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Can you hear us? Children with a hearing loss in rural Australia

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Children with disabilities living in rural Australia have difficulty accessing specialist medical, allied health and educational services. There are several identified barriers to accessing services in rural areas including a lack of services, poor communication, travel demands and a low socioeconomic status (SES). Children with a hearing loss require timely access to specialised hearing testing and intervention to achieve optimal speech and language outcomes. Support needs include regular access to paediatric audiologists, teachers of the deaf and speech pathologists, particularly in the early years. There is no identified national research examining the availability of services for children with a hearing loss. This presentation reports the preliminary results from a national study investigating the experience of accessing services for children 0-12 years old with a hearing loss in rural and urban Australia. This study also investigates the rollout of the National Disability Insurance Scheme (NDIS) in rural Australia.

Method

Organisations that serve children with a hearing loss throughout Australia were asked to distribute an invitation to complete a survey to parents of children with a hearing loss and the specialist professionals who work with these children (e.g., audiologists, teachers of the deaf, speech pathologists). The survey contained both closed and open questions regarding the child's hearing loss, the availability of services and the National Disability Insurance Scheme (NDIS).

Results

At the time of writing, the survey had responses from 96 parents and 95 professionals. The majority of parents reported that their child used spoken language to communicate and attended mainstream education. The preliminary results indicated that children with a hearing loss in rural Australia experienced reduced quality and frequency of service. Families often had to travel to larger centres to access specialist services such as paediatricians, ear nose and throat surgeons, paediatric hearing intervention and cochlear implant programs. Families in rural areas experienced higher costs than families in urban areas due to travel and accommodation requirements. Although each state government has a Patient Assisted Travel Scheme (PATS), it does not cover the travel costs to allied health and educational appointments. Regular service from audiologists, teachers of the deaf and speech pathologists is essential for children with a hearing loss. The option of teleintervention is now offered to many rural families. While parents were generally satisfied with teleintervention, they viewed face-to-face intervention as more effective.

The majority of families who completed the survey already received National Disability Insurance Scheme (NDIS) funding. Parents reported a wide range of experiences of the NDIS. Some parents reported that the NDIS had improved services for their child, while other parents reported multiple challenges. Parents in both rural and urban areas had difficulty starting on the NDIS, communicating with the NDIS and reported frustration at the yearly requirement to prove their child continued to have a hearing loss. Parents in rural areas also reported that the introduction of the NDIS did not expand their choice of service providers.

Professionals reported a more consistent experience of the NDIS. Professionals were dissatisfied with many aspects of the NDIS. Professionals reported poor communication with the National Disability Insurance Agency (NDIA). Professionals found the NDIA difficult to contact, the NDIS website difficult to navigate and did not feel confident with NDIA systems. Professionals serving both rural and urban areas were dissatisfied with the lack of consistency in funding allocations. Professionals were concerned that families that experienced disadvantage received less funding than families that were able to advocate for their child.

Discussion and recommendations

Children with a hearing loss require intensive support to achieve their communication potential, particularly in the early years. Children who live in rural areas experience more barriers accessing services than their urban peers. This study found the barriers reported in rural areas included a lack of specialists, limited information, and a limited choice of services. Parents in rural areas experienced higher travel demands and the associated costs.

Parents in both rural and urban areas reported a wide variety of experiences with the NDIS. Some parents were satisfied, and some parents were dissatisfied with service provision through the NDIS. Parents in rural areas did not find more choice or a greater number of providers with the introduction of the NDIS. Overall, professionals in rural and urban areas were dissatisfied with the NDIS due to poor communication and inconsistent funding packages.

There are a number of solutions to improve service provision for children with a hearing loss living in rural areas. Parents were satisfied with teleintervention, but also valued the opportunity to receive face-to-face intervention. Several service providers offer intensive support in an urban centre over a few days to provide specialist services and to network rural families. Families valued this alternate service delivery, particularly the formal and informal connections they made during these intensive support periods.

Another solution to improve access for children from rural areas is to consider the expansion of the Patient Assisted Travel Scheme (PATS) to include educational and allied health appointments. In addition, providing specialist NDIS planners in subtypes of disability could improve the consistency of NDIS funding packages. All families, regardless of where they live, should be able to access specialist NDIS planners through the option of videoconferencing. Innovative solutions to service delivery could improve the access to the specialist support received by children with a hearing loss living in rural areas.

Presenter

Megan Barr is a speech pathologist and special education teacher who has worked with children with a hearing loss for more than 20 years. She is currently a PhD student at The University of Newcastle where she teaches in the speech pathology and special and inclusive education programs. She has worked at centres that service large areas of NSW, including the Sydney Children's Cochlear Implant Centre and 17 years at the Royal Institute for Deaf and Blind Children in the Hunter. She has spent the last five years working with Indigenous children at a local school.