

Child and Adolescent Health Community of Practice

Women's and Children's Health Network

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Letter to Joint Standing Committee on NDIS Planning

Re: Child and Adolescent Health Community of Practice feedback and recommendations in relation to NDIS Planning in South Australia

As Deputy Chair of SA Child and Adolescent Health Community of Practice (SACAHCop), which provides clinical governance for child and adolescent services across the state, I write to you to raise issues of concern about the National Disability Insurance Scheme (NDIS) Planning and the state-wide impacts on children, young people, their families and the SA Health system. SACAHCop welcomes this opportunity through the Joint Standing Committee on NDIS Planning and appreciates consideration of this feedback.

Governance:

SACAHCop is conscious of the complexities involved in National Systems' reform, and has been actively advocating for planning improvement with the National Disability Insurance Agency (NDIA) and their various partners such as; Mission Australia, KUDOS and FEROS throughout the complex evolving process. Significant governance issues impact NDIS planning and disadvantage vulnerable children and their families.

Workforce:

Acknowledging the rapid demand for a NDIS skilled planner workforce, the increased recruitment came without the required quality systems and governance processes in place to ensure children's needs are equitably and consistently assessed within a reasonable timeframe. Experienced clinicians from across the health system report planners regularly fail to recognise or understand the complex needs of children with disability. There is major concern in Health about the expertise of planners, as clinicians try to advocate on behalf of individual children, support distressed families and deal with the fallout of ineffectual planning. Adopting the findings and recommendations of the assessments undertaken by health professionals, would utilise this expert resource, reduce duplication and significantly streamline NDIS planning discussions. The current system enables families with more health literacy or ability to advocate for their children to receive different levels of funding than more vulnerable families.

Navigating the system:

Finding the right pathway into NDIS is difficult enough for many families already within the system, but for vulnerable families the challenge of navigating the system is overwhelming. This includes psychosocially disadvantaged families with poor literacy, Migrant and Refugee populations, families living remotely and children in Out of Home Care. A deep concern is that Aboriginal families are further disadvantaged by this complex system. Family vulnerability impacts how such families enter the system, how they struggle to navigate it, and ultimately the package of support they receive.

The large volume of ever changing NDIS communication challenges health professionals; so for some families is very difficult to comprehend and keep on top of. There are many recent examples reported by health professionals utilising recommended links for South Australian NDIS providers, that link to agencies in Victoria and NSW! Moreover, it is often unclear what services each of the providers deliver and whether they have the necessary expertise to deliver the support required. Some families simply give up trying, experiencing frustration accessing false links or waiting hours on the telephone only to be diverted elsewhere. It is challenging for many disadvantaged families to repeatedly take the initiative, have the persistence to keep asking questions so that eventually they may obtain the correct advice.

Children under the Guardianship of the Minister:

The NDIS does not specifically prioritise services to this group of children and young people, and does not recognise issues such as Post Traumatic Stress Disorder, disruptive behaviour, language impairment and other issues specifically related to the early neglect and trauma these children have experienced when considering eligibility for the NDIS.

Plan costs:

The NDIS planning information related to cost rebates should be transparent and available to health professionals and consumers alike. There are increasing reports from families that NDIS funds are running out 6- 9 months into their plans as well as increasing numbers of appeals to generated plans. This results in cessation of vital therapies, plus timely and resource intensive renegotiations of plans to reinstate the required support.

These costly inefficiencies would be reduced with structured and transparent information and the appointment of consistently skilled planners. An analogy which describes the experience of families with poor health literacy trying to work with NDIS planners is akin to being in a court room without a lawyer; a very stressful and complex experience.

There are inequities and inconsistencies in cost and packages offered and a wide variation in the amount of funding approved for children with similar diagnoses and circumstances that appear dependent on the planner's skills and the strength of advocacy of the family.

Inconsistencies and lengthy delays:

Some children automatically meet eligibility criteria, but for others, for example those with developmental delay, the definition is less clear, open to interpretation, and has changed over time. Early intervention therapy and support are critical to enhance the periods of rapid development in the early years in which foundations for learning patterns are laid down as a basis for increasingly complex skills. Early childhood intervention for children with disability and developmental delay has the potential to positively impact all areas of development in the long term through to adulthood. In the NDIS as it is currently functioning, children are waiting for extensive periods for services, and are missing this critical period for early intervention. Moreover, these children are being redirected to Health service waiting lists, exacerbating pressure on an already strained system and increasing waiting times for other health consumers.

Families battle with a lack of clarity and changing position of services in-scope for the NDIS and service gaps continue to widen. The NDIA continues to make changes to what services it will fund, and there is a lack of transparency with other Agencies about the changes or planned changes. There appears to be little appreciation of the impact on the broader system when changes are made by the NDIA (e.g. Autism funding).

Default System:

Not all services previously provided successfully by the disability sector in SA are now covered by the NDIS. The public Health System is increasingly being seen as the 'default' provider for these services that in SA have never previously been delivered by the Health system, and cannot be provided from within existing resources and expertise.

SACAHCOP understands the complexities involved in NDIS reform and is hopeful that the Joint Standing Committee on NDIS Planning will recommend significant simplifications to the approval and planning process together with, improvement of system governance and development of the planning workforce, so that greater capability and capacity are available to meet the needs of vulnerable families.

Health Professionals across the system including GP's in the community want to work with NDIS planners to support children's care plans, so that they receive a fair and timely response to enable best developmental capacity and functioning.

We understand that many of these concerns are likewise experienced by our counterparts in other jurisdictions. The roll out of a national scheme that aims to improve access to services for children with disabilities and developmental delays is instead difficult to navigate and unnecessarily fragmenting the care of children and particularly in vulnerable families, impacting their lifelong developmental trajectories and opportunities, with considerable flow on effect to social and community outcomes.

Thank you for considering these concerns, I am happy to meet and provide further information as appropriate to support these issues.

Yours sincerely

Maeve Downes

D/Chair, SA Child and Adolescent Health Community of Practice

Cc: Lindsey Gough, Chief Executive Officer Women's and Children's Health Network