



**Submission on the
Draft Report of
The Productivity Commission
Disability Care & Support Inquiry**

Office of the Chief Executive

Novita Children's Services

PO Box 2438

Regency Park SA 5942

T +61 8 8243 8202

F +61 8 8243 8218

E enquiries@novita.org.au

W novita.org.au

Further Information

Further information regarding this documentation can be obtained from the Office of the Chief Executive, Novita Children's Services - 171 Days Rd, Regency Park, South Australia, 5010.

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1. INTRODUCTION

Novita Children's Services provided a lengthy submission (number 560) to the Productivity Commission last year, followed by a verbal presentation at the Commission's public hearing in Adelaide on 18 April 2011.

Novita welcomes and supports the overall concepts, proposals and themes in the Productivity Commission's Draft Report on Disability Care and Support.

In this paper we will not repeat the matters mentioned in Novita's previous written and verbal submissions, other than to reiterate the importance of those matters in relation to the significant number of children and young people with disabilities with whom Novita is engaged within South Australia and the Northern Territory.

Novita's submissions have emphasised the need for the proposed National Disability Insurance Scheme (NDIS) to ensure children, young people, families and carers continue to access current services, while providing the structure to build and fund a service system that addresses the gaps, reduces the delays and replaces crisis-driven models of service with a national, equitable system empowered by people with disabilities and their families. Novita has highlighted the unique and critical set of needs from infancy to adulthood for those individuals who have a disability and for the families and carers who provide them with support.

Moreover, Novita has urged in its submissions that the special needs of the 0-18 age group must be given particular attention in the design of the NDIS. This is due to the complex and changing needs of children and families, together with community interest in the provision of intensive supports and interventions to help Australian children diagnosed with disabilities manage their condition within an appropriate treatment framework.

Novita's verbal submission highlighted critical issues that include the need to consolidate services for children and young people with disabilities, not diminish them; the need to ensure that all Australian children with a disability are eligible under the NDIS from early identification of impairment, which will often precede formal diagnosis; the desirability of having assessments that are empowering and creative and which avoid multiplicity and duplication; a recognition of the critical importance of funding specialist disability supports provided at intersections with mainstream services; an understanding of the differentiations between disability services and mental health services; the essential requirement for maintaining and monitoring consistency of quality in disability service standards; and a suggestion that requiring families of children with disabilities to make co-payments is unfair.

Historically, much of the responsibility for service provision for children has been left by Governments to the not-for profit sector which, in the process, has been obliged to raise a substantial portion of funds that Government has not been prepared or has not been able to commit to children's disability services. The NDIS must ensure that a

market-driven, insurance model of service design covers the enormous funding gaps for which the not-for profit sector currently takes responsibility.

Disability reforms under the NDIS must ensure that care and support services to children and young people with disabilities are specialised, personal and caring, while those individuals in need of equipment, aids and assistive technology can get them. Novita's previous written submission gave a comprehensive description of those services that are provided to South Australian children living with disabilities. Demand for all of those services is high and waiting lists are common.

Novita's comments and observations on issues from the Productivity Commission's Draft Report are set out below.

2. DIAGNOSIS

Novita agrees with the comments made by the Royal Children's Hospital Melbourne, in its submission (number 405) concerning diagnosis:

"the current system relies too heavily on strict adherence to medical diagnoses...children with very complex medical presentations and high care needs who are midway through the process of acquiring a specific diagnosis miss out on services and funding,." (p 3) and "a person/carer/family should be determined as being in need of support if it is established there is actually a need for help, not just a diagnosis...families with a child with developmental delays but no formal diagnosis should still be eligible for services" (p 4-5)

Because medical diagnosis often takes many years it is imperative to ensure that support for children and families is in place during that diagnostic period.

TIER 2

It is highly problematic for many families with an infant with a disability to comprehend the service system and to navigate their way along the pathways to access appropriate services and supports.

The proposed Tier 2 should aim to help families to get meaningful information about disability support options. Particularly in the early years of identification and diagnosis, the strain for many families is immense and capacity to cope in the NDIS market place for services will be far from uniform.

3. ASSESSMENT OF CARE AND SUPPORT NEEDS

Novita has adopted the philosophy of Family Centered Practice (FCP). We believe that parents have the right to determine what is most important for their child and to be recognised as experts regarding the needs of their families. Novita has implemented an individualised planning process for children and their families offering a customised program that includes flexibility in service, location, model and timing.

Parents and carers are experts at recognising and understanding their child's disability and their role needs to be respected in the new system. Novita supports the concept of community based case managers who are trained and have expertise in assisting families to access a range of services for their child.

There will be a series of developmental changes for children and young people with disabilities that will require re-assessment and review from time to time. With a series of medical interventions likely for many of those individuals, their health and support needs will change dramatically and will inevitably take on different forms for certain periods. These changing needs must be addressed by the assessment process in the NDIS in a timely manner. Assessors will need to be trained and skillful, with sound knowledge of the types and extent of childhood disability.

TIER 3 ELIGIBILITY

In relation to Tier 3 – Individually tailored funded supports, Novita notes the Draft Report comments as follows:

“.... the terms of reference for the inquiry indicate that the scheme is not intended to address the care and support needs of all individuals, but rather should focus on those where such needs are greatest (p 3.9)..... in contrast to the other tiers of the NDIS, the delivery of individualized, funded support under tier 3 of the scheme would be targeted at a subset of individuals. They are people whose support needs:

- would not otherwise be reasonably met without NDIS funded services; and*
- are not more appropriately met by other systems, like the National Injury Insurance Scheme or health care.*

.....the terms of reference for the inquiry indicate that the scheme is broadly intended to address the needs of individuals with a severe and profound disability (3.10)“

In reaching a definition of the criteria to be met for someone to be regarded as Tier 3 eligible – i.e. having a “severe and profound disability”, the criteria which the Commission suggests are:

3a - *significant core activity limitations in communication, mobility or self-care*

3b - *intellectual disability (not already included in 3a)*

3c - *early intervention group* - two groups identified here - one group is those for whom cost effective, early therapeutic interventions will be beneficial (as in autism, acquired brain injury, cerebral palsy and sensory impairments); the other group is those with newly diagnosed degenerative disease, e.g. Multiple Sclerosis, Parkinson's disease,

3d - *others optimally supported* - a criterion to be used in a discretionary not a routine manner

(p 3.10-3.15)

Under 3a and/or 3c, consistent with Novita's verbal submission to the Commission, we urge that all children and young people with a disability should be deemed eligible.

While noting that a medical diagnosis can often be delayed for lengthy periods (with a provisional diagnosis of "global developmental delay") and that in relation to intellectual disability it is rare to get a diagnosis during infancy/early years, it is essential that provision of essential therapy and supports should not be delayed pending delays in a substantive, medical diagnosis.

4. MAINSTREAM SERVICES

Draft Recommendation 4.5 of the Report states –

"Services that meet the needs of much wider populations, including people with disabilities not covered by the NDIS, should lie outside the scheme: health, public housing, public transport and mainstream education and employment services, should remain outside the NDIS, with the NDIS providing referrals to them but specialised employment services, disability-specific school to work programs, taxi subsidies, and specialised accommodation services should be funded and overseen by the NDIS."

Novita provides a range of allied health services, disability support services, rehabilitation services, together with services to prescribe and support provision of equipment and assistive technology. In addition to those "direct" services, Novita provides a range of "indirect" services through inputs for individual clients into mainstream areas - predominantly education, transport, health, vocational training; some components being advocacy, some being disability - specific support, information and co-ordination; all in the cross-over between disability specific services and mainstream services. We reiterate that the NDIS needs to recognise and fund those "indirect" disability supports.

The Commission's report highlights the notion of the shift towards more inclusive mainstream services. However, it is more in a context of de-institutionalisation (less whole-of-life responsibility).

It is important to understand that the provision of children's disability services are already taking place within or are connected to mainstream activities. In addition to continuing supports, key disability interventions are required at times of significant, developmental milestones and at significant times of life transitions. Those transitions include transition into childcare; transition to preschool; transition into primary school; transition into middle school; transition into high school; transition from pediatric services to adult services; transition into employment; transition into vocational education and training; transition into tertiary education.

In further analysis about the provision of services to children and young people with disabilities, it may be necessary to acknowledge the mainstream focus that these services already have and to see the contrast between them and the more traditional "whole of life services". The question arises whether the needs of infants, toddlers, children, and young people are so uniquely specialised and acute that the economic rationalisations and financial rewards of an NDIS need to be defined (or re-defined) for children in the context of notions of life needs, essential health services and disability support.

5. COMPLAINTS AND APPEALS

Novita strongly supports the need for an appeal process for families and carers who are denied a service.

Novita acknowledges the complexities and risks which the Commission describes (Chapter 7.8) concerning processes for investigating complaints, resolving disputes and processing appeals. Novita strongly agrees that there needs to be a tiered set of informal and formal complaint and dispute resolution processes and agrees in general with Draft Recommendation 7.12, in preference to the alternative approach outlined in Draft Recommendation 7.13. The proposals in Draft Recommendation 7.12 provide for a practical, stepped approach to resolving problems.

It is important that the NDIS legislation provide for the independence of the office, role, function and resources of the statutory review officer. In addition, it is sufficient, appropriate and sensible for there to be appeals on matters of law rather than on merits, to the Courts. The financial sustainability of the NDIS will be critical and is more important than risking the diversion of funding to a plethora of legal actions dissecting findings of fact, rather than adjudicating on matters of law.

6. NDIS LEGISLATION

Novita welcomes the discussion in chapter 7 of the Report about the NDIS having its own legislation. In particular, Novita supports Draft Recommendation 7.5 and agrees with the notion that *“an entitlement to reasonable support should be enshrined in legislation, together with details about people’s eligibility for services and the range of services offered.”*

Draft Recommendation 7.5 goes a small way towards adoption of Novita’s suggestions (Submission 560, pages 36-42) calling for a legislative framework that recognises the rights of people with disabilities, including the right to participate in the NDIS.

Development of NDIS legislation provides the opportunity, indeed the necessity, to review the State and Commonwealth legislation about disability, discrimination and disability services. As Novita and other agencies have suggested in many forums, there are widespread deficiencies and gaps in current disability legislation which need to be overhauled and replaced with strong and effective rights based legislation. A first step is the entitlement to reasonable support ‘locked’ into national NDIS legislation, as recommended by the Commission. In fact, that legislation could be suitable to enshrine the entitlement to a range of essential disability supports in education, employment, allied health, vocational education and training, access, aids and equipment and assistive technology.

Novita agrees with the Commission’s comments about the need for single overarching legislation. This is a welcome, first step towards compliance with the Australian Government’s obligations under the United Nations Convention on the Rights of People with Disabilities.

7. RURAL/REMOTE AREAS

While welcoming the Draft Report’s assurance that *“the proposed NDIS should represent a considerable improvement for disability care and support in rural areas”* (8.52), it is respectfully suggested that further analysis of the regional issues would be worthwhile, to supplement the brief analysis in the Draft Report.

Novita’s written submission (560, p 16) provides a short summary of the extensive work already undertaken through our Regional Service and Inclusion Support Service teams.

In the past fifteen years, Novita has delivered services state-wide, with a visiting service to every major centre in regional South Australia. Novita services have linked with the regional community, health and education services ensuring that regional staff skills are developed and supported to provide ongoing services to children and their families. Novita has close links with the three education sectors, visiting schools throughout regional South Australia.

Since beginning the country outreach service, Novita has provided services in conjunction with local indigenous agencies in Ceduna to Yalata and Oak Valley communities and to Mimili in the APY Lands. Novita designs services for a particular country area in response to the needs of families and the local community. Country areas vary regarding the availability of local therapy services, requiring Novita services to be provided in a variety of ways. Outreach visits, lasting up to four days, generally take place four times per year (once per school term), depending on need, and may involve a combination of:

- information, resources and support to local therapists;
- direct input to the client, family and community (in the absence of local supports);
- information and training activities on a range of topics;
- telephone contact between visits; and
- provision of selected services in Adelaide (such as specialised equipment provision).

Under the NDIS it will be essential that a way is found to continue to develop these services to individuals and families in need in regional and remote regions of Australia. Novita welcomes the Commission's comment that an increase in funding through the NDIS would be highly effective in a rural setting (8.51), and agrees that a competitive tender for block funding is a potential option.

8. INDIGENOUS COMMUNITY

Draft Recommendation 9.1 is noted, supported and to a degree already in place in South Australia through services which Novita provides in rural communities.

The Commission has sought feedback on the merits of the NDIS funding prevention and early intervention measures that target indigenous communities and how this could work in practice.

Novita has had significant experience in working in the APY Lands (in particular, Mimili, Indulkna, Freegon) and other Aboriginal communities (Yalata, in particular). In the APY Lands, Novita staff have worked collaboratively with the Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council (NPYWC), using a model of service delivery whereby the non-indigenous staff always work alongside their indigenous counterparts in their direct service delivery with children and families.

Novita also has links with Nganampa Health, who run clinics on the APY Lands and Anungu Education, who run schools across the APY Lands in South Australia, Northern Territory and Western Australia. Novita has provided consultative therapy services, including speech pathology, physiotherapy, occupational therapy and psychology, on a fee-for-service basis to non-Novita clients on the APY Lands. This has been at the request of NPYWC and Anungu Education Services, with permission from communities.

Novita also has experience with delivering services to indigenous people in metropolitan Adelaide and rural South Australian centres. Novita has visited Alice Springs to provide services to clients from the APY Lands in South Australia who have been temporarily living in Alice Springs and Novita's network extends into the southern areas of the Northern Territory.

As part of Novita's Inclusion Support Program, an Inclusion Support Facilitator with knowledge and experience in delivering inclusive Aboriginal cultural practices in children's services collaborates with the Aboriginal Resource & Management Support Unit (Network SA) to ensure culturally relevant and appropriate support is provided when responding to service needs.

The Commission suggests (9.23) that non-government service providers may be unwilling or unable to service remote communities, with the result that government-run service providers may be the only practical option. In fact, it is possible that a more effective outcome may be through non-government agencies continuing to provide these services, appropriately funded and developing them to their full potential for the benefit of indigenous children and young people with disabilities.

9. FUNDING

Under the NDIS and in the absence of block funding, Novita expects a new environment with an array of business challenges that will require a fundamentally different way in which disability agencies go about business. Novita welcomes an increased level of competition and flexibility while extending choices and improving services for children with disabilities and their families. The NDIS will promote much-needed funding equity across the disability sector which should reduce current unacceptable levels of unmet need.

Implementation of the NDIS will bring with it opportunities and risks for all stakeholders, including people with a disability, their families, carers and service providers. For some children and young people with disabilities it may be imperative that such risks are identified and adequately mitigated to ensure a safety net of service certainty.

Care must be exercised in applying NDIS reforms to children and young people, to ensure that their special needs are not overlooked either directly or indirectly by the application of such a system.

Novita suggests that evaluation of both the funding and operating environments in respect of children and young people with disability is critical. Specifically, the evaluation of market forces, including the degree of purchasing power of families, the bargaining power of service providers and the degree of industry rivalry and competition, could be assessed. In Victoria, PricewaterhouseCoopers (PwC) was engaged by the Department of Human Services in 2008 to undertake a review of cost drivers and prices for out-of-home disability services. Their report provided key

findings to guide the future direction of disability reform and also included an evaluation of the impact of the introduction of the self-managed funding mechanism in Victoria. The PwC report on individualised funding highlighted the following:

- inconsistency of understanding about future funding arrangements;
- inconsistency and unpredictability of cash flow/income;
- concerns regarding the impact of competition; expected issues were a detrimental effect of reduced cooperation between agencies and the sector as a whole, increased marketing and business development costs, and medium to long term threats to the existence of some agencies;
- concerns regarding bad debts in respect to payment of fees;
- increased administrative costs requiring the introduction of new systems and practices; the report noted one agency had spent in excess of \$4.0M; and
- concerns regarding increases in report requirements.

The risk of a commercial based approach for some clients in children's services may be that the services they require are deemed unviable, unsustainable and subsequently cease. Potentially, this could be an unintended consequence of the NDIS for allied health and associated support services for children with a disability, if strategies implemented by services providers to address fixed costs and remain sustainable became a priority over unsubsidised services and benefits provided by not-for-profit organisations.

The NDIS could further evaluate such risks, in the context of vital services to children and young people, and consider the introduction of a transition mechanism to ensure service providers are supported to operate in a new market driven funding environment. This will ensure service delivery certainty and that service quality can be achieved into the long term.

Novita expresses its concern that some service types may be identified as not cost effective, with the consequence and risk that the options available for children and young people with disabilities will be substantially reduced or become unavailable. For those young people with a disability and their families, a service safety net mechanism may be necessary to ensure continuity of care occurs, as service provider's transition to a market based model of service delivery.

In South Australia, as a result of inadequate Government funding, the provision of disability services to children and young people has relied on substantial annual funding contributions made by not-for-profit organisations. These contributions to the cost of essential services for children have been possible through fundraising and investment endeavours of not-for-profit agencies.

As detailed in the South Australian Government's Submission to the Productivity Commission (p 16), it states, *'A lack of funding is leading to large unmet need in South Australia – in December 2009 Disability SA had a total of 2,667 eligible clients waiting for services. These figures are not comprehensive as they do not record unmet need for some key areas (e.g. sensory disability and some children's*

services) and only record 'identified' need i.e. does not include many people who are being cared for by unpaid/informal carers who have not approached our system but who wish to receive a payment under a national insurance scheme'

10. WORKFORCE CAPACITY CHALLENGES

Lack of workforce capacity to meet the demand for disability services, in particular the recruitment and retention of staff, is a key concern and a common issue for many non-government disability services providers.

In the disability sector, workforce pressures are often exacerbated by low public recognition of disability services as a career option.

Novita acknowledges the discussion in the Report at chapter 13 on workface issues, and the recognition that labour supply for an expected growth in the disability sector will be one of the challenges for the NDIS.

Under current policy, indexation on National Disability Agreement (NDA) funding continues to be applied on an equal basis to all service providers irrespective of the specialist nature of labour or services being delivered. This methodology is outdated, unsound and places at risk the viability of these critical services to children and young people with disabilities in Australia.

Under the current situation, the South Australian Government, with its dual role as funder (given its NDA contribution responsibility) and provider, potentially places itself into a position of conflict. As a consequence, non-government service providers often experience a competitive disadvantage against Government service providers in relation to accessing funds and competing on an 'even playing field' for staff. Given that the South Australian Government controls the distribution of funds and provides disability services, there is a view that the needs of the State Government as a service provider are being addressed ahead of non-government service providers.

A KPMG report commissioned by the National Disability Administrators group, recommended the development of a 15–20 year national disability workforce plan. This report recommended improved workforce data collection and analysis; the development of national marketing materials; and stronger links with the education sector occur in order to provide opportunities for school and university students to engage in work experience in the disability sector.

The KPMG (p 110) report was critical of the view that workforce planning is a diversion from service delivery:

'There is a need to embed workforce planning into organisational structures and culture, both at a state and territory level (Government and Non-Government) and from a national perspective. A clearer connection must be established between the

implications of good workforce planning practices and the achievement of service delivery and client outcomes.'

At this time, Novita is not aware of any strategic state based coordinated effort to address disability workforce challenges. This is a position acknowledged by the South Australian Government in it's submission to the Productivity Commission (p 21) which states:

'..it is known that the disability sector in South Australia faces challenges in workforce development. The sector is characterised by fragmentation with no sector wide strategy for workforce development.'

Under a market based approach, it is likely that such market pressure for labour, compounded by high fixed costs such as infrastructure and administration will be addressed by the market through placing upward pressure on the equilibrium price determined by the market in providing services to children and young people with a disability.

If there is an erosion of funding certainty, some service providers will experience an increased difficulty in providing employment security for some types of services, which may in turn impact on higher risk service types being pursued by the market.

To improve the ability of disability service providers to attract and retain staff a workforce strategy should address:

- the low public profile of disability services as a career option;
- the perception that the work is unskilled;
- the low funding/low wage environment within which the sector operates (exacerbated by indexation rates which have not kept pace with general wage adjustments); and
- the lack of national workforce data to inform planning.

It will be essential that any long term workforce plan also undertakes an assessment of the need for increased training places in the education sector to ensure the foreshadowed increase in demand is addressed.

Furthermore, large increases in salaries and wages are driven by national wage decisions that flow-on to State awards. For organisations such as Novita which employ health professionals, who are in high demand for their skills, this means they can choose between non-government organisations and the public sector. It may be necessary for the NDIS to ensure that the playing field for the delivery of services between Government and non-government organisations are provided with sufficient financial capacity to attract and retain staff and maintain existing service levels.

Novita suggests that the NDIS should recognise that there are many varied skills required to deliver the range of services required by children and young people with disabilities. Notably, clinical services require highly trained allied health professionals to enable effective delivery.

While the Commission has acknowledged that its report focuses on lower skilled disability support workers, there are several professions that also provide essential services for people with disabilities (Report 13.45). For children and young people with disabilities, this specialised workforce is the norm. The Commission has acknowledged the ongoing shortage in some of the professions and the adverse impact for people with a disability. The Commission goes on to say:

“.. a detailed analysis of this problem is beyond the scope of this inquiry.” (13.45)

Nonetheless, that analysis may well be required elsewhere in relation to services for children and young people with disabilities in view of the preponderance of professional services which they require in health and allied health.

11. RESEARCH

Novita welcomes the importance placed on research in the Commission’s report.

Novita’s commitment to research has been longstanding and in 1999, a dedicated Clinical Research Department was established to ensure that Novita had in place the expertise and capacity to deliver research outcomes. This dedicated research department was the first clinical research department in Australia to be set up in an organisation providing services to children and young people with disabilities. Novita has developed research knowledge evidenced by undertaking and completing more than seventy research projects in children and adults with physical and multiple disabilities over the past eleven years.

In 2008, Novita undertook a comprehensive stakeholder engagement and consultation process, including academics, researchers, staff and clients. Throughout the consultation phase, stakeholders emphasised the unique nature of Novita’s research program in being co-located with service provision, having a link with clients/research participants and being well placed for knowledge transfer from research to practice. Novita has capitalised on this over the years, with increasing experience in participatory research, sourcing research questions from service providers and clients, and formal roles within the organisation for the embedding of evidence based practice.

Novita identified four key areas of research excellence to be pursued, including:

- evaluating and enhancing participation of children with disabilities at home, school and community;
- communication (including Accessible Telecommunications);
- clinical use of Assistive Technology; and
- rehabilitation of children with Acquired Brain Injury or other neurological impairments.

Each of these research areas is pursued under the leadership of a PhD qualified researcher, working with a team of researchers.

Novita has a Service Agreement with South Australia's Children's Youth and Women's Health Service (CYWHS) for a range of collaborative programs. Through the Agreement, Novita is able to access the CYWHS Clinical Research Ethics Committee. Where research is conducted in partnership, ethics approval may be sought from the partnering organisation such as the Department for Families and Communities Research Ethics Committee or relevant University Ethics Committees. In all other instances, Novita seeks ethics approval from the CYWHS Clinical Research Ethics Committee.

While noting the Commission's discussion (10.15-10.17) concerning models of undertaking research, through its experience, Novita would be inclined towards the logic, flexibility and range of the "mix of the four models" (10.17).

Novita has a commitment to evidence based practice, namely the process of combining best research evidence with clinical knowledge and reasoning to provide assessments and interventions that are effective for clients. Novita agrees with the Commission that an effective evidence base under the NDIS is required.

12. CONCLUSION

Novita supports the establishment of the NDIS and expresses its gratitude once more to the Commission for developing a comprehensive, landmark Draft Report in relation to the disability community.

In this submission and in its previous submissions, Novita has raised a number of discrete issues around disability services for children and young people with disabilities. Novita recommends that these issues receive continuing analysis in the Commission's compilation of its final report.