



Transitional arrangements for the NDIS

Can:Do Group submission to the Joint Standing Committee on the National
Disability Insurance Scheme

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About the Can:Do Group

Can:Do Group is the umbrella organisation that encompasses South Australia's two oldest charitable service providers, Can:Do 4Kids, Townsend House and Deaf Can:Do, The Royal South Australian Deaf Society.

The Can:Do Group also incorporates Can:Do Hearing, an audiology business whose profits directly contribute to Can:Do 4Kids and Deaf Can:Do services.

With over 140 years of experience, we are the leading experts in specialist services for people with hearing and vision impairments in South Australia, - and each year we touch the lives of over 20,000 people.

Can:Do 4Kids, Townsend House, is South Australia's oldest charitable service provider, offering vital therapy and support to children and young people who are blind, deaf or have vision, hearing or sensory impairments and their families.

Established in 1874 by William Townsend as a school and accommodation for deaf and blind children, Townsend House has provided family-centred support for over 140 years.

Deaf Can:Do, The Royal South Australian Deaf Society, delivers vital services and support to Deaf and Hard of Hearing South Australians.

Established in 1891 by Townsend House Superintendent Samuel Johnson as the Deaf and Dumb Mission, Deaf Can:Do is South Australia's second oldest registered charitable service provider. Throughout the years, our services have evolved to meet the ever-changing needs of the South Australian Deaf community.

Our work aims to alleviate isolation and equip people who are Deaf and hard of hearing with the assistance, knowledge and confidence to live independently and contribute to the community.

About this submission

The Can:Do Group, and in particular Can:Do 4Kids, Townsend House, have been delivering services under NDIS since the inception of the children's services trial site in South Australia in July 2013..

In our implementation of these services we have developed significant experience and expertise in NDIS service delivery. We have provided NDIS claimable services to nearly 500 children over the last four years.

We have also consulted broadly with our client cohorts to gather their feedback in order to ensure this submission is representative of their experiences.

We would value the opportunity to present further to the committee in order to share our experiences, and help shape a robust system for the future of our services and the improvement of outcomes for all Australians living with a disability.



Terms of Reference Part A - Interface

The boundaries and interface of NDIS service provision, and other non-NDIS service provision, with particular reference to health, education and transport services.

We hold the view that interface and collaboration across government sectors was significantly better prior to the introduction of the NDIS. In our experience, NDIA has communicated poorly with the health and education sectors in particular, and these sectors are particularly affected by NDIS. There is a distinct lack of clarity for organisations in these sectors around what NDIS is and does; and HOW to interface.

During the initial roll-out NDIS seemingly did not acknowledge the different sector relationships that were already effectively in place, and effective in supporting clients to achieve their desired goals. The fact that providers were more willing to collaborate or communicate when they were not 'fighting for their patch' means that in the end service delivery is more siloed than ever.

NDIS was not set-up to address all aspects of a child's life and therefore these other departments must be kept in the loop. We have experienced a lot of 'stepping back' under the auspice that "NDIS will take care of that". On the other hand we see some duplication of roles as well as the NDIA attempts to provide pathways and referrals that other departments continue to have in place at the same time.

The need for everything to be the standardised across the country has also impacted communication and relationships negatively.

An example of this is that no one in SA tendered for the ECEI partnership. In our view, this happened for a several reasons:

1. NDIA required an entire state tenderer and this role has not previously been in place in SA (unlike other states).
2. To submit a tender it was required that you not already be providing paediatric services under NDIS, yet as we were the paediatric trial site so anyone involved in this space was providing services already.
3. All children in our state had already been on-boarded into NDIS so if you were successful in the tender the first few years of operation would be limited to reviews with limited new clients.

Given all of the above, there was no acknowledgement that the NDIA could have taken a different route in this state; and now we are faced with a lack of clarity around what to expect of the Access Partner and what continues to happen internally by NDIA staff, as well as when and how to access all services. In SA the priorities for this partner are unclear to us and we also feel that there has been a lack of transparency in knowing what the future plans are for this role. Note that we are one of two states without a partner listed on the NDIS website so the expectation that participants will self-refer is not possible.

The interplay between systems continues to present barriers and challenges for families. Those accessing services from all systems; health, education and disability, report little or no collaboration or effective communication to amongst their range of cross-sector service providers to ensure good outcomes. One family reported feeling the systems were working against each other and the "battle" between systems impacting on outcomes.



At the end of the day, all systems are talking about the same child- the child who is having challenges within the home and requiring supports for this is not a different child when they are transported to school, or are receiving services from the health sector. Though they are the same child, there are different priorities and focuses and the family are required to tell their story over and over again to try and coordinate all of the systems to work effectively together.

This also disadvantages families that are less able to advocate for their child as they are likely to receive less coordinated support across multiple services.

The health sector, and in particular those on the ground delivering services in the health sector, seem to know very little about NDIS. When we ask staff high up within the health department we are told that there are lots of meetings, and there is lots of knowledge around NDIS, but this is not our experience when interacting with those delivering services, and in our case specifically with specialists in the vision and hearing fields.

An example of this is that there remains an internal referral system that occurs in this state when a child is diagnosed with a hearing loss through the Universal Newborn Hearing Screening (UNHS) process. When we inquired one year ago why these children were not being referred to NDIA we were told that the department knew very little about NDIS and was not comfortable referring directly there.

Recently the Department of Education and Child Development (DECD) transitioned a position into the Department of Health to work with families with this diagnosis – and they continue to not be referred directly to NDIS. Whilst we believe this is system duplication we do not advocate for this initiative to be dismantled at this time as we believe it is positive that families with diagnosis of deafness are continuing to get information relevant to them and are being advised about all service providers who work in this specialist field. In the future we believe the NDIS could take a modified approach to planning that includes similar roles – having people with specialist knowledge.

Currently families report of disjointed/disconnected systems all working within their own silos, negating good outcomes and a significant waste of time and resources through the duplication of services, or advocating for services that are required and not being provided.

Our question would be; how can we ensure a streamlined system where clients/families are seen in the same way and not defined or impacted on by what system is providing which service? Communication is the key and we believe having a key person/lead that coordinates, manages and supports families to navigate systems is vital. We have lost the traditional case management/coordination role with the introduction of the NDIS, service providers have stepped back and are only providing what they are being asked to provide by the family as they are only being paid for that service. This negates the importance of coordination, collaboration and navigation alongside families – yet outside of most initial plans which do have some support coordination no one is being paid for this, nor has resourcing to do so at no charge, so it is not being done.

Families state that they now have NDIS funding but have no idea what or how to use it. Support connection/coordination is the NDIS answer, however, in reality the value of this function is more than just linking families to services and discussing bringing a plan “to life” it is about walking alongside a family (if this is what they need) to develop advocacy skills, understand the system and navigate for best outcomes, and capacity building is at the heart of this. This is noted most for children and families needing early intervention services. Research indicates that what parents



prefer is a single point of contact with services and an effective, trusted person to support them get what they need (Drennan et al., 2005). An effective way to approach this challenge is to use a key worker model of service delivery (Alexander & Forster, 2012; Luscombe, 2010; Greco et al., 2004; Shelden & Rush, 2013).

One of the biggest issues currently seen around the poor interface between sectors (NDIA, health and education) is goal setting – each agency seems to deem their goals for the child as paramount and often these are at conflict with each other and/or with the family's aspiration and/or the child's current and future abilities. There are constant inconsistencies between school and NDIS, it is stated that NDIS is not supposed to support school endeavours but then some people get these supports in their plan.

Evidence states that parents prefer interventions that are meaningful, easy to do, fit into their daily lives, and support their child in learning skills that help them be part of family and community life (Dunst et al 2010). When parents provide intervention in daily routines they are more likely to attribute progress to what they do between home visits, rather than to what the professional does during a home visit (McWilliam, 2010a; McWilliam, 2010b).

We would like to advocate for the NDIS to make a broad decision on particular goals such as literacy and handwriting. Some planners see them as educational goals and do not give funding for therapy to address, them whilst others fully fund activities to support the achievement of these goals as they realise the overarching need in a child's life to become literate.

Examples

- *Lack of consultation in NDIS goalsetting. A family received a plan stating a goal to be "...she will be able to use public transport independently and find her way around". The family hadn't even mentioned this as a goal however, when they received their plan, this had been specified. This client actually already catches public transport on her own, so support toward this goal is not needed.*
- *NDIS goals are either extremely broad; "I want my child to communicate"; or very specific "I want my child to read an age appropriate story", there is no consistency to the goals.*
- *There is inconsistency regarding families accessing tutoring supports within their NDIS plan, specifically around literacy skills and utilising core supports to access these services. The blurred line around what sits within the realm of 'education' versus falling within NDIS funding, both in regard to the goals set but also in the limited transference of skills and particularly equipment. i.e. NDIS challenge supporting equipment which is linked to education goals, however we believe would be beneficial to look more broadly at the child in multiple contexts, home, community, use of same equipment across all domains.*
- *Most Occupational Therapy (OT) included in plans has goals 'to improve handwriting' - approximately 50% of OT caseloads include handwriting goals (some planners see handwriting as school and some do not). Client M.A's OT has provided 2 years of handwriting support, but no follow up from their teacher means this was not achieved.*
- *Client C.D.'s school requests functional supports such as getting ready for camp, hygiene, versus parents goal to read and write (unlikely to happen). There is a disconnect between NDIS and families – NDIS is not supporting functional goals for the client because of parents directing goal setting to their preferences.*



- *The DECD policy of not letting Service Providers into some schools (at the discretion of school) can be challenging. Service Providers have to give lots of information and develop a plan for service/goals and schools are very specific about times and rooms to work in. This differs from the way providers want to work with schools e.g. upskilling education staff, provision of programs, in-class support and environment modifications. Parents often want service to happen in schools when the child is less likely to be tired – we get caught in the middle.*
- *Specialist School (SASVI) not allowing service providers to use NDIS funding in school so we are required to continue to use MAC funding.*
- *Service providers are often seen as additional helpers/SSOs for NDIS funded students. ‘Can you work on English assignment?’ Schools are often not entirely aware of NDIS goals and aims.*
- *There are significant issues when a whole school chooses one type of Assistive, Augmentative Communication (AAC) approach e.g. Adelaide North, Modbury Special School using PDD and Proloquo2Go. There has been no parent training or access to devices and no parent choice on system. Service providers have to work with the system that the school has chosen. There is no transference from school to home and when therapists attend these schools they are required to use the communication tool given by school. We advocate that to create transference of communication skills NDIS ensures access to these devices to families as school is not doing this for home studies.*
- *Schools want Speech Pathology (SP) and OT support to focus on goals as outlined in student NEPs. These goals may differ vastly from NDIS plans e.g. Client B.W. school goal of AAC exposure and social skills, whereas parent wants clearer articulation of speech sounds.*
- *Client G.S. has an NDIS goal to improve oral communication skills with intensive speech therapy support. However at school uses Auslan + exposure to Auslan with Teacher of the Deaf (TOD) and deaf SSOs at school. This is a disconnect from families wishes.*
- *NDIS is favouring a particular App which is a one approach fits all – there is a lack of awareness around communication options. We have made recommendations of other devices which get knocked back because of cost but they have significant improvements on the chosen App.*
- *Client M.S. has toilet training goals on NDIS plan. This is not supported at school due to restrictions e.g. one toilet facility, limited staff available, time restrictions on independence. As such, this goal is unable to be achieved and once again illustrates the disconnect between school and NDIS.*
- *Client L.H presents with severe speech delays, severe language delays, significant fine and gross motor delays, vision impairment and is receiving PT, OT, SP weekly. There is no SSO support at school and the client was not found to be eligible. The school then requested the speech pathologist to complete an assessment for DECD approval/use. As an NDIS plan does not equal eligibility for school support often children require 2 assessments (one per government department).*
- *Working with multiple external services e.g. SASVI/Kilparrin advisory teacher services, private practitioners, DECD therapists, other service providers there is a disconnect in service delivery methods. All parties are unsure of who is involved, how to coordinate and who works on what goals? Families wanting more therapy for better outcomes but this leads to over servicing. Client T.H has 3 OTs plus a play therapist, Psychologist, 2 x developmental educators, SP and music therapist.*
- *Communication between school and home in regards to behaviour management strategies/supports differs. School strategies vs therapist strategies at home E.g. Client R.J.*



school organised boxing for sensory regulation client went home and hurt their mother. The mother is unable to implement this strategy. School requested equipment to be prescribed via NDIS plan e.g. mats. Therapist not recommended this equipment so schools using the therapists. Our SPs are regularly requested by schools to apply for iPads on behalf of children via NDIS.

- *Client C.H. has goals of increased independence, successful school transitioning, improved health and wellbeing, whilst his speech is unintelligible. Inconsistency of plan/vagueness as parents may not have put correct goal. We advocate that organisations should be able to be paid for time spent preplanning or to attend NDIS planning meeting.*

In summary:

- Staff in the Health and Education sectors are lacking in knowledge of the NDIS and its overlap/interfaces with other sectors.
- Clients are disadvantaged by the lack of communication across agencies.
- Plans and goal setting are very inconsistent, with each agency unclear as to what is in their remit.
- We believe the NDIS would be best placed to have planners with specialist knowledge/expertise in specific areas.
- The one-size-fits-all approach is not always appropriate across states, diagnoses and clients

Terms of Reference Part B – Inconsistencies

The consistency of NDIS plans and delivery of NDIS and other services for people with disabilities across Australia;

We have experienced significant inconsistencies in all aspects of NDIS plans and planning.

One of the specific areas we are concerned about is the amount of interpreting funding allocated in plans, we have seen a vast difference in interpreting funding amounts for both parents who are Deaf, children who are Auslan users and also for ESL families.

In regards to other inconsistencies across plans, we have also seen recent plans which are written around Early Intervention (EI) supports which identifies the need for flexibility in the use of the funding allocated, however then go on to stipulate the number of sessions allowed within this cluster i.e. 15 Occupational Therapy, 10 Speech Pathology etc. This presents a challenge, particularly for the younger client group, for whom the importance of service provisions is around engaging with a range of services to proceed with determining the need and priorities in conjunction with the family. When a plan outlines the specific number of sessions per discipline, this then results in confusion for the families and can limit the perceived flexibility of the supports.

There are also many differences in services received by self-managed vs agency managed plans. E.g. more easily able to purchase and control equipment/tech/programs they would like (FM systems, iPad Pros).

In addition to this, families with greater advocacy/language skills appear to receive more money in their plans. This means that those clients already facing a range of disadvantages are being further disadvantaged by the system.



Examples

From a Deaf client with a Deaf child:

- *“Chloe was due for a review of her NDIS plan in April 2017 – we attended an appointment at the St Marys office. Chloe’s NDIS case manager (Anthony Armstrong) also made a booking for an interpreter for me. The appointment took place mid-April.*

After reviewing the plan from 2016 and providing letters from providers regarding progresses etc, some adjustments was made for Chloe’s plan for upcoming 2017/2018

I then made a request to receive extra funding to cover interpreting costs (Chloe is Deaf and relies on Auslan – she still needs me present with her at any of her appointments as she is a child). I was advised that NDIS CANNOT give me separate funding – according to their reasons, NABS CAN AND WILL fund any appointments Chloe attends. This is not true and the NABs website advises participants to get NDIS funding for this.

Even after several support letters from CD4K, who even contacted the case manager, I was still denied funding for interpreters for Chloe. Up till now they are still denying me extra funding.”

- *One child has funding for more than one session a week of therapy, however interpreting for only a few hours.*
- *Inconsistency across plans/planners regarding supporting literacy development. Client G.K.’s parent had ‘to read at an age appropriate level’ as main goal of plan, and also had an iPad approved to support literacy goals because she advocated well - but no one else is getting iPads except for people needing it as a specific communication device.*
- *Client A.M got funding without diagnosis (slow learner on psych report) with an NDIS goal ‘to read an age appropriate story and to be able to write sentences’*
- *Inconsistency between clients above; similar age, specific vs nonspecific goals in plans, diagnosis vs no diagnosis, similar money given one plan specific and one plan vague without goals.*
- *Client brother and sister’s core support funding differed from \$34,000 to \$11,000 with the same diagnosis and same severity. The same planner made a plan twice for the sister, when this planner left NDIS, a new planner for brother’s plan resulted in significant drop in funding though he actually has higher needs than his sister.*

In summary:

- Interpreting allocation is inconsistent and often grossly underfunded in plans.
- Plans and goal setting are very inconsistent across planners and diagnoses.
- There is often a lack of flexibility in plans when required, or conversely plans are very vague.
- Those more able to advocate for themselves/their families receive higher funding.
- We would advocate for siblings (age 0-18) having the same planner. This should occur to ensure consistency for family and a broader understanding of the family context including what is in the other siblings plan.



Terms of Reference Part C – Information, Linkages and Capacity Building

The rollout of the Information, Linkages and Capacity Building Program

The rollout of ILC has highlighted several ongoing and/or transitional issues to us.

Many of the services previously provided under state disability grant, block or tier 2 funding cannot be individualised. Services such as our community Auslan interpreting services, provide vital community wide support but the current ILC framework does not support the successful tendering for the delivery of such services, nor does it acknowledge their importance to the community.

We would advocate that organisations previously receiving state disability funding that was block funded should be able to tender NDIA to support the same services under ILC. We would prefer to see this under special dispensation rather than be included with everyone else asking for general ILC funding.

We also believe that ILC is significantly underfunded and that there is far too much emphasis on national organisations, to the detriment of local service providers and to the detriment of effective service provision to local communities.

In summary:

- ILC does not cover some important services to the community that were state funded.
- ILC focus on national service provision is problematic.
- ILC is underfunded.

Terms of Reference Part D – Related matters

Any other related matters

We have many related concerns about the planning process in general.

We were told the planning process would be caught up by 30 June yet we still have more than 10 clients awaiting plan reviews. Multiple families have been told their initial paperwork has been 'lost' or not lodged in the system - even when a family went and handed it directly to a NDIS office. This requires the whole process to start again meaning more delays for families. Families have reported they feel this is buying NDIA more time by delaying families...

Some families that have difficulties with computer access which limits accessibility with the NDIS interface. Sometimes there is no plan in place due to difficulties for families and a lack of understanding how to interface with NDIA.

Additionally, families not wanting assessment or diagnosis means they are not eligible for NDIS or school support.

With regard to Assistive Technology, there are myriad planning and planner issues and inconsistencies such as;

- iPads were initially prescribed frequently, but now only as communication devices once approved – and this varies between children.
- Liberator (an Assistive Tech company) reported that specialist AAC devices are not being approved despite recommendations from specialised therapists and successful trials (e.g. Dynavox with Minspeak) iPads with Proloquo2Go are often seen to be more cost effective but are not always appropriate for clients.



- We have had many issues around our recommendations for equipment for vision impaired children getting knocked back for cheaper and often ill matching equipment

Client examples

- *Client JP lost all funding after first plan (change in parameters now needing diagnosis, APD not considered, significant learning delays at school now unsupported). No diagnosis and the family cannot afford to have this done.*
- *Client JM had 4 hours allocated to Oral Eating Drinking Care plan. No goal associated to feeding difficulties. Transport funding included but not utilised or requested by family.*
- *Client LP had a goal of 'to maintain adequate levels of hearing' set, but we do not understand how this relates to OT and SP therapy allocations for a hearing impaired client? To maintain hearing levels a child needs hearing aids. Child does have goals to be addressed by SP and OT but these were not captured on plan.*
- *No plan due to difficulties for families who do not understand how to interface with NDIA. Client MO has DHI and ASD diagnoses plus level 1 school support, no NDIS. Client MT has DHI, ASD, ID no NDIS plan. Occupational Therapy and Speech Pathologist targeting school goals when support required at home. We have some very high needs children and families just not engaging with NDIS. We would advocate that some families may not have or want to get a diagnosis but do not understand why they cannot not access NDIS when their child has functional needs.*
- *Families not wanting assessment or a diagnosis means they are not eligible, and there is no school support either. Client ZS has both school and Speech Pathologist querying ASD but family not wanting a 'label'.*
- *We have consistently seen many clients see a significant reduction in funds money from one plan to the next this year. Client Family G: have seen a reduction in their plan allocation from approx \$20,000 to \$10,000 this year.*
- *Client C.H: has had a reduction in the length of plan. We are seeing 3 month and 9 month long plans and are unsure as to the reasoning of this.*

In summary:

- Planning is still behind.
- There are accessibility issues which see some clients with inadequate or no NDIS plans.
- Formal diagnosis is required which disadvantages families not wishing to seek one.
- Assistive Technology supports are inconsistent and expert recommendations are often ignored in favour of cheaper options.

Conclusion

Whilst we acknowledge that the NDIA are working to resolve issues with a large and complex system, the inconsistencies and issues are causing considerable distress to our clients each and every day.



Our staff also struggle to support families to navigate the system.

Additionally, the adult Deaf community are becoming increasingly concerned about the impact that the NDIS will have on services to them and their ongoing ability to participate equally in the community.

We welcome the opportunity to provide feedback to the Joint Standing Committee and would welcome any further questions, to provide more examples or clarification, or to present directly to the committee.

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