



# Autism Diagnosis in a Rural Community: Are There Opportunities for Improvement?



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**Aim:** Diagnosis of autism at the youngest possible age can reduce family stress, provide earlier access to intervention services and lead to better developmental outcomes for children. This study aims to understand the barriers and enablers in the autism diagnostic pathway of children in a rural area. It seeks to understand the underlying issues that cause delay in diagnosis, and look for opportunities for improvement.

**Methods:** Using a critical realist approach, semi-structured interviews were conducted with parents of children who were diagnosed with autism after January 2007, whilst living in a rural community. Nine parents were interviewed about their child's diagnostic pathway and any opportunities they saw for improvement in the process. Three focus groups were then conducted with a total of 22 local health and early education professionals about their experience of identifying, referring and/or diagnosing children with autism. Possible improvements to practice were identified by the group members. Thematic analysis was used to analyse the data.

**Results:** Four major themes emerged from the data:

**Labels -** The label of autism provided a description of behaviours, but also some stigma. For parents, it gave them and others greater understanding of their child and assisted them to access help. Parents were keen to pursue a diagnostic pathway when they considered that a label of autism could assist in explaining the behaviours of their child in an education context.

**Process -** The process of diagnosis was problematic for most participants. It was characterised by confusion, lengthy delays, multiple steps, travel, expense.

**Relationship -** Professionals were concerned about building and maintaining relationships with families. They considered this crucial when they needed to raise developmental concerns with parents. Professionals found it very confronting to discuss these concerns with families. Parents valued professionals who were honest, non-confrontational and whom they considered knowledgeable.

**Knowledge -** There was a lack of knowledge about the process, and also about the indicators and characteristics of autism of both parents and professionals. Parents lacked knowledge in the diagnostic process of what was being assessed. They wanted to know that professionals were considering autism when concerns were first raised. Most professionals said they would never use the word autism in a conversation with a parent, unless they used it first.

**Conclusion and Implications for Practice:** There are several opportunities to improve the process of autism diagnosis for children in rural communities. Further training about early autism indicators, and having challenging conversations, is important for health and early childhood professionals. Consideration needs to be given to trialling innovative models of accessing autism assessment professionals in rural communities. Families require written and verbal evidenced based information during the diagnostic process, and would like to understand that autism is being considered during assessment. Both families and professionals require clarification of the autism diagnostic process.

*For the full report on this project visit our website, follow the link to the Rural Research Capacity Building Program and click on 'view completed' projects'*

Catherine is a social worker with over 20 years experience in both the government and non-government sectors. She currently works as a social worker at Mudgee Community Health Centre where she provides individual counselling and group work to children and families, including those with an autism spectrum disorder. Catherine is passionate about innovative models of care that allow better access to services for those in rural communities.



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