Disengaged services and disempowered rural consumers: implications for NDIS in the bush

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Aims: The aim of this study is to assess key issues in service provision for families of children with developmental disabilities living in rural areas. A particular focus is on challenges of appropriateness and adequacy of support services in meeting the needs of rural clients.

Methods: The overall project used a multi-method research design, including postal surveys and in-depth qualitative interviews with parents of children with disabilities residing in northern rural NSW. This presentation focuses on findings from the qualitative component.

Relevance: Children with disabilities who live in rural Australia are doubly disadvantaged: first, by having a life-long disability; and second, by living in an Australian region that has limited services and opportunities. Given the debates around the implementation of the National Disability Insurance Scheme (NDIS), the findings from rural studies, of which there are very few, are useful in understanding the challenges associated with service provision from the consumer perspective.

Results: The overall parental perceptions were of fragmented and overly bureaucratic services, and disengaged service providers who were unsympathetic to the considerable needs and unique challenges of rural families. Some of the major themes included:

- **Lack of information**—Many rural parents were not made aware of types of services and eligibility criteria.

- **Bureaucratic barriers**—Parents reported a maze of bureaucratic processes to access even basic services. Often they had to provide the same information on multiple forms across different agencies.

- **Lack of training**—Health and other service providers, with a few notable exceptions, were perceived to have inadequate training and experience for their respective roles; and were reported to lack empathy for rural clients.

- **Fear of retribution**—Parents were ‘apprehensive’ of voicing their dissatisfaction with quality of services for fear of punitive action and withdrawal of few available rural services.

Conclusions: The study provides insights into consumer (parental) perceptions of inadequacy of support services and attitudinal issues of service providers. Policy makers need to focus on both increased availability and better integration of relevant support services, as well as commit to improvements in pre-service and ongoing staff training and professional development that is cognisant of perceptions and needs of consumers in rural areas. Implications of the present study for service provision for rural clients under the National Disability Insurance Scheme (NDIS) will be discussed.