The term Autism spectrum disorders (ASD) refers to a number of neurodevelopmental disorders affecting, to varying degrees, people’s capability for social interaction and communication. ASD knows no borders, happening across all cultures and communities, and is understood to occur in as many as one in 110 people.1 Wherever ASD occurs it can compromise the quality of daily living for both affected individuals and their carers and families,2,6 and has longer-term implications for their educational achievement,3 mental health,4 and ability to make and maintain good relationships.5

A range of educational and behavioural interventions are available which address the main features of ASD to optimise family cohesion and opportunities for affected children to fulfil their potential. These therapies tend to be resource-intensive, requiring a lot of time and sustained one-on-one attention from qualified professionals. When it comes to accessing such services, it’s easy to imagine that families living in rural and remote areas must find themselves at a significant geographic disadvantage.

The Lishman Health Foundation has funded a program of research tackling the question of the impact that living outside the main cities has on access to ASD services. The research, conducted by Curtin University in collaboration with the Disability Services Commission, has taken the form of a survey to identify what processes families go through to obtain an ASD diagnosis and to access services, and how having a child or young person with ASD affects everyday family life—measuring stress, quality of life and daily routines. Nearly 300 families have been involved in the survey, with a number of publications under way.
Quality of life

Trialling different approaches
Alongside the survey, a number of families have been participating in a randomised controlled trial of a tablet-based app designed to complement in-person early intervention services. The trial is using both quantitative and qualitative methods to assess the actual and perceived effectiveness of the innovative technology for families in regional areas.

Works in progress
In addition to work already published, a number of papers coming out of this research are planned or in progress, due to be completed in 2019. These include:

• a poster summarising the impact of sleep disorders in children with ASD on caregiver quality of life
• a series of papers relating to the tablet app and its usefulness
• a study of the effect of regionality on variation in stress, coping routines and quality of life for parent of children with ASD
• a summary overview of service use by families of children with ASD in Western Australia.

The Lishman Health Foundation is a private organisation established to fund and promote health research carried out in, and for the benefit of, people living in regional and remote areas.

Donations to the Foundation are tax deductible and may be made via the website at www.lishmanhealthfoundation.org.au/donate or by contacting the Executive Officer via email to admin@vlfoundation.com.

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References

www.lishmanhealthfoundation.org.au