be shared with the young person if appropriate.
- **Involving** the young person in decisions that may result from the diagnostic change (for example, asking them whether they are comfortable with the new diagnosis being shared at school or with extended family).
- Engaging in **self-care**. The parent is the main support for the child, so it is important they feel strong enough to perform that role. Before speaking about the diagnostic change with their child, parents may wish to process their own responses by talking things through with a trusted friend or seeking support from a licensed mental health professional. Some parents find online or in-person support groups helpful in meeting other people with similar experiences.

## Important things to remember

Every child is different and every situation is different, so there is no 'one size fits all' solution or advice. It's normal to feel a bit disconcerted when a diagnosis changes, but most families adjust well to the new diagnosis after a little time has passed. The PAEDS project has created free information resources on diagnostic changes that are suitable for young people of different ages. These may be helpful in explaining a diagnostic change to your child. They can be accessed at https://paedsdiagnosis.ucd.ie/.

*This resource was produced as part of the Prevalence and Experience of Diagnostic Shifts (PAEDS) research project, run in University College Dublin and funded by the European Union's Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No 702970.*

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PREVALENCE AND EXPERIENCE OF DIAGNOSTIC SHIFTS IN YOUTH MENTAL HEALTHCARE

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