

Insights into DLD: Parental Narratives of Diagnosis and Beyond

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Abstract

Introduction: In supporting children with developmental language disorder (DLD), it is the role of speech and language therapists (SLTs) to make the diagnosis and usually, to disclose it to parents. Research indicates however that many families do not receive a clear diagnosis from their SLT (Ash et al., 2020; Porter et al. 2020). Porter et al. (2020) also found that many families value having a diagnosis and consider it to be important for accessing resources. When talking to families, SLTs may avoid using terms such as DLD due to concerns that they are complex and potentially stigmatising (Harvey, 2023).

Receiving a diagnosis can be an emotionally heightened experience for parents, and the impact is long-lasting. This study seeks to provide insight to the perspective of a diverse group of UK parents, with a view to developing a co-designed resource to support SLTs in the delivery of diagnoses.

Method: The aim of the current study phase is to explore the experiences of parents in relation to receiving a diagnosis of DLD and identify their priorities for clinical interactions.

It is being led by a steering group of 4 parents to children with DLD and uses experience-based co-design (EBCD) methodology. Semi-structured interviews conducted with a culturally diverse group of parents reveal key issues in the diagnostic process, identified through thematic analysis. These will be edited into a film and presented to parents in a workshop, where together, they will select priorities to take forward to subsequent stages of this research (co-designing a diagnostic resource with SLTs and parents).

Preliminary Findings and Next Steps: While still in progress, preliminary findings suggest that parents highly value the DLD diagnosis. Shared stories highlight the emotional impact at the time of diagnosis, including the setting, people present, expectations, and the processing of feelings and information. The findings will indicate ways that parents wish to receive a DLD diagnosis, and how SLTs can support them in the delivery.