

# Diagnostic Changes in Child & Adolescent Mental Health

## Young Person's Information Leaflet



If you're reading this, you may have just found out that your mental health diagnosis has changed. You might be upset, even a bit annoyed. But you might also be relieved, because you may feel the new diagnosis better explains the difficulties you've been having. And you might want to find out more about your new diagnosis and where you can look for help if you need it. This leaflet will hopefully make things a little bit easier to understand.

### What is a diagnosis?

When young people are struggling with difficult thoughts, feelings or behaviour, they might go to a specialist doctor called a psychiatrist or psychologist. Sometimes the doctor gives the young person a diagnosis. A diagnosis is a name that doctors use to understand the difficulties the young person has been experiencing. **Mental health diagnoses** are given when the young person is experiencing difficulties with feelings or behaviour. Some examples of mental health diagnoses are 'depression', 'anxiety disorder' and 'obsessive compulsive disorder' (OCD). **Neurodevelopmental diagnoses** are given when the young person's brain is developing in a different way than typically happens. Some examples of neurodevelopmental diagnoses are 'Autism Spectrum Disorder' (ASD) and 'Attention Deficit Hyperactivity Disorder' (ADHD).



### How do doctors decide what diagnoses to give a young person?

When health professionals are deciding whether to give a diagnosis, they follow rules that are laid out in 'diagnostic manuals'. These are booklets written by scientists and doctors, which list the diagnoses that are possible and the symptoms of each diagnosis. Health professionals try to match up the symptoms a young person is experiencing with the most appropriate diagnosis. To work out what the young person's symptoms are, they might ask the young person and their parents to do questionnaires or assessments, watch how the young person behaves at school or at home, talk to their teachers, and ask the young person and their family questions about their thoughts, feelings and behaviour.

### What is a diagnostic change?

A diagnostic change happens when doctors decide to change the diagnosis that a young person was previously given. This may involve removing the previous diagnosis altogether, replacing it with a different diagnosis, or adding in an extra (comorbid) diagnosis.

### How frequently do diagnostic changes occur?

About one in five young people who use mental health services have experienced a diagnostic change, so it is fairly common!

### Why might a diagnosis change?

There are a few different reasons why a diagnosis might change.

**First**, a young person's emotions and behaviour can change as they grow up, and the doctors might decide that a new diagnosis would better describe the symptoms they are now experiencing.

**Second**, it is tricky to diagnose mental health and neurodevelopmental conditions because we can't directly see or measure them. This means doctors have to rely on information from the young person's family and school. That information can change over time, which can lead to a change in diagnosis.

**Third**, different doctors can sometimes disagree about which diagnosis best describes the symptoms someone is experiencing.

**Fourth**, the diagnostic manuals mentioned above are updated every few years to take into account the latest discoveries in mental health science. This means that the names and criteria for diagnoses can change over time.

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

A research project in University College Dublin spoke to parents and young people across Ireland who had direct experience of diagnostic changes. The families reported that diagnostic changes had affected their lives in a few different ways.

- Changing the diagnosis could lead to a change in the treatments or therapies offered to the young person. For certain diagnoses, doctors might recommend that the young person start taking medication. Young people were sometimes nervous about this but most got used to it fairly quickly.
- Some young people had to change doctors or services so that they could get support from people who were experts in the new diagnosis.
- Some young people felt relieved when they heard the new diagnosis. They felt it gave a better explanation of the difficulties they had been experiencing.
- Other young people felt confused about why the diagnosis has been changed. Some felt frustrated or angry that they were originally told one diagnosis, and now this had changed.
- Young people sometimes found that the diagnostic change made them think about themselves in a different way. Some were happy about the new diagnosis as it seemed a good fit, whereas others needed a bit more time to get used to it.



- Some young people reported that their parents or teachers started to treat them differently after the diagnostic change. Usually this was a good thing as others became more understanding – but the changes at home or school could take a while to get used to.



#### What can help young people cope with a diagnostic change?

Every young person's situation is completely unique, depending on factors like their age, personality and the reasons why the diagnosis changed. It's normal to feel a bit confused and even upset if your diagnosis changes. Other young people in your position have given the following advice based on their experience:

- **Take your time** getting used to the new diagnosis – no big decisions need to be made immediately after learning about it.
- Don't be shy about **asking your doctors questions** about the new diagnosis or the reasons for the change. Helping you understand what's going on is part of their job so they should be happy to help!
- **Talk to your parents** or other people you trust about your feelings about the diagnostic change. Be honest, even if you're angry or upset – people can only help you if they understand what you're feeling.
- Ask your parents and doctors for help finding **reliable information** about the diagnosis. It's important to remember that you can't trust everything you read online, so stick to the websites that the doctors and your parents have suggested to you.
- There is **no need to tell** your friends about your diagnosis unless you feel comfortable doing so. Who and what you tell is completely up to you.



Important things to remember

A diagnostic change does not change who you are – you are still the exact same person as you were the day before your diagnosis changed! It's normal to feel a bit confused for a while, but most young people get used to the new diagnosis fairly quickly. If you have any questions or worries, talk to your parents, doctors or teachers.

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