



NDIS and the Family Support Program Interface

**Consultation Report for the Disability and
Carer Alliance NDIS Engagement Project**

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1. BACKGROUND

1.1 Children with Disability Australia

Children with Disability Australia (CDA) is the national peak body that represents children and young people with disability, aged 0—25 years, and their families. The organisation is primarily funded through the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) and is a not for profit organisation. Additional project funding is also received by the Department of Education, Employment and Workplace Relations (DEEWR). CDA has a national membership of 5000.

Vision

CDA's vision is that children and young people with disability living in Australia are afforded every opportunity to thrive, achieve their potential and that their rights and interests as individuals, members of a family and their community are met.

CDA's Role

CDA has the mandate to advocate for children and young people with disability living in Australia and undertakes the following to achieve its purpose:

1. **Education** of national public policy-makers and the broader community about the needs of children and young people with disability.
2. **Advocacy** on behalf of children and young people with disability to ensure the best possible support and services are available from government and the community.
3. **Inform** children and young people with disability, families and care givers about their rights and entitlements to services and support.
4. **Celebrate** the successes and achievements of children and young people with disability.

Guiding Principles

Children the Priority: The rights and interests of children and young people with disability are CDA's highest priority consistent with Australia's obligations under the UN Conventions, Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities.

Right to Childhood: Children and young people with disability are children first and foremost and have a right to all aspects of childhood that children without disability are afforded.

Right to Participation: Children and young people with disability have the right to participate, in whatever capacity, in the decisions that impact on their lives.

Inclusion: Children and young people with all types of disability, from all cultural and religious backgrounds and all geographic locations are supported by the work of CDA.

Recognition: For the contributions made by families and care givers to support the rights and interests of children and young people with disability.

Partnerships: CDA works collaboratively with relevant government, non-government and private sector agencies to promote the rights and interests of children and young people with disability.

Transparency: CDA is accountable, effective and ethical as the national peak body charged with the mandate of advocating for children and young people with disability.

1.2 The Family Support Program

The Family Support Program (FSP) is comprised of two key areas, Family and Children's Services and Family Law Services. Family and Children's Services aim to improve family functioning, safety, child wellbeing and development. They cover four key areas. These are Communities for Children, Family Relationship Services, Specialist Services (including family violence, drug and alcohol and relationship) and Community Playgroups. Family Law Services include Family Relationship Centres, Post Separation Co-operative Parenting; Supporting Children after Separation Program, Parenting Orders Program, Children's Contact Services and Family Dispute Resolution.

2. CONSULTATION OVERVIEW

CDA undertook this consultation as part of the National Disability Insurance Scheme (NDIS) engagement project. It focuses on children and young people with disability and their families engaged with the Australian Government's Family Support Program (FSP). CDA conducted discussion forums examining the envisaged impact on children and young people with disability and their families of the NDIS and the interface of the FSP and other programs. Feedback was sought on how to most effectively facilitate the coordination and support across programs. Face to face sessions were held in Hobart and Melton (Victoria) with families of children and young people between the ages of 8 and 23.

The Hobart forum was attended by 12 people and the Melton consultation by 5 people. There were 3 others registered for the Melton consultation but they could not attend on the day.

The consultations were conducted in the first week of March 2013 before the second reading of the NDIS bill, and so concentrated on the design of the scheme contained in the first reading of the Bill and the draft rules that had been made available. Participants accepted that the operational details were yet to be finalised, but were still able to talk about their key impressions and needs in regard to the scheme.

Each participant who agreed to attend was briefed in advance of attending the forum about the project and the nature of the consultation.

CDA sought participants' views on the likely impact the NDIS would have on their children and families and how it may interact with the other service systems in their lives. The emerging NDIS design was provided as background, including individualised funding, self-management and service coordination.

The interface between the NDIS and FSP had previously been identified by CDA as being critical to the establishment and effective operation of the NDIS for child participants and their families. Discussions regarding program interfaces to date have not included a significant focus on the FSP. However, it is vitally important that this interface is prioritised as being equally important as other program areas, such as health and education, and receives the required policy attention.

Many of the participants attending the consultations are currently or have previously utilised a number of service programs within the FSP in addition to other service programs. In the FSP, disability is identified as an indicator of vulnerability for families however the FSP does not provide disability specific supports. These have typically defaulted to being provided through the existing disability service system, meaning that many families are part of at least two unlinked systems. CDA is aware that currently there is a need for the linking of these service systems. It is imperative that the NDIS provides better coordination between services to alleviate the complexity for children and young people with disability and their families.

In both consultations, participants referred to their providers by name or type, not the funding program itself. They discussed that they were accessing a range of services such as counselling, support groups, case managers, family relationships, mediation and other services from organisations that are funded through the FSP. The participants' frame of reference for a discussion of service systems they use is their service provider, not the funding program that funds them. This was the case for FSP services and disability services used by participants in both meetings.

Many participants at the Tasmanian forum had been to local NDIS forums and were following the development of the scheme closely because they are in a launch site. However, they identified that they required clearer, more succinct information. They look to the NDIS to provide greater continuity and service access than the current disability system.

Participants in the Melton forum had not had access to the same level of information and background about the NDIS as those who attended the forum in Hobart. They sought basic information around the NDIS design throughout the forum as well as discussing issues with other service programs.

Repeated questioning about the design and operation of the NDIS came up throughout the forums as each new interface discussion topic raised different questions.

While participants generally thought that the focus on control and choice in the NDIS was positive, they made it clear that there was more to their lives than just disability or disability services. The reality of having other children, other services being present, other family demands and income security matters were mentioned as factors of life in participants' families in addition to the manifestation of disability. A number spoke of their priority being to exercise control over all parts of their lives, not just segments.

The consultation highlighted that careful consideration needs to be given to practical interface issues in order to ensure the NDIS can enable the goals of participants and families to be identified and resourced without competing with, duplicating or displacing other service programs.

3. KEY ISSUES RAISED IN THE CONSULTATION

3.1 The impact of the NDIS

Participants did not have universally similar views about what they thought the NDIS would mean for them. All participants said they needed more information about exactly how the NDIS will work in practice before they can come to a solid opinion about it, or could make any concrete plans for their child or their family as a whole.

Participants wanted information not only for them, but also said that their community service providers also needed information to ensure they have a good working knowledge of the NDIS.

"I need clarity before I decide anything. I need information about how the NDIS will work. What do I have to do to get into the scheme and who can assist with the information and following through with applications? Is this going to be another layer to have to deal with?"

"I don't know if we are going to be better off yet, too many unknowns. I'm not going to know whether to sign up until I see it."

The change to an individualised funding system for disability services was cautiously welcomed, however participants did express some concerns about the potential for additional bureaucracy.

A number of participants were concerned about how the planning and service coordination functions of the NDIS would interact with their existing supports and services, and what role they would be able to play in the NDIS processes.

Participants accessing FSP family and children's services sought clarification as to whether service providers and programs they currently access would exist in their current form with the introduction of the NDIS, including support groups they currently attend. Their concerns related to whether current relationships with and between providers would be maintained under the NDIS, and what they may look like.

Participants said that they had formed a good working relationship with their providers and this was something they did not want to change because of the introduction of a new disability program. The main issue pertinent to this point was that participants had disclosed significant personal and family information as they had developed a high level of trust in these providers. These participants were happy with their current arrangements and assumed that the providers were "experts" who knew their role and could understand and interpret the system with and for the participants. This active advice about "the system" was seen as being essential for participants and their children to achieve the best outcome from the NDIS

In addition, those attending the forums were keen to explore whether a move to individual funding would see service providers running the same programs as they do currently and how families would find these programs and services in an individualised system, for example vacation care, respite and after school care.

"I need vacation care for my daughter, and there isn't enough money for that as it is. If we get the money directly, how will we know what the providers are going to provide and how do services know what to provide and where?"

Some participants using FSP services thought that their providers should have a key role in information gathering and linking for the NDIS, as well as assisting families with NDIS planning and review processes.

Participants were unanimous in not wanting the assessment burden to increase, and wanted continuity in support and communication with all programs:

"Will it be another person doing the assessment? Why can't they access who they have already been assessed by? Our child has already been assessed, then reassessed then reassessed again. They need to involve the family as it takes my child a long time to accept new people coming in the house, and won't talk to anyone he doesn't know or trust."

Participants were aware that different programs had different definitions of disability, such as in education and disability services. Some families questioned whether the NDIS eligibility was going to be the same as in education where an IQ threshold is often used to determine eligibility for student support services.

Participants expressed desire to link eligibility for multiple systems so that it would be easier to access and keep services without unnecessary additional assessments.

A small number of participants were not currently using the disability service system and were yet to be convinced about whether they would access the NDIS. These participants were aware that they would need to utilise external support services in the future, but wanted to wait and see what processes the NDIS develops before making the decision to apply on behalf of their children.

"My children are not getting any disability services, and we are not sure when we will register. We don't want to be accountable as a family to another service system. We know a time will come when we will have to register and get extra assistance, but it is not just yet. I know other families in our support groups are not registered for disability services. I don't know if the government has made room for them in the NDIS when they do apply."

It was clear from both consultations that participants were interested in the potential of the NDIS to improve the provision of disability services, and in particular cut down the waiting times currently experienced.

All participants placed a high value on accessing information about services and community options, and said that they obtained their information from a number of sources including service providers, support groups, the internet and brochures.

Many spoke of a sense that there was more out there than they knew about, and seeking information was a feature of their role as a parent of a child or youth with disability.

Participants commented on the fact that they generally trusted the information they obtained from their support groups more than other sources.

"My wife gets more information about what is going on from her support groups than anywhere else. If the NDIS is going to do all the planning and tell us what is out there, will the support groups still be there if the NDIS is going to do everything?"

There was also a concern raised about providers gouging on price for their services with individual packages having a negative impact on families:

"What will be the price controls with the NDIS? How will we know that services are reasonable? When we were allocated funding for early intervention and we would ring up to get speech therapy assessments, they would ask are you using funding or paying yourself. If we said we were using the funding they would jack up the prices."

Overall it was clear that there is a need for accurate and accessible information about the NDIS and community service options for children and young people with disability and their families. It is believed that this should be provided by a range of sources, not just from the NDIS itself, and that FSP providers are well placed to work with families in this capacity.

3.2 Planning and co-ordination of supports across systems

The participants had strong views about having multiple service systems in their lives. Many had experience of the inevitable gaps between programs, communication difficulties between services and staff, and the need to comply with different eligibility and other criteria. At times there had been a need for multiple assessments.

Participants revisited the theme of needing to have trust in skilled staff of service providers. They thought that staff needed to build a strong relationship with the whole family and understand the way the family works. Participants wanted to limit the number of people that they shared personal information with, or had to have in their homes. They identified that not every worker from every system had the ability or the mandate to do this, but was a quality that they looked for. For any service intervention to be effective it must be a partnership with the child or young person with disability and their family.

Participants wanted support where they felt they needed it, but resented situations where systems or providers exert inappropriate influence over their families or made unreasonable demands.

Participants expressed a great deal of frustration with using multiple service programs. Participants understood that the various programs and providers they were involved with did have separate responsibilities and performed different functions, but overwhelmingly they wanted them to be better linked. They also expressed their desire to be kept informed of contacts between agencies. In essence there was an expectation that providers should be all aware of theirs and each other's roles, liaise with each other productively and work collaboratively to benefit of the family.

Those participants that had family support workers made mention of the respect they had for their contribution. In regard to disability services however, a number of participants recounted instances where the system did not act in their best interests, and required intervention from FSP agencies and advocates.

"My son was prescribed an electric wheelchair by a highly qualified physiotherapist. The worker from disability services said that it was too expensive and that he could get by with a cheaper one. What do they know about wheelchairs and how can they dispute a professional assessment? They don't have to move him around and see how much he needs that chair. We fought them and eventually they approved the chair but it was a real hassle."

Participants expected that the extra money flowing into the NDIS would change this type of illogical rationing, but still thought that advocacy from someone that knew them well would be required and should be incorporated in their plan.

Participants expressed a preference for a NDIS plan to be organised in such a way that it could dovetail with their other supports and key workers.

Who would be involved in the NDIS planning process was also of concern:

"...planning also needs to take into account the views of people who are around periphery of the person to get the best picture of what the person actually needs and what support they have around them once the plan is approved. Being individualised is OK but it's usually more complicated than that."

A number of participants expressed concerns about the impartiality of planners or case managers if they were employed directly by the NDIS. Some thought that they would approach their jobs with a responsibility to keep the scheme costs down, and may not provide a full range of options.

They talked of a "missing link" in the design of the NDIS as there was no capacity for an independent party to be involved to provide unbiased information and advice, double check proposals that emerge from the NDIS planning process and represent participants and families in negotiations. Some participants had used disability advocacy services and thought that they could perform this function, but others thought that the option of having independent planners and case managers to work with families needed to be designed into NDIS processes from the start.

"Advocates can be good but in my experience they only get involved if something goes wrong. We need someone independent from the start during the planning."

Those participants who had a range of services in place expected that the NDIS would generally bring about better service coordination, but did not say how this may occur across the systems. A number of these people spoke about how much time they currently spent organising their services, and their preference for it to be somehow better organised. One participant however did have clear views on how their service coordinator should work:

"I really need a case manager or co-ordinator. I am currently going to 5 separate services for things I need. If I was to get a coordinator I'd need to know they were working for me, not them, and they'd need to know our situation pretty well."

The issue of how the NDIS would deal with separated families and those in the midst of conflict situations was raised in the forums. Participants spoke about the need for NDIS planners and managers to have expertise regarding dealing with family conflict for situations that demanded it.

“How will the NDIS hand out funding where families have split up and aren’t on good terms? They need to find a way of not making the conflict worse.”

“What services are going to be available to help parents decide when there is severe conflict? Should the courts be left to decide? Maybe there should be a process within the regulations?”

Some participants also said that NDIS staff working with children, young people and their families in these situations would need a working knowledge of the Family Court and Family Mediation Services to ensure that could work effectively in these situations of severe conflict.

3.3 NDIS plan management

Both forums discussed the plan management options in the current NDIS design. Participants generally had limited experience with individual funding, although a small number had individual packages and used agencies to manage funds on their behalf.

One participant in Victoria had experience using a financial intermediary and thought it enabled them to deal effectively with the changing needs and service requirements of their child.

Once they had become used to the system of having a package and understanding how to draw down on it, have changes made and review the services in the package, it worked well for them.

“I just make a call and they usually sort things out. I need to always know how much is in my balance so I don’t go over with my services. Everything has to be finely tuned. It took a while to get used to it, but having someone there to make things happen and answer any questions is good. They can also shop around to make sure we are getting a good deal.”

In Hobart the participants were interested in the individualised funding model for disability services. Different participants spoke about the stresses of having to wait indeterminable periods of time for supports, or having plans and assessment recommendations knocked back due to cost. The approach of the NDIS of bringing individualised planning, funding and service provision together was well supported.

Overall however there was a degree of indifference to the notion of self-managing funding packages, primarily because of the perceived additional administrative impost, and the impact it would have on their current situations. A number of participants expressed the view that it may a good option for some families.

“How people cope with coordination will depend on how old the child or adult is. It would be completely overwhelming for a new parent to have to do coordination but may be easier later on. I think I could do it now but at first there was no way.”

A number of participants said that they would consider it but would see what support was available to assist them:

“There would be lots of stuff to go through and I’d also need to get help to sort through the main decisions.”

Others said that they would much prefer to leave it to those who were paid to do it:

“Why would I want all the extra hassle? I have enough going on without taking on more responsibility. There are experts out there, and they should be doing it. I just want services provided.”

The majority of participants said that they would be likely to opt for an organisation to manage a plan as long as they had the right expertise and could be trusted with personal information, money and compliance. Further, it was suggested that such organisations would need to provide information and regular updates. Some participants in Hobart said that they would like to use their existing community agencies for this, as they had an ongoing relationship with them that could be expanded to accommodate managing an individual plan.

One related issue raised in one forum was that of families having more than one child with a disability, and how the planning and plan management function would happen in these families. One participant expressed concern as to whether the individual planning processes embodying the NDIS may lead to a scenario of each child being dealt with in isolation:

“What happens if there is more than one child with a disability in the family? Do we get 3 plans or one joined up plan? Do we get 3 planners and coordinators or can we organise to select just one?”

In the discussion that this question generated, it was suggested that it should be possible for the scheme to be flexible enough to adapt to each family’s circumstances. For families with multiple eligible children, participants thought that it should be possible to have their plans linked to integrate their supports to reduce the administrative burden and the traffic through the home.

3.4 Other issues

In Hobart, workforce issues were identified as a major concern, particularly in regard to non-metropolitan areas. Participants were aware that there was a shortage already of trained professionals, and were concerned that breaking up the current service configuration may make things more difficult

“It’s OK giving me the funding but if I can’t spend it because there is no one here to do the work, then what’s the point? Where I live there aren’t many trained early intervention workers. Speech therapists have to travel from the city and only come every few months. I don’t think the extra money will make these people move permanently to where we are. If the provider who has the Helping Children with Autism funding loses that because it goes directly to different children, where do we go for information and referrals to get these workers to come over? At least they know what is available or should be there and what it takes to get the services we need.”

Participants were also concerned about evaluating the value for money proposition for individualised services and how anyone would know if providers were overcharging or underservicing children and young people and the scheme. This commercial and quality oversight is something that some participants thought may be something that the FSP agencies could undertake for their clients.

4. CONCLUSION

Overall it was clear that there is a strong desire for more detail about the NDIS and how it would work in practice. At the time of the consultation there were many aspects of the NDIS not settled, so there was a great deal of conjecture about the actual scheme operation.

While this consultation provided a snapshot of the views of families using multiple systems, it was clear that there is a gap in the NDIS design in how it deals with participants who are children and young people living in families receiving services through the FSP. Concern was expressed about how the NDIS was going to interact with separated families, and those experiencing separation, conflict or Family Court proceedings.

The overlay of a new and separate planning process for disability services was viewed with some level of cynicism, as participants want the NDIS reform to bring about less bureaucracy in service delivery and a reduced assessment expectation, particularly avoiding unnecessary assessments across different programs. This includes having extra people that they need to accommodate in their lives and to whom they have to disclose their personal details.

Participants were clear that they expected their service providers to have the requisite skills to undertake their duties. Further, there was a strong desire expressed for services to be well coordinated, and the assessment burden in accessing services kept to an absolute minimum. Participants could see a role for the FSP providers in the NDIS planning function.

One of the key aims of the NDIS is to provide an equitable system across Australia so every person with disability receives the level of support they require. The main process of determining that support requirement, and therefore equity, is the planning process. CDA believes a nationally consistent regime for individualised planning is required that is family sensitive and multidimensional in that it formally recognises other programs used by participants and their families. Targeted regular training should be mandatory for all planners, with continual professional development. Processes for planning and plan management with families with more than one child with disability will also need to be developed that take into account the practical dynamics of families.

All participants wanted more detailed information about the NDIS, particularly around eligibility, assessment and planning, information provision about available services and community options, plan management and reviews. It is important that the NDIS provide comprehensive information not only in launch sites, but also across Australia. The participants in the Victorian forum were concerned that they did not have even basic information about the NDIS.

The capacity for participants and their families to choose planners and case managers/service coordinators was seen as a critical design feature for families already engaged in a service system like the FSP. It appeared that this flexibility could become a highly useful part of potential interface arrangements without compromising control and choice.

The consultation raised a number of themes that underscored the need to integrate the NDIS into the existing suite of service systems in its early development. It cannot be reduced to be just a bigger service silo through not having effective interfaces. Participants made it clear that the NDIS needs to be equipped with the capacity to work with other services used by participants and families at both the administrative level as well as the service level. Indeed if this is not done, the NDIS will not be able to deliver much of its promised reform, but merely entrench the traditional program silos that exist at present.

For this to happen in practice, the NDIS will need to have agency level protocols with the FSP that spell out the key program boundary issues and responsibilities where NDIS participants and their families are eligible for both programs. It is also incumbent on the NDIS to develop detailed work practices and training for its staff to guide their practice with these participants and families. The Tasmanian and South Australian launch sites provide unique opportunities to trial cross program collaboration.

5. Recommendations

1. The NDIS urgently undertake specific work on the interface of FSP and the NDIS. This needs to occur at the agency level and in the launch sites. This is to ensure that the emerging NDIS work practices do not cut across or undermine FSP programs, and that there is a high degree of policy compatibility. This work must be led by the NDIS, with collaboration from the FSP sector.
2. The NDIS needs to undertake detailed orientation and training for planners and local area coordinators to ensure consistency and quality interaction in dealing with children and young people within the NDIS using the FSP and other service systems, such as education, health and justice.
3. NDIS staff will need to develop professional networks that include the FSP so that they can obtain real time advice and work collaboratively with FSP providers.
4. The NDIS evaluation project being led by FAHCSIA needs to have a specific component dedicated to the FSP interface to monitor the impact of NDIS work practices on participants and families and FSP providers. This evaluation must inform the ongoing development of work practices and interface arrangements within the NDIS.
5. Families of participants who are children or youth must be given the option of utilising NDIS funding to engage an impartial planner or case manager, who may already be involved with the child or young person with disability and their family, to assist with the planning and/or co-ordination of services and supports.
6. The NDIS develop work practices for NDIS staff working with families accessing the FSP to ensure they understand the eligibility criteria for FSP, the role of providers in supporting the capacity of eligible families, and the role of FSP providers. This is essential knowledge to apply when the NDIS is examining the question of what reasonable informal care a family should be expected to provide to a participant who is a child or young person.
7. The NDIS must define the roles and required capacities for organisational plan management providers (PMP) at the earliest opportunity in the launch sites. This would enable FSP service providers to consider becoming a PMP if families wanted to pursue this as an option.
8. A review or auditing process should be initiated at 6 monthly intervals to ensure planners around Australia are consistent in their approach with child and youth participants, and that they are involving families and providers from FSP, and other service systems, where required in developing plans.