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Submission to the Joint Standing Committee on the National Disability Insurance Scheme

Cairns Corporate Office
Phone: 07 4047 6400
189-191 Abbott St, Cairns QLD 4870
P.O Box 7410, Cairns, QLD 4870

Alice Springs Office
1/1B Stokes Street, Alice Springs NT 0870

Adelaide Office
29-31 Hakkinen Rd, Wingfield SA 5013

www.crana.org.au

ABN: 31 601 433 502
Registered Training Organisation (RTO) No. 40719

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Thank you for providing CRANAplus (Council of Remote Area Nurses Australia) the opportunity to submit feedback to the Joint Standing Committee on the National Disability Insurance Scheme Inquiry – NDIS participant experience in rural, regional, and remote Australia.

CRANAplus is a grassroots, not-for-profit, membership-based organisation founded in 1983. We provide a wide range of services, support, and opportunities to nurses, midwives, and other health professionals to ensure the delivery of safe, high-quality primary healthcare to remote and isolated areas of Australia. We advocate for change on issues affecting the health workforce and remote populations, including safety, health inequality, and workforce availability. We offer feedback from this position.

CRANAplus members were consulted in developing our submission. Their feedback reflects the diversity of the communities in which they live and work and highlights that geographically isolated communities are not only thin markets for support and care services. They are each unique, with community norms, expectations, strengths and weaknesses, services, resources, and infrastructure. Options and redundancies within infrastructure, services, community relationships, and human support are not equivalent to those in regional and metropolitan communities. Rural, remote, and isolated communities face challenges in social determinants of health, leading to increased experiences of ill health, accidents, disability, and shorter life expectancy. Those living with disability in isolated communities do not have the same experience of disability or engage with the NDIS in the same way as those in more metropolitan settings. Services can and do deliver excellent outcomes for NDIS participants in some areas, but the reach and scope of such services are limited and broadly tenuous.

NDIS Entry and access

Member reports indicate extreme divergence in communities' accessibility to NDIS. For instance, one community reports that potential Aboriginal and Torres Strait Islander NDIS participants are declining assessment for reasons such as personal safety (MMM 7). NDIS funding can further complicate potential participants' social, housing, and financial circumstances and community relationships. At the other extreme, significant resources were applied in another community to support participants to access NDIS. Plans and packages were implemented, but *no* providers have been available to support them, even from health services where access to allied health professionals has ceased (MMM7).

NDIS service access and provision

CRANAplus members report a variety of barriers to accessing NDIS-supported services in remote areas included in plans.

- There are locations (MMM7) where no service is available to participants, and potential providers and potential service providers are not applying to be NDIS providers, knowing they cannot meet the service need.
- Where available, NDIS providers are neither consistent nor reliable, particularly in providing personal support, transport, and cleaning. For example, support workers (and transport) frequently do not attend as planned without notice or explanation.
- Incomplete service delivery is an issue. In one example, a lift and personal equipment were provided to support a NDIS participant in attending and using a local swimming pool. However, the lift still needs to be installed. There is no timeline for installation, and the wait has been over 12 months.

- There are multiple instances of service providers with little to no disability awareness. For example - registered nurses providing specialised care are additionally cleaning a participant's home as a NDIS provider subcontractor cleaners refuse to do cleaning beyond what they would do in a 'usual' domestic context and are asking NDIS participants not to spill food and clean the residence before they attend, among other requests.

NDIS service coordination

Distance and workforce availability are barriers to providing NDIS-supported services in rural and remote communities. Members have provided service coordination feedback, primarily regarding MMM6-7.

- There is reportedly good access to telehealth for some allied health services through remote health services. However, in-person services are intermittent, less frequent than planned or do not match participants' needs (particularly for children experiencing rapid growth). It is unclear if an unintended consequence of improved telehealth is fewer in-person allied health visits to the community. Another member indicated that allied health visits have ceased in their community, with all previously visiting allied health professionals leaving to work privately.
- NDIS coordinator turnover is high, and each new coordinator sparks a repeated round of questioning and justifying the level of support required and planned. In one example, a member explained that with multiple coordinator changes, one participant has been repeatedly moved to the end of the respite waitlist based on questioning of support needs.

Care service intersections

There needs to be a better understanding and accommodation of the needs of NDIS participants and the processes and goals of NDIS across the health (acute, ACCHO's and primary health care), aged care, and education sectors. This need is amplified in smaller communities. NDIS participants meet resistance and, at times, overt friction at the interface of non-disability services, particularly when these services face high to extreme workforce turnover, at times inexperienced and disability-unaware staff, and are under pressure to deliver services within a defined scope limiting flexibility.

There are a small number of cross-sector coordinator roles in the health sector in some geographically isolated areas (complex care coordinators/nurse navigators). These positions assist those with complex care to navigate the health system but occasionally assist across other care sectors. Members report that these positions do help support those living with a disability to some degree but are overwhelmed by the need and limited resources. Most stay in their position briefly, taking community and service knowledge when they leave.

Complex disability and health care can require NDIS participants to attend appointments in metropolitan areas. There is support for this through NDIS; however, once there, stays are often extended, sometimes by multiple weeks, as additional appointments (allied health and medical specialists) are scheduled to take advantage of the person being 'in town'. There are cultural implications, and the person and their supporters are isolated from participating in their community and family for long periods. The disability workforce is also impacted. Support workers and other services are inclined to seek other employment opportunities when a participant, who may represent a significant proportion of their employment, is not in their community for extended periods.

NDIS Workforce challenges

Ideally, disability services should employ local community members. Education and training are barriers to establishing and building this local workforce in MMM6-7 locations. External support providers will likely always be needed; however, this as a primary strategy presents clear challenges.

Access to quality, culturally safe training, and flexible assessment strategies are the most frequently identified barriers to capacity building across all care sector workforces in isolated locations. Education and training need to be locally accessible at a minimum. Additionally, training to develop disability awareness and cultural safety and to apply a human rights approach across all care and service settings in rural and remote areas is required. CRANAplus members also identified preparation to meet the minimum requirements to undertake training, particularly literacy and numeracy requirements, as an initial barrier in some communities. If present, in-place literacy and numeracy programs are generally community-resourced and run. Access is also limited.

Recommendations

NDIS in remote communities is one component of a highly complex care and community context. Broad and prescriptive systems such as NDIS, applied to small, highly complex contexts, will inevitably fail to equitably meet the needs of individuals immersed in the nuance of diverse, small communities. The NDIS can also add complexity to the lives of not only the person living with a disability and their supporters but also their broader community.

The challenges facing NDIS participants are shared community-wide and across sectors. One CRANAplus member explained the wicked problems faced.

> *'[The service has] no more on-the-ground staff or expertise than they ever did and are unable to attract anyone to do the NDIS work on the ground. That's why our health service didn't apply to be an NDIS provider. It's not possible. There is no accommodation remotely to put up employees, even if organisations had funds and wanted to train local people to be workers, there is no accommodation for trainers even.'*
>
> (RAN, in MMM 7 community)

There is value in taking a community-centred, cross-sector approach to disability, health, aged care, and education in remote communities, more so than in metropolitan areas where sectors are more siloed and options to support choice are present. Sectors necessarily work together in remote areas. However, where this happens, it is underpinned by goodwill and is unsustainable. With fewer options and multiple barriers, sharing resources, capacity, workforce, and skill development is an option. Significant and formal collaborative strategies to share knowledge, skills and resources between sectors and services at the community level are needed to meet NDIS participants' goals within their unique community context and require funding and support.

Should further clarification or information concerning feedback from this submission be sought CRANAplus would be pleased to assist.

20th February, 2024