# Working together to improve autism diagnosis in a rural community

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## Abstract

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. Research was completed by the presenting author about the experience of families during the diagnosis of their child in a rural community, and the perceived enablers and barriers for local health and early education professionals in the process of identification, referral and diagnosis of autism in children. The final report included recommendations for improving the process of autism diagnosis in rural communities. A working group was subsequently formed in the rural community of the author to support translation of the research recommendations into practice. The group currently includes a GP, public and private allied health professionals, a consumer representative, a nurse and a community agency representative. The group are working collaboratively to reduce the complexity involved in the autism diagnostic process for young children in their rural community. The group has coordinated training for professionals in a developmental surveillance tool to identify young children at risk of autism, and are developing improved referral pathways and resources. Models of assessment and referral are being trialled, with the aim of improving local diagnostic processes. There continue to be barriers in the diagnostic process, yet also clear opportunities for improvement. Consumer outcomes can be improved when there is collaboration across disciplines, services and systems that is informed by research, local context and a shared vision.

## Introduction

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. The recognition of this has led to research about developmental surveillance tools to identify children at risk of autism.[1]There is, however, little qualitative research about the diagnostic experiences of families in rural communities, and the perceived enablers and barriers for local health and early education professionals in the process of identification, referral and diagnosis of autism in young children. The bringing together of the experiences, attitudes and insights of both local parents and professionals from rural communities is important in understanding what needs to be considered when aiming to reduce the age of autism diagnosis. The recognition of this led to the author undertaking qualitative research on this topic in her rural community.

The findings and recommendations of this research led to the establishment of an autism working party. This group has focused on translating the findings of this research into practice, and working to have a real impact on the health outcomes of local community members.

## Background

### Autism
Autism Spectrum Disorder (ASD or autism) is a life-long neurodevelopment disorder characterised by repetitive behaviours and restricted interests, and varying degrees of difficulty with social communication.[2] Long-term trajectories of those affected can include increased levels of anxiety and

depression and significantly reduced employment outcomes.[3,4] For diagnosis, impairments must be evident from childhood and impair daily functioning. As biological testing is currently not possible, autism is diagnosed through clinical assessment of behavioural features, as defined by the DSM-5.[2] A diagnosis is made by either a paediatrician, child psychiatrist, or psychologist as part of an approved multidisciplinary team.[2] Current international estimates suggest that 1 in 100 people have autism.[5]

### *Early intervention*

Children with autism who have had therapeutic intervention at a younger age, have shown better developmental progress[6], and have a greater chance of improvements over time.[7,8]Large scale studies have also examined the benefits of early intervention, and the importance of early diagnosis.[9,10] Most agree that the best approach is to identify autism as early as possible in a child's development, and then implement appropriate intervention and support. It is argued that this is the best approach to minimising the effects of autism on a child's development.[6]

There is financial support for children to access therapy and early intervention services if they are diagnosed with autism before their seventh birthday. Currently, the Helping Children with Autism (HCWA) package provides access to funding for privately provided early intervention therapy services.[11]

### *Age of diagnosis*

In Australia, the mean age for diagnosis of autism is approximately four years of age, with many children not being identified until after commencing school.[6] There is evidence, however, that autism can be reliably diagnosed from two years of age.[12,13]Children are often diagnosed at an older age in regional and rural areas than in large cities.[14]

To facilitate earlier diagnosis, recent research in Australia has focused on developing and testing screening and developmental surveillance tools to identify children at risk of autism at the youngest possible age.[1,7,15] The Australian Autism Cooperative Research Centre (Autism CRC) and several program partners, are undertaking the training of 400 community based primary health care professionals across four states, in the use of a developmental surveillance tool, the revised Social Attention and Communication Surveillance (SACS-R) program. This tool can be used at 12, 18 and 24-months of age during routine health assessments to identify children at risk of autism. In this study, if children are identified as being at risk of autism using the SACS-R, they are referred to local paediatric and diagnostic services for further assessment. It is hoped that this will result in 50% of children with autism being identified and diagnosed by the age of two years, and 70% by the age of three years.[16]

In an article in the Medical Journal of Australia, the frequency and age at diagnosis of ASD in children under seven years of age in Australia was examined.[14] The article concluded "…there may be a substantial gap between the age at which a reliable and accurate diagnosis is possible and the average age at which ASD is diagnosed in Australia. Future research should examine this gap, and investigate barriers that delay the diagnosis of ASD to ensure that families and communities can benefit from best-practice approaches to early intervention ". [14]

### *Qualitative research in rural NSW*

The author completed qualitative research in 2015 through the HETI Rural Research Capacity Building Program. This research added to the limited qualitative literature about the barriers and enablers in autism diagnosis in a rural community, and opportunities for improvement. This study aimed to examine the experience of parents of children in a rural area of being identified and

diagnosed with autism, including the enablers and barriers along that pathway. The researcher set out to answer the question, "What are the enablers and barriers in the diagnostic pathway of children who have been identified as being at risk of autism in a rural community? Are there opportunities for improvement?

Using a critical realist perspective, semi-structured 1:1 interviews were conducted with nine parents of children who had been diagnosed with autism. Parents were interviewed about their child's diagnostic pathway. Three focus groups were conducted with 22 health and early education professionals about their experience of identifying and/or diagnosing children with autism. Possible improvements to practice were identified by participants. Thematic analysis was used to analyse the data. Four major themes emerged from the data; labels, process, relationship and knowledge.

This research demonstrated that in the rural area studied, the diagnostic experience of children, as described by their parents, is often challenging and requires improvement. Parents described a process that is lengthy, confusing, costly, and often requires travel. Study participants agreed that professionals do not communicate with each other enough. Parents indicated a strong desire for more knowledge about the process of diagnosis, and autism. Professionals described a strong commitment to their relationship with parents and the developmental progress of children, but some felt they lacked expert knowledge of the early indicators of autism. Many professionals find it confronting to discuss developmental concerns with parents. Enablers for parents moving along the diagnostic pathway include understanding the usefulness of a diagnosis in terms of accessing help, educational support and understanding and professionals who communicate in a non-confrontational manner and provide good quality information on autism. Parents indicated that they would be more inclined to pursue a diagnosis if they knew that a professional was concerned that their child had autism.

It was concluded that there are several opportunities to improve the process of autism diagnosis for children in rural communities. Further training about 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 process.

### *Autism Working Party—putting the research in to practice*
At the completion of the author's research project, a local autism working party was formed. It was initiated by the author, and expression of interest was sought for membership through local community networks. The current membership includes a GP, private speech pathologist, public speech pathologist, private psychologist, public child and family health nurse, public social worker, preschool director and a community worker from a disability service. All members participate in a voluntary capacity, mostly during their lunch breaks. No general additional funding is provided to the group by their workplaces. The group's aim is to improve local referral pathways for children at risk of autism, and look for opportunities to ensure children are diagnosed at the earliest possible age. The group has been working together to facilitate change based on the findings from the local research, local observation and any new evidence that emerges.

To address the identified gap in knowledge of the early indicators of autism, the group applied for a NSW Health "HETI allied health workplace learning grant ", and used this to provide training to 70 health and community professionals from across the Western NSW Local Health District. The training was in the early indicators of autism and the SACS-R, an evidence based developmental surveillance

tool developed by La Trobe University. This tool can be used to detect children at high risk of autism when they are between 6 and 48 months of age. Feedback from training participants indicated that the vast majority had improved their knowledge about the early detection of autism and felt very confident in using the tool in their own clinical practice. As per report recommendations, training was also provided in having challenging conversations. Participants were given an opportunity to discuss possible local referral pathways with other professionals from their own communities.

In response to the recognition that many professionals and parents find the diagnostic process confusing and lengthy, the autism working group are developing a local referral pathway document. A draft referral form has also been developed by the working party to be used by health and education professionals in the community when they have used the SACS-R developmental surveillance tool and the child is assessed as being at high risk of autism. It is sent to the child's GP, with a recommendation that they refer the child to a paediatrician for a development assessment. It is currently being piloted at Mudgee Community Health and will then be extended to other local community professionals.

To assist with the use of the referral form, decrease the time taken to have a diagnostic assessment and provide knowledge to local professionals, two GPs assisted to coordinate training for local doctors. This training was supported by the Primary Health Care Network. At the education evening, representatives of the working party presented information about the SACS-R developmental surveillance tool and draft referral form. Information was given about possible use of the tool in the community and how the referral pathway to the GP and then paediatrician was a crucial part of this process. This was coupled with an education session presented by an LHD paediatrician (who also attended the developmental surveillance tool training) about autism and developmental disorders. It is hoped that use of the tool, referral form, and the increased knowledge of GPs will assist to reduce the amount of time between identification of a child at risk of autism and their diagnosis.

The author, as a community health centre social worker, and a speech pathologist from the same centre, have begun piloting joint assessments of children who have been referred for language concerns. In these sessions, the speech assessment is undertaken by the speech pathologist, whilst the social worker completes the SACS-R assessment. A family and developmental history and play observations are also gathered. These are then forwarded to the child's GP with the referral form.

As in many areas of Australia, there are often long waits for appointments with paediatricians due to limited resources. Most appointments require return travel of at least 3 hours. The private and NGO autism diagnostic assessment services available require payment, and sometimes travel that adds barriers for many families. The group continue to consider what innovative models of assessment, such as tele-health could be used to address these issues.

## Conclusion

There are clear opportunities for improvement in the diagnostic process for children at risk of autism in rural communities. Whilst more research about autism is strongly warranted, improvement in outcomes will only occur when research findings are also effectively translated into practice. For genuine practice change, additional funding can be useful, but collaboration across public and private sectors and between professional groups is essential. This can be effectively driven from a shared passion and vision of those working at the front-line of these issues, with the support of the higher tiers of their organisations.

Access to diagnostic services that are affordable and timely are critical. It is, however, also crucial for the front-line professionals whom are expected to identify children at risk of autism, to receive training in early indicators of autism, skills based training in having challenging conversations and clinical support in this work. Local contexts, such as those in the diversity of rural locations, must be considered when implementing any identification or assessment tool.

## Policy recommendations

It is recommended that:

1.  Additional funding be provided for children to access multi-disciplinary developmental assessment and diagnostic services in rural areas, with priority given to local health districts where there are currently no existing publically funded developmental assessment clinics;

2.  In NSW, Isolated Patients Travel and Accommodation Assistance Scheme payments be available to families when travelling to Autism Spectrum Australia in Sydney for diagnostic assessment when they have been referred by a paediatrician;

3.  Primary Health Care Networks or equivalent, through their professional development program, provide education to GPs and health professionals about early indicators of autism and the benefits of early intervention;

4.  Consideration be given to use of the word autism, in the context of one of the developmental concerns that professionals consider, when professionals identify a child as being at risk of autism when using a validated tool such as the SACS-R.

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## Presenter

Catherine Bourke is a social worker at Mudgee Community Health Centre in rural NSW. She has 20 years' experience in counselling, group work and case work with children and families in both the government and non-government sectors. Catherine has recently completed a piece of qualitative research, "Autism Diagnosis in a Rural Community: Are There Opportunities for Improvement? " This has led to the establishment of Mudgee Autism Working Party. This cross-disciplinary group aims to examine and implement improvements to local clinical practice. As a member of the NSW Carers Advisory Council, she helps provide advice to the NSW Government on matters relating to carers. Catherine is passionate about using evidence to improve practice in rural areas.