Medical Xpress

Living with a disability in rural Australia

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Rural families in Western NSW who have a child with a disability are faced with difficult decisions about whether or not to stay in their communities, according to a study by the University of Sydney.

"The lack of access to therapy services such as speech and physiotherapy in rural Australia often means families are forced to compromise on services if they decide to stay," said Dr Angela Dew from the Faculty of Health Sciences.

"It's testament to the sense of community of small rural towns that many people do stay when faced with such limited options."

When a child is born with, or acquires a disability, one of the biggest decisions faced by rural families is whether to stay or move to a larger metropolitan centre to improve their access to support services.

Researchers from the University of Sydney spoke to 80 families in Western NSW about their experience and found that social factors such as friends, family and the local community were strong influencers for staying. Conversely, personal and economic factors made it a very difficult decision, often putting a strain on family relations and imposing significant financial hardship.

"When regular trips to the specialist mean four hour drives or overnight stays and days off work they aren't sustainable, especially when caring for other children," said Dr Dew.

A co-author on the report, Vicki Happ felt forced to make the move closer to a regional centre, and away from extended family, to give her twelve-year-old son with Down syndrome better opportunities.

"There was limited access to therapy, we were always on waiting lists, there was a limited choice of providers and when we did get service it was inconsistent. We tried to go down the private path but even if we had the money private therapists weren't available," Ms Happ said.

"If we couldn't get Reggie's speech improved I knew that in the long run he wasn't going to make friends, get a job, and get independence.

"The situation of rural carers means there is always a trade-off and it depends on what your expectations are and what you rate most highly."

Dr Dew said the study raises some concerns about how the National Disability Insurance Scheme (NDIS) will provide users with greater choice and control when there currently is no choice in many rural areas.

"It highlights the need for the NDIS to consider different financial compensation and support arrangements for rural users, as well as the introduction of more innovative service delivery through local support roles which use online technologies to link to specialists in larger centres."

About the study

This study, published in the inaugural issue of *Research and Practice in Intellectual and Developmental Disabilities*, is part of a larger four-year research project exploring the experiences of the estimated 40,000 people with a disability living in rural NSW. Funded by the National Health and Medical Research Council, the Wobbly Hub and Double Spokes Project aims to develop, implement and evaluate new models of

therapy service delivery for people with a disability living in rural areas.

More information: "Rural Carers of People with Disabilities: Making Choices to Move or to Stay." Angela Dew, et al. *Research and Practice in Intellectual and Developmental Disabilities*, Volume 1, Issue 1, 2014. DOI: 10.1080/23297018.2014.908481

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