Diagnostic Changes in Child & Adolescent Mental Health

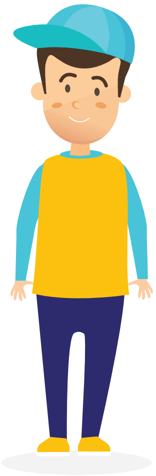
Health Professional's Information Leaflet

Background

The PAEDS (Prevalence and Experience of Diagnostic Shifts) research project was funded by the European Commission and carried out by researchers in University College Dublin between 2017-2019. The project's key aims were to explore the prevalence and patterns of diagnostic changes in child and adolescent mental health services (CAMHS) and the implications of diagnostic changes for young people and their families.

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

To estimate the prevalence of diagnostic changes in CAMHS, the PAEDS research team extracted the CAMHS records of over 12,500 children from a British mental health case register. Analysis calculated the proportion of children whose clinical records showed a longitudinal diagnostic adjustment (i.e. original diagnosis later revised/supplemented). This study found that 19.3% of CAMHS attendees had undergone a longitudinal diagnostic adjustment. Affective and anxiety/stress-related disorders longitudinally predicted each other, as did hyperkinetic and conduct disorders, and hyperkinetic and pervasive developmental disorders.



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

The PAEDS researchers conducted interviews with children and parents across Ireland who had experienced diagnostic shifts. Qualitative analysis of this data 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 young people and parents felt a sense of relief that the revised diagnosis improved their understanding of the difficulties they were experiencing. Others felt confused by the change and regretted the 'lost time' they perceived as resulting from a misdiagnosis or missed diagnosis. Young people could experience the new diagnosis as challenging their existing self-concept, but could also value the sense of explanation the new diagnosis provided.
- **Social implications** were also variously 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 adjust 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 shifted 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.

Clinicians delivering a new diagnosis should be aware of how this diagnosis relates to the young person's diagnostic history (i.e. previous diagnoses given at different times or in different clinical settings). In order to best support families, health professionals should consider the range of possible implications a diagnostic change may have, both inside and outside the clinic.

How can health professionals support young people and their families when a diagnosis changes?

The families who participated in the PAEDS research made a number of suggestions for how instances of diagnostic changes should be managed.

- Parents appreciated when the clinical team apprised them about the possibility of the diagnosis changing and the rationale for any re-assessments **before any final decision was made**. Diagnostic changes that were 'sprung' on families without prior warning often elicited negative responses.
- The delivery of information about a diagnostic change should occur in a comfortable and relaxed **environment**. A meeting with the parents in the absence of the child was generally preferred, as parents felt inhibited from asking questions when their child was present.
- Initial communication about a diagnostic change should include an account of the **clinical rationale** for changing the diagnosis and an explanation of why the new diagnosis is more appropriate.
- Parents are the ultimate experts on their particular child. Positive clinical relationships acknowledge this expertise and welcome parental opinions on the proposed diagnostic change. Demonstration of **respect for the parent's perspective**, even if this deviates from that of the clinical team, is greatly appreciated by families.

- Families are often very concerned about the implications of a diagnostic change for their child's service entitlements. The clinician should be clear about what the diagnostic change means for the child's **treatment pathway** with specific attention to what will change and what will remain the same. Likely implications for the child's **educational provisions** and overall **development** should be sensitively discussed.
- Parents often struggle with determining the extent of information they should share with the young person. An open discussion with parents about the potential **risks and benefits of disclosing** the diagnostic change to the child is welcome.
- Developing a **strategy for telling the child** about the diagnostic change should be a collaborative exercise between the clinical team and the parents. 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.
- A diagnostic change can be disorienting for the young person. Health professionals should ensure the diagnosis is **explained to children in terms they can understand** and provide the family with up-to-date resources that can reinforce this information at home.
- Parents feel strongly that communication of a psychiatric diagnosis to young people should be **optimistic** in tone. Young people who receive multiple diagnostic labels can interpret this as meaning there is something irredeemably 'wrong' with them. This message can be subverted by emphasising the common nature of mental health difficulties, the importance of valuing diverse ways of thinking, and the availability of effective intervention strategies.
- Questions or concerns often occur to families after the clinical consultation, when they have had time to process the information. Ensure they remain supported in between meetings by making **follow-up phone calls** that query how the family are adapting to the diagnostic change, providing **written resources** for families to revisit at home, and **referring** to appropriate non-clinical supports such as support groups.

Resources

The PAEDS project has created information resources on diagnostic changes that are suitable for parents and young people of different ages. These can be accessed at https://paedsdiagnosis.ucd.ie/. These resources are freely available for download and dissemination.

The PAEDS website also contains more information on the project's research activities and academic publications.

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