



**SUBMISSION  
TO THE  
PRODUCTIVITY COMMISSION  
DISABILITY CARE & SUPPORT INQUIRY**

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## EXECUTIVE SUMMARY

Novita Children's Services (Novita) is a non-government, not for profit organisation based in Adelaide, South Australia. Novita provides a wide range of services to children and young people with disabilities. These services are paid for through funds generated by Novita and subsidised by government.

Novita welcomes the opportunity to contribute to the discussions, research and design of a National Disability Insurance Scheme (NDIS). This is a topic of profound importance for children with disabilities, their families and carers and it is of great significance to the disability sector.

Novita representatives have participated extensively, primarily in Adelaide, in discussions about an NDIS, which have taken place in forums, groups and meetings. Considerable assistance has been derived from the information and papers circulated by the Productivity Commission and by peak organisations, such as National Disability Services (NDS).

This submission provides a perspective about disability issues and services, derived through 70 years of history and experience accumulated by Novita in serving children and young people with disabilities. The submission addresses the key issues which the Productivity Commission has raised about an NDIS, namely:

- who should be eligible
- who gets the power
- what services are needed and how they should be delivered
- funding
- organising and implementing a new disability policy.

This submission includes a brief history of the structure and delivery of disability services in South Australia, which may have similarities to aspects of services interstate. Information is also provided about the range of services in which Novita is engaged, not as an advertisement for those services, but rather as an indication of the breadth, complexity and nuances in the range of life issues and needs that shape disability care and support for children and young people.

The history of disability policy moves through generational trends, at home and overseas, which oscillate between extremes of government intervention through to government withdrawal. The forthcoming generational change needs to be carefully analysed, both by looking at lessons from the past and opportunities in the future, for government to ensure and fund the structure that will empower people with disabilities through the next generation.

# SUMMARY OF KEY ISSUES

- **Who should be eligible**

Novita considers that all children and young people with disabilities should be eligible for inclusion within the NDIS. It would not be fair to confine the system to those who are described as having profound and severe disabilities, because of subjective and judgmental considerations that will always lead to disagreement and dispute.
- **Who gets the power**

Novita considers that services must be driven and empowered by people with disabilities. There must be real power, and this submission argues in favour of the establishment of rights based legislation for children and adults with disabilities. Such legislation does not need to be a charter of rights. Rather, it needs to be an Act of Parliament that provides measures to ensure governments and agencies are accountable to people with disabilities in exercising their right to an equal opportunity to participate meaningfully in all aspects of life. This could include the right to eligibility, entitlement and secure and stable funding through an NDIS.
- **What services are needed and how should they be delivered**

Novita's submission maintains that disability services (support and care) for children must be personalised, caring and specialised. They should be of the highest standard, enshrining the principle of early intervention, and led by the disability sector because of the sector's unique understanding of the needs, across life domains, of children and young people with disabilities.
- **Funding**

Funding must be consistent across Australia. In South Australia, the Public Advocate has reported that, on a per capita basis, South Australia has a proportionally higher rate of people with a disability accessing services compared to other States. However, when assessing South Australia's disability expenditure compared with other States on a total population basis, South Australia is midway in funding. Accordingly, with the combination of trying to provide services to more people with less funding, the result is that funding per client in South Australia is less than in any other State.<sup>1</sup>
- **Organising and implementing a new disability policy**

Novita recommends that requirements of uniformity and equity must be balanced by the desirability of having local assessments, community support and flexible responses, which are critical for children and adolescents with disability as they deal with changing life needs.

A new disability policy must ensure that children and young people with disability have access to assistive technology, which assists with the fundamental right to communicate, together with provision of aids and equipment to enhance mobility, independence and community participation.

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<sup>1</sup> Disability Services | South Australian Office of the Public Advocate OPA Annual Report 2008-2009 pg18

# 1 History

## 1.1 Disability Services – SA history – a Snapshot

Since South Australia's colonial beginnings, the care of children with disabilities has continued to be marginalised in both the public and private sector. It is a history that includes decades of confinement of children with disabilities in mental hospitals, in specialised institutions and finally a movement towards providing support within the home and in foster care.

There is a useful, brief summary in the report of the Children in State Care Commission of Inquiry, March 2008 [p127]:

*Until the mid-20th century the care of children with disabilities was left largely to non-government agencies. Townsend House was established in 1874, Minda Home in 1898 and the Somerton Home for Crippled Children in 1939..... Governments endorsed the provision of residential and associated care by non-government agencies and contributed funds and subsidies. Successive governments endorsed the placement and restraint of children with disabilities in adult mental hospitals from the mid 19th century to the mid 20th century. It was not until 1958, when Lochiel Park opened, that the government assumed direct responsibility for the provision of residential care to children with disabilities, including those in State care. With the establishment of the Strathmont Centre, a facility built in the early 1970s, the government displayed its awareness of the distinction between providing residential care for children with disabilities and children with mental health problems.*

By the 1970s, the admission of children for long term residence in Parkside Hospital, Hillcrest Hospital and Minda Home was coming to an end. Children from Hillcrest Hospital and Parkside Hospital were moved into the Strathmont Centre from the early 1970s. This group included children with severe physical disabilities who were later moved to Ru Rua Nursing Home at North Adelaide and then at Tennyson, in highly unsatisfactory conditions.

During this era, children from indigenous communities in the Northern Territory were also transported to South Australia and accommodated at Parkside Hospital and Hillcrest Hospital. For many years, the Northern Territory had sent people with mental illness and people with intellectual disabilities to South Australia for long term care. The children from indigenous communities were all in the actual or de facto care of the State. This practice came to an end in 1984.

In 1980-1981, the South Australian Government established the Intellectually Retarded Persons' Project and its report recommended the complete separation of services for people with intellectual disability from mental health services. Before this time, there was little coordination of services by government; for example, the South Australian Health Commission provided funds to Minda; Mental Health Services had responsibility in government for Intellectually Retarded Services; the South Australian Health Commission administered the Ru Rua Nursing Home; the Commonwealth Government

provided funds to major non-government agencies, Orana and Barkuma. In an attempt to bring about better coordination, the Intellectually Disabled Services Council (IDSC) was incorporated in 1982 as a health unit under the South Australian Health Commission Act of 1976. Later, it changed its name to Intellectual Disability Services Council and remained in existence until 2006, when it was dissolved and its responsibilities relocated into a government department, Disability SA, which is part of the South Australian Department for Families and Communities.

IDSC's mission was to re-shape services for people with intellectual disability. The priorities were to have services provided locally and in an accessible way. Clients of IDSC would be allocated a specific service coordinator, who would be responsible for the individual service plan of the client. The philosophy was that people with intellectual disability should be able to participate to the maximum degree possible in their communities.

Over the following 20 years, the number of children living in residential units gradually reduced, alongside an increase in the number and scope of community services in metropolitan and regional areas. Government policy has been to encourage families to provide continuing care at home for their disabled relative, with access to respite care and various supports through specialist and mainstream services in the community.

The growth of respite care in the 1990s saw the development of a small number of residential facilities and programs across the disability sector offering overnight respite care and day services for children. Some of these facilities and programs were licensed under appropriate community welfare or child protection legislation. IDSC provided case management for some of these young people and their families.

In 1995, Options Coordination was launched on a state-wide basis, with the aim of improving access and equity in services for people with disabilities. The community-based Options Coordination Services were developed in five areas, with two of them, through the Crippled Children's Association (now Novita) and Guide Dogs SA, being under the auspices of non-government agencies. The other Options Coordination Services through IDSC, Brain Injury Options, Coordination (BIOC) and Adult Physical and Neurological Options Coordination (APN), were delivered through government. In 2005, BIOC and APN were transferred to Julia Farr Services which, in turn, has become part of Disability SA, together with IDSC.

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## COMMENT:

Where does that leave the current state of disability services in South Australia? According to Monsignor David Cappo, the Commissioner for Social Inclusion SA:

*"The service system is increasingly broken and in crisis.....for many South Australians with disability – as well as their families –*

*dealing with the disability system can make everyday tasks of ordinary life even more difficult.*<sup>2</sup>

In June 2010, the South Australian Department for Families and Communities confirmed the challenge that exists today. It stated that, 'In South Australia, the number of people receiving disability services have grown significantly. Over the past five years, the number of people receiving disability services increased by more than 28%, from 15,081 to 19,350 people in 2007/08. Despite the numbers of people being assisted through disability services increasing by 14% between June 2007 and June 2008, unmet need grew by 22% between November 2008 and December 2009'<sup>3</sup>

There is widespread, well known concern about dysfunctional, unsatisfactory aspects of the disability system. However, there also needs to be recognition of the history and achievements of the disability movement that, in South Australia, spans some 150 years. Disability services owes much gratitude to the efforts of earlier generations.

The design of the NDIS must take into account that the current system is not a recent invention and that some of its features are popular, highly sought after, staffed and supported in many instances by experienced and able practitioners, and at the leading edge of international best practice in some areas.

The design of the NDIS must also take into account the range of services currently available to children with disabilities. In addition to direct disability support that is provided to children, their families and carers, there are considerable overlaps with other systems, particularly health, education, recreation and transport.

The next part of this submission provides details of the nature of services that Novita provides, with the aim of demonstrating the issues that arise in direct disability care and support to children with disabilities, together with the many, vital inter-connections between disability and other sectors. Those other sectors are predominantly "mainstream". One vital historical lesson from the development of disability services is the importance of its specialisation in all aspects of its operation. If various parts of disability are left to be the responsibility of education, or health, or recreation, or transport, or any other mainstream area, then disability will be sidelined, marginalised and neglected even more than it might be today. The NDIS must ensure this does not happen.

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<sup>2</sup> Activating Citizenship- A Social Inclusion Blueprint for Disability in South Australia, 2010

<sup>3</sup> South Australian Department for Families and Communities - Ageing and Disability Service Improvement – Consultation Paper p3 <http://www.dfc.sa.gov.au/pub/Default.aspx?tabid=908> – June 2010

## 1.2 Novita Children's Services

It may be helpful to summarise briefly some key milestones in the history of the organisation, in order to provide an overview of Novita's current activities, service priorities and strategic objectives.

Novita, originally named the Crippled Children's Association of South Australia when it was incorporated in 1939, and subsequently referred to as CCA, has a long history of service provision in South Australia. It was initially supported by the South Australian Government with a grant of £2,000 per annum. Services were commenced at Somerton Home for children with poliomyelitis.

In 1946, a school for children with cerebral palsy was established at the Adelaide Children's Hospital, along with a cerebral palsy clinic under the auspices of CCA. In 1951 Somerton Home began to provide services to children with disabilities other than polio, for example, neuromuscular diseases. In 1952 Ashford House, in the south western suburbs, was purchased with State Government assistance and used as a school and therapy centre for children with cerebral palsy.

In 1976, children were transferred from Somerton Home and Ashford House School to the newly developed CCA premises at Regency Park. In 1992 the residential facility at Regency Park was closed, with all children supported at home. In 1993 a regional structure for children's therapy services was developed. Services were exchanged with the Spastic Centre of South Australia, resulting in CCA providing therapy for all children with physical disabilities in South Australia.

In 1995, the CCA Options Coordination service commenced, providing support services, including respite care and home help, to CCA clients and their families

In 1997, CCA entered into partnership with the Women's and Children's Hospital for the provision of medical, paediatric rehabilitation services.

During its 70 years of service to children with physical disabilities and their families, the organisation has actively raised funds to provide those services, which are subsidised with recurrent funding allocations principally from the South Australian Government.

## 2 About Novita Children's Services

Novita Children's Services is a South Australian, non-government, non-profit organisation established in 1939 as the Crippled Children's Association of South Australia, to care for children diagnosed with polo. Today, Novita is a service provider and recognised leader in the provision of research, development and provision of innovative services to children and young people living with disabilities, and their families.

Novita currently provides essential therapy, equipment and family support to more than 1300 children. Novita's primary services include Early Childhood Services, Child and Adolescent Services, Regional Services, the Inclusion Support Program, Outside School Hours Care Programs, Autism Early Intervention Program, and Home Interaction Program for Parents and Youngsters.

In addition, Novita provides a number of specialist services and programs, including the Equipment Service, the Rehabilitation Service, and the Acquired Brain Injury Program. Primary and specialist services are delivered by teams that include staff from the professions of occupational therapy, physiotherapy, psychology, speech pathology and family support, provided at home, at kindergarten, at child care and at school. Novita also provides essential equipment, such as wheelchairs, walking frames and communication devices, to help children to move, speak, play and 'connect with their worlds'.

Novita's services are provided in partnership with children, their families and communities. No two children are the same, so Novita's services aim to be individualised, responsive and flexible, allowing each family to make choices about the services they receive.

Novita is a company limited by guarantee, incorporated under national corporations law.

### 3 Children with Disabilities

According to the Australian Institute of Health and Welfare (AIHW)<sup>4</sup>, in 2003, the Australian Bureau of Statistics (ABS) 2003 Survey of Disability, Ageing and Carers reported that:

*“About 1 in 12 children had a disability (8.3% of all children, 317,900 children); About half of these children, 1 in 24, had a severe or profound core activity limitation (4.3%, 165,300)*

*Boys were more likely than girls to have a disability (10% compared with 6.5%); and to have a severe or profound core activity limitation (5.4% compared with 3.1%)*

*Autism and intellectual impairment were associated with high proportions of severe or profound core activity limitation - 87% and 75% of children with these respective conditions also had a severe or profound core activity limitation;*

*An estimated 54,600 people were primary carers of co-resident children with a severe or profound core activity limitation; and the vast majority (91%) were mothers*

*About 1 in 2 (48%) co-resident primary carers of children reported needing more support — in fact more respite care and financial assistance were their greatest needs*

*Almost all (97%) children aged 5-14 years with a disability were attending school — 89% of them in ‘mainstream’ schools and 9% in ‘special’ schools;*

*Around 63% of school children with disabilities experienced difficulty at school — intellectual/learning difficulties, ‘fitting in’ socially and communication difficulties were the most common.”*

Historically, many of the clients of Novita have cerebral palsy. The Centre for Cerebral Palsy, Western Australia, provides the following summary about cerebral palsy.

*“Cerebral palsy is a permanent physical condition that affects movement. It can be as mild as just a weakness in one hand, ranging to an almost complete lack of movement.*

*Cerebral palsy, except in its mildest forms, can be seen in the first 12-18 months of life as it presents when children fail to reach movement milestones. Babies most at risk of cerebral palsy are those born prematurely or with low birth weight.*

*Sometimes the movements of people with cerebral palsy can be unpredictable, muscles can be stiff or tight, and in some cases people may have shaky movements or tremors. Some people may have seizures and other impairments affecting their speech, vision, hearing and/or intellect.*

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<sup>4</sup> Australian Government – Australian Institute of Health and Welfare (AIHW) – Disability Updates: children with disabilities Bulletin Issue 42 – July 2006

*Key facts about cerebral palsy:*

- *There is no pre-birth test*
- *It is a permanent condition*
- *It is non-progressive, however can be a changing condition*
- *There is no known cure*
- *Incidence and severity are on the increase*
- *Worldwide more than 15 million people have cerebral palsy*
- *In Australia, a child is born with cerebral palsy every 18 hours”<sup>5</sup>*

Compelling information about adults and children with cerebral palsy is provided by Access Economics in an incisive report prepared in 2007 for Cerebral Palsy Australia.<sup>6</sup>

The following key points are noted from that report:

**CP in Australia**

1. Overall, 33,797 Australians are estimated to have CP in 2007.
  - CP is a life long condition; disability increases with age, and ageing occurs earlier (and possibly for longer).
  - The number of Australians with CP is projected to increase as the population grows (to around 47,601 by 2050), although the share remains at about 0.2% of the population.
2. Compared to other health conditions, CP is:
  - more common in any year than the most common types of cancer, stroke, eating disorders, appendicitis or road traffic accidents;
  - in the top five most costly conditions on a per capita basis of 15 conditions studied by Access Economics in recent years; and
  - a condition with a higher disability burden than being blind, deaf, having severe asthma or diabetes. CP is also more disabling than having heart failure, localised cancer or the most severe forms of Attention Deficit Disorder with Hyperactivity (ADHD).
3. Severity of CP has traditionally been based on the severity of the motor impairment, with a particular emphasis on function and mobility. Approximately 50% of individuals with CP are able to walk independently, 25% can walk with an assistive device and 25% are unable to walk.
4. For people with CP, more than half had a severe or profound limitation either with self-care or mobility or both, and about 40% had that limitation with communication. Over 40% of people with CP were also using aids or equipment for mobility or communication activities.
5. The likelihood and severity of associated impairments increases with the severity of motor impairment. It has been reported that for individuals with a severe motor impairment up to 70% will have epilepsy, 50% will have a severe intellectual impairment, 55% will be non-verbal, 25% will be blind and 3% will be deaf ... many will have a number of these impairments, and their presence complicates therapy, decreases health status and quality of life for the individual and their family, and increases costs for the family and society.

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<sup>5</sup> Website - The Centre for Cerebral Palsy, Western Australia

<sup>6</sup> "The Economic Impact of Cerebral Palsy in Australia in 2007". Report by Access Economics Pty Ltd. Pages vi-x; 1-21.

6. There is general consensus that the incidence of CP is around 2-2.5 per 1,000 live births, which makes it the most common physical disability in childhood.
7. CP Australia estimates that approximately 600 to 700 infants are born with CP in Australia each year.
8. CP is a life-long condition and usually the weakness, stiffness or unwanted movements remain throughout the person's life. While CP cannot be cured, treatment can improve a person's capabilities, allowing them to enjoy near-normal adult lives if their disabilities are properly managed. In general, the earlier treatment begins, the better chance children have of overcoming developmental disabilities or learning new ways to accomplish the tasks that challenge them.
9. There is no standard therapy that works for every individual with CP. Doctors use tests and evaluation scales to determine a child's level of disability, and then make decisions about the types of treatments and the best timing and strategy for interventions. Once the diagnosis is made, and the type of CP is determined, a team of health care professionals ... will work with a person and his or her carers to identify specific impairments and needs, and then develop an appropriate plan to tackle the core disabilities that affect the person's quality of life.

A coordinated CP management plan will combine the services of various health professionals with experience in the following areas:

- physical therapy aimed at improving the functioning of muscles, walking and gait, and preventing deformities;
  - occupational therapy to develop methods for participating in activities such as dressing, going to school, work and participating in day-to-day activities;
  - speech therapy to address swallowing disorders, speech impediments and obstacles to communication;
  - counselling and behavioural therapy to address emotional and psychological needs;
  - drugs to control seizures, relax muscle spasms and alleviate any pain;
  - surgery to correct anatomical abnormalities or release tight muscles;
  - braces and other orthotic devices to compensate for muscle imbalance, improve posture and walking and increase independent mobility;
  - mechanical aids such as wheelchairs and rolling walkers for individuals who are not independently mobile; and
  - communication aids such as computers, voice synthesizers, or symbol boards to allow severely impaired individuals to communicate with others.
- 10 Treatment is not limited to the services of medical professionals, with the majority of work to manage CP being done outside of formal care settings. The role of the treatment team is often to act as a coach or mentor giving people with CP, and their carers, methods and strategies to practice at home., While mastering specific skills is an important focus of treatment on a day-to-day basis, the ultimate goal is to help people with CP grow into adulthood with as much independence as possible.

As a child with CP grows older, the need for therapy and the kinds of therapies required, as well as support services, will likely change. Counselling for emotional and psychological challenges may be needed at any age, but is often most critical during adolescence.

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**COMMENT:**

These statistics indicate the prevalence and effects of CP in Australia and they clearly underpin the need for government policy that does not marginalise disability.

This data clearly demonstrates the challenges that exist in addressing the specific needs of children with disabilities and, in particular, the need for governments to recognise these challenges and the unique circumstances these children and their families face. Planning for a NDIS must recognise and take account of these matters.

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## 4 Services to Children with Disabilities

Specialist disability services enhance the capacity of families to provide for the additional needs of their children. Investing in services for children from an early age reaps significant long-term benefits for children's health and well-being and their future ability to be educated, find employment, develop relationships and participate in community life. To respond to the individual needs of children and their families, services need to be flexible and locally delivered.

At Novita, there has been considerable development and long term expansion of service in three principal areas, namely:

- Client Services
- Assistive Technology Services and
- Research and Innovation.

This submission will summarise key elements in each of those areas.

### 4.1 Novita Client Services

#### 4.1.1 Early Childhood Services

Novita Early Childhood Services (ECS) provides services to 250 clients from birth to 8 years of age, and their families, across metropolitan Adelaide. The Novita definition of metropolitan remains as one hour's drive from metropolitan offices and includes the Greater Adelaide regions of the Barossa, southern Fleurieu Peninsula and the Adelaide Hills. Services are based at Regency Park, Paradise and Christies Beach.

Following referral to the Novita Central Intake Team (CIT), families are part of the ECS Welcome Program, which provides information about services, links families with other families through the Parent to Parent initiative, and establishes goals and intervention programs with families.

Dependent on the family need, a case manager, key worker or contact person is allocated to the family as their point of contact with Novita. The client / family is allocated a therapy team and services begin, ranging from home and school visits, group programs to referral to specialist service teams, if complex equipment or post medical intervention follow up is required. A waiting list for specific services is established where there are staff shortages or greater demand.

#### 4.1.2 Child and Adolescent Services

Child and Adolescent Services (CAS) provide services to 600 clients from 8-18 years of age, and their families, across metropolitan Adelaide. Services are based at Parafield Gardens and Parkside.

On initial referral, a case manager, key worker or contact person is allocated to each client. Specific needs are identified with the client / family and clients are placed on a waiting list for services. CAS relies on families requesting further services rather than having available staff at this point for regular reviews. CAS offers home and school visits, clinics and group programs.

The waiting list is significant, with the greatest area of need being oral eating and drinking care plans, partly due to the national shortage of speech pathologists.

#### **4.1.3 Novita Regional Services**

Novita Regional Services (RS) currently provides services to 232 clients living in regional areas of SA. In supporting Novita's clients, RS works closely with 256 Allied Health and Family Support Professionals (i.e. Community Health, Disability SA) and 252 Schools/Preschools/Childcare Centres within 14 regional communities.

There are 2 teams within RS. They are:

- North West Team (NW) which covers the Eyre Peninsula, Mid North, Port Pirie, Port Augusta and Far North regions
- South East Team (SE) which covers the Murray Mallee, South East, Kangaroo Island and Broken Hill regions.

The RS service delivery model has a focus on working in partnership with local communities and, where possible, developing the capacity of the community to support Novita's clients.

#### **4.1.4 Novita Inclusion Support Service**

Novita's Inclusion Support Service assists child care services in the north-west of South Australia to include children requiring additional support, such as children from culturally and linguistically diverse backgrounds (CALD), children with ongoing high support needs and indigenous children. The Inclusion Support Program is an initiative of the Inclusion and Professional Support Program, subsidised by the Australian Government.

The Inclusion Support Program (ISP) commenced in April 2006 with funding now extended to 2012.

Novita Inclusion Support Facilitators work directly with child care services to support staff to develop an environment that includes all children, including those with additional needs. There are 71 eligible child care services supported by Novita in the far North West region of South Australia, which extends from Clare, Yorke Peninsula, and Eyre Peninsula, to the borders of Western Australia, Northern Territory and New South Wales.

Novita's Regional Service and Inclusion Support teams have been working together, wherever possible, to support the needs of shared clients in the far north west regional areas of South Australia.

#### **4.1.5 Novita Care Options**

Novita receives government funding to broker respite and personal care support packages for Novita clients across South Australia. This is provided through National Disability Agreement (NDA) funding and Home and Community Care (HACC) funding. In addition, Novita is required to contribute significant amounts of its own funds to augment the HACC funding. These funds are provided through Novita fundraising and investment initiatives. Individual client funding allocation is undertaken by Novita's Family Support

staff each financial year, using priority allocation criteria. Contracts are let for individual client packages with a range of agencies that provide respite (in home and out of home), personal care and support services.

The NDA Funding is identified within the Case Management service type.

HACC funding is targeted to clients with moderate – severe disability with functional limitations. Through the HACC Care Options Packages (2008-2011), Novita receives annual funding; allocated for 5% domestic assistance, 25% personal care and 70% respite care and split 27% country and 73% metropolitan. Novita also receives a small amount of Flexible Personal Care funding for clients in the metropolitan area.

Families registered with Novita are referred to Family Service Coordinators (FSC) by other team members, directly by the family or from other agencies. The FSC works with the family to identify their specific needs, such as health issues, personal care, respite, practical support and information.

The role of the FSC is to identify community based supports that meet the identified needs, in the first instance, not requiring a funded package. They may refer to any or several of a variety of community-based mainstream agencies. Where community based supports cannot be sourced and needs remain unmet, the FSC will locate an agency which is able to provide a worker with the required skills and at the time requested.

A Priority of Access and Independence Rating identifies issues such as need for physical care, family stressors and indicators of disadvantage. This is consistent with the HACC requirements to prioritise brokerage funds to support clients with moderate to severe disability in greatest need.

#### **4.1.6 Novita Autism Program**

Novita's Autism Early Intervention Program commenced in April 2009.

Children must have an Autism Spectrum Disorder (ASD) diagnosis to be eligible for the Government funding. This funding is for children aged 7 years and under and is available over 2 years with a maximum of \$6,000 per year. The focus is on early intervention in preparation for children attending school.

Novita's fees are provided to Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) and displayed on their website. Novita bills the government directly for services provided to clients, via the FaHCSIA Online Funding Management System (FOFMS).

In addition, Novita is contracted by the Parenting Research Centre to provide Early Days workshops to parents of children with ASD. To date, five metropolitan and one country workshop have been provided.

Novita staff provide services throughout the metropolitan area. Services include speech pathology, occupational therapy and allied health support.

#### **4.1.7 Novita Out of School Hours Care Programs (After School Care and Vacation Care)**

The Novita OSHC-TeenZone program provides care for teenagers aged 12 - 18 years living with a disability, and their siblings, outside of school hours, at Regency Park. It is subsidised by the Australian Government through FaHCSIA, under the “Extra Support for Children with Disability Outside School Hours Care Funding Program”

The funding does not cover the full service and Novita is obliged (by government) to charge parents a fee. Parents are then able to access the childcare benefit. Originally the age range was specified as 12-18 years; however, approval has recently been obtained to provide care for younger children when places are available.

FaHCSIA has announced further funding available to expand services and Novita will provide a Vacation Care Service for children with disabilities in the southern metropolitan area of Adelaide, at Hamilton High School.

#### **4.1.8 Rehabilitation Service**

The Novita Rehabilitation Service provides specialised, co-ordinated time-limited services to enhance the outcomes of Novita clients following major injury, illness or medical procedures which affect their physical function.

The Rehabilitation Service has 3 specialist programs:

- the Physical Rehabilitation Program (PRP), which supports rehabilitation after medical procedures (such as Botulinum Toxin (Botox) or surgery)
- the Acquired Brain Injury Program (ABI), which specialises in rehabilitation after an acquired brain injury (such as head injury or brain tumour), and
- the Acquired Disability Program (ADP) which focuses on rehabilitation after a major injury or illness (such as a spinal cord injury).

##### **4.1.8.1 Physical Rehabilitation Program**

Novita’s Physical Rehabilitation Program (PRP) is based at Regency Park.

Approximately 200 of Novita’s 900 metropolitan clients are receiving rehabilitation services at any point in time (22%). Approximately 700 of Novita’s 900 metropolitan clients (80%) will require one or more rehabilitation episodes of care while registered with Novita. Rehabilitation episodes last between 6 weeks and 2 years and are of varying intensity.

Medical Paediatric Rehabilitation Services, purchased from the South Australian Government’s Children’s Youth and Women’s Health Service (CYWHS), are managed through Novita’s Rehabilitation Service.

Community based multidisciplinary Rehabilitation Clinics are held in metropolitan Adelaide for pre-intervention planning and post-

intervention follow-up. Approximately 90% of Novita's clients require ongoing review and monitoring through the Rehabilitation Clinics.

The coordinated approach to managing these clinics has resulted in collaborative relationships with the CYWHS staff and a more consistent approach to the management of rehabilitation for Novita clients.

Medical services required by children with disabilities are a specialised area of paediatrics. Novita provides access to a range of such services via an agreement with the CYWHS. Services include special clinics held at Novita regional offices, and specialist clinics and treatment services at hospitals (including the Women's and Children's Hospital). Strong links are encouraged and maintained between families, paediatricians, paediatric rehabilitation physicians, community agencies and the Novita therapy team working with each child.

Rural paediatric rehabilitation clinics are regularly conducted in Alice Springs (by special arrangement with the Northern Territory Government) Mount Gambier, Naracoorte, Port Lincoln, the Riverland and Whyalla.

Novita provides Physiotherapy services to Northern Territory Health, resulting in the provision of 3 Rehabilitation Clinics at the Royal Darwin Hospital with a Paediatric Rehabilitation Specialist from CYWHS and local clinicians.

PRP is an area where most services cannot and do not wait (ie those where the timing is integral to the outcomes of medical interventions eg Botox, orthopaedic surgery).

- **Movement Disorder Clinic**  
The Movement Disorder Clinic (MDC) is for the assessment, management and long term monitoring of children and young people who present with disorders of movement, such as spasticity, dystonia, gait disturbances, as well as clients with neuromuscular disorders such as Muscular Dystrophy (MD) and Spinal Muscular Atrophy. Medical interventions may include Botulinum Toxin, Intrathecal Baclofen (ITB), or Selective Dorsal Rhizotomy (SDR).

Hip surveillance is also conducted through the MDC, as well as referral through other clinics at Novita and CYWHS, such as the Rehabilitation Orthopaedic Clinics. Clinics are held at each Novita office and are attended by a Paediatric Rehabilitation Specialist (PRP), Physiotherapist (PT), Occupational Therapist (OT), client and parent/carer.

- **Rehabilitation - Orthopaedic Clinics**  
These clinics are generally for discussion of lower limb orthopaedic surgical issues. For surgical opinion on other areas, there may be a referral to an alternative clinic, such as the Upper

Limb (UL) Surgical Clinic or to the spinal clinic at CYWHS, via a referral by a Paediatric Rehabilitation Specialist at a MDC. Rehabilitation – Orthopaedic Clinics are held one half day per term in each Novita office and are attended by an Orthopaedic Surgeon, Paediatric Rehabilitation Specialist, PRP PT, client and parent/carer.

- **Upper Limb Management Clinics**  
These clinics are PRP Occupational Therapy (OT) focussed and located at each Novita office, once per term, if required. These clinics are run with the aim that the OT's from primary service areas and their clients have access to one-on-one sessions with PRP OTs, so that specific upper limb (UL) management issues can be reviewed and clinical management options discussed.
- **Upper Limb Surgical Clinic**  
The upper limb surgical clinic is a CYWHS-based clinic where the discussion and lead up to surgery as a possible option of intervention occurs and post-surgical review of procedures is completed. The clinic is attended by a Paediatric Rehabilitation Specialist, Orthopaedic Surgeon, Senior OT PRP, client and parent/carer.
- **Oral and Mealtime Management Clinic**  
This is a multi-disciplinary clinic to support clients with oral and mealtime issues. Initially, the team will review videos of clients and make recommendations for oral and mealtime management. The clinic is staffed by a Paediatrician, Dietician and PRP Speech Pathologist (SP).
- **CYWHS / Novita Video Fluoroscopy Swallow Study**  
A CYWHS-based clinic where clients have a video swallow study to further assess a client's swallowing, using x-ray. This clinic is staffed by a PRP SP, CYWHS Radiographer, CYWHS Radiologist, CYWHS Medical Imaging Nurse, and CYWHS SP.

#### **4.1.8.2 Novita Acquired Brain Injury/Acquired Disability Program (ABI/ADP)**

The Novita ABI/ADP team is usually involved with the client and family prior to discharge from hospital. Clients have a Key Worker and a service plan is developed with the client and family. ABI/ADP is the primary service area for clients with an ABI/AD.

ABI/AD clients represent 18% of clients registered with Novita, and include:

- AD – Spinal cord injury, Guillan-Barre, amputees
- ABI – trauma, brain tumour, infection, other event eg CVA.

Novita is funded to provide services to children with a physical disability and those with severe and multiple disabilities. This represents 24% of clients in the ABI/ADP Program. The ABI/ADP Program is not funded by government for children with an ABI without

physical disabilities, meaning that 76% of current clients are funded by Novita fund raising.

The ABI/ADP offers 2 streams of services:

- Rehabilitation  
The rehabilitation phase is usually in the 1-2 years following the ABI/AD and interventions are time limited, episodic, goal directed and evidence based. Ideally, therapy intervention should be provided up to 3 times a week (across disciplines), dependent on the severity of injury and the client's rehabilitation potential.
- Habilitation  
The habilitation phase following the ABI/AD involves case management and monitoring by the Novita ABI/AD team. At times, a need for intervention is defined in the habilitation phase of intervention. These needs are provided, based on priority and available resources.

Services provided by the ABI/ADP are community based, which involves attendance at appointments in a range of community settings. Both individual and group interventions are offered by the ABI/ADP. The ABI/ADP is available to all eligible children in South Australia, although direct service provision is limited in regional areas (20% of clients live in country areas, with a further 17% living in peri-urban areas). In regional areas, the ABI/AD team's intervention focuses on facilitating service provision for the child and family in their local community and providing specialist support and consultation to local service providers.

ABI/ADP Clinics are specialist Rehabilitation Clinics. Clients discharged from CYWHS will have a six week post-discharge review at CYWHS. Priority for the ABI/AD clinics will be for those children less than 12 months post injury/diagnosis. These clinics are held at Novita offices and attended by a Paediatric Rehabilitation Specialist, relevant ABI/ADP staff, client and parent/carer.

While a waiting list has been established for services, waiting is not at point of entry and service provision is prioritised in the 1-2 year post injury phase.

#### **4.1.9 Nutrition and Dietetics Services**

Many children and young people, because of their physical disability, have special problems with eating and drinking; therefore a good diet is necessary to ensure they receive the nourishment they need.

There is a partnership agreement between Novita and CYWHS that enables a nutrition service to be provided to Novita patients. The dietitians visit two of the Novita regional offices and also see Novita clients at the Women's and Children's Hospital. The dietitians are members of the CYWHS.

The dietitians also work closely with the home enteral nutrition services of the Women's and Children's Hospital and other hospitals, for those children requiring nasogastric or gastrostomy feeds.

#### **4.1.10 Novita ConnectABILITY**

The ConnectABILITY project is a program that aims to provide children living with physical disabilities, aged five to 18 years, with greater access to community-based sport and recreation activities.

ConnectABILITY is a program funded by the South Australian Government's Office of Recreation and Sport, to link children with disabilities with sporting opportunities.

ConnectABILITY is delivered via a range of services, including:

- a supported recreation program that increases the number of children with physical disabilities participating in community-based recreation programs
- additional, individualised, expert support to community-organised recreation groups and clubs that are looking to enhance their inclusion strategies and increase their membership base
- involving members of the community through the development of volunteer mentoring opportunities within the program.

#### **4.1.11 Novita Home Interaction Program for Parents and Youngsters (HIPPY)**

This is part of an international program established in 1969 by the Institute for Innovation at the School of Education of the Hebrew University of Jerusalem.

HIPPY is an active program in 10 countries around the world. The Brotherhood of St Laurence holds the international license to operate HIPPY in Australia. Novita provides the program in the Adelaide metropolitan western suburb of Mansfield Park.

HIPPY is a two-year home-based parenting and early childhood enrichment program, comprising weekly activities that parents and children work through together with the support of home tutors.

Eligibility for services is based on families living in the South Australian metropolitan suburb of Mansfield Park with children who are likely to commence school within the next 2 years.

Services include:

- a two-year, home-based early childhood enrichment program
- weekly activities involving visits from a home tutor
- group meetings with other participants available on fortnightly basis
- casual employment for parent as home tutors.

There are no costs to participating families.

#### **4.1.12 Novita E-Mentor Program**

Novita's eMentor Program, providing support for teenagers with acquired brain injury, is funded by the Telstra Foundation. It is an example of a new service initiative that benefits Novita clients through a national, private sponsorship arrangement.

The E-Mentor Program aims to connect teenagers with disabilities with their peers and the wider community, through specially-trained Novita 'E-Mentors', who will help them develop the skills, knowledge and motivation they need to participate fully and successfully in their personal, academic and professional lives.

The program has initially focused on Novita clients aged between 13 and 18 who are living with Acquired Brain Injuries, with the objective of extending the program eligibility to include all Novita clients aged between 13 and 18. This program is particularly helpful for teenagers living in rural communities, where social isolation can be compounded by their remote location.

E-Mentors are specially trained to help teenagers improve their self esteem, improve their relationships with family and friends and gain access to innovative communication techniques to increase their social and independent living skills. Novita staff match E-Mentors with teenagers, based on the qualities each teenager is looking for in a mentor.

#### **4.1.13 Novita Employment Assessment Services**

Novita is a service provider on the new National Panel of Assessors (NPA), as part of the Australian Government's Disability Employment Services.

Novita NPA approved assessors provide services as part of the Employer Incentives Scheme in the areas of:

- ongoing Support Assessment
- Supported Wage System Assessment
- Workplace Modifications Assessment.

Service provision extends to metropolitan Adelaide, Gawler, Adelaide Hills, Fleurieu Peninsula and Kangaroo Island.

#### **4.1.14 Novita Toy and Resource Centre**

The Toy and Resource Centre (TRC) is a specialist library that provides a wide range of resources for children living with physical disabilities to assist them to play, learn and 'connect with their worlds'.

The TRC also supports the professional and research requirements of Novita staff. TRC services include toy and software collection, disability collection (books, CDs, DVDs, etc), Variety SA software collection, online catalogues, online databases, Online journals, literacy materials, Parenting resources, children's books on physical disability, brochures about TRC resources.

#### 4.1.15 Professional Services

Novita Allied Health staff are actively engaged in working with government departments and other agencies in providing disability specific support for children and young people engaged in activities in the community.

Three examples are highlighted in this paper, namely:

- the Negotiated Education Plan
- the Transfer and Positioning Care Plan and
- the Oral Eating and Drinking Care Plan.

##### 4.1.15.1 Negotiated Education Plan

Novita staff help children with disabilities join in with school life by:

- assisting school staff understand a child's abilities and needs
- working out with school staff how therapy ideas can be included in the educational program
- training school staff in:
  - ways to lift
  - how to use equipment
  - effective positioning
  - how to help with mealtimes
  - how to develop communication
- providing therapy for a short time to achieve a particular goal
- advising on special equipment or changes to the school
- assessing and providing advice on learning, behaviour, social and emotional difficulties and giving advice to families and school staff, if requested.

In South Australian Department of Education and Children's Services (DECS) schools and pre-schools, Novita participates in the development of Negotiated Education Plans. They are detailed plans for how services are to be provided to a student with special needs. The plans are developed by the school with parents and others who support the child

Similarly, Novita participates in the development of Action Plans for children with disabilities in Catholic Education and in the development of Student Support Plans for children with special needs in independent schools and pre-schools.

##### 4.1.15.2 Transfer and Positioning Care Plan

A Transfer and Positioning Care Plan is required for any child who needs more than light assistance or guidance with their transfers and positioning.

The Transfer and Positioning Care Plan is completed by the child's physiotherapist at Novita.

Transfers and positioning may be required at:

- child care centres
- schools
- preschools
- home
- Family Day Care

- Out of Hours School Care
- Vacation Care.

Transfer and Positioning Care Plans developed by Novita are part of the Personal Care Support Plans developed by DECS.

#### 4.1.15.3 Oral Eating and Drinking Care Plan

The Oral Eating and Drinking Care Plan is a plan that describes the safest, most efficient and most effective ways to provide mealtime support to a child who has some difficulties with eating or swallowing

The plan is designed to support people who are assisting a child at mealtimes. The child's parent or guardian will provide their school with an Oral Eating and Drinking Care Plan, prepared and compiled by Novita speech pathology staff, if requested. Without this plan, school staff may be unable to assist the child with mealtimes.

The Oral Eating and Drinking Care Plan may be required at:

- Educational settings including pre-school and school
- Childcare
- Family Day Care
- Respite
- Out of School Hours care
- Vacation Care.

The Oral Eating and Drinking Care Plan is provided by Novita as part of the Personal Care Support Plans developed by DECS.

Care plans provided by Novita speech pathologists are often done with the involvement of other team members, such as a dietician, physiotherapist, occupational therapist and medical specialist.

#### 4.1.16 Assessments and Early Intervention

Assessment is carried out for many reasons. It can help to work out:

- the things a child may need or want to do in their lives
- the cause of a child's disability or what kind of disability they have
- what and how things are changing
- what equipment to use and the best way for a child to use it
- how a child is going in their development compared to other children of their age
- the answer to a specific question about the child
- the answer to a particular research question
- what skills a child has, and consequently, the skills with which a child needs help. This information enables planning of goals.

Some assessments can be done very quickly, while others may take several sessions. Assessments are about getting to know the child better and gathering information, not about 'passing' or 'failing' a child or their family.

Repeat assessments occur over time for a child as they change, grow, do different things in their life, and as the things that are important for them change.

Methods of assessment at Novita may include:

- videoing things that are hard to describe in words, such as how a child moves or how a child plays. This can be a great way of keeping track of changes in the child's abilities
- using a team approach - carrying out and discussing the results of the assessment with other therapists
- using standardised (formal) assessments - assessments that have been performed on a large number of children with the scores being grouped together (group norms) to provide an overall picture of the range of scores a person can achieve. A child's assessment scores can then be compared to the grouped norms to work out how a child compares to others of the same age. Sometimes, to be useful and meaningful, assessments may need to be repeated under exactly the same conditions (words, testing materials and methods).

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### **COMMENT:**

Functional assessments – in recent years it has become apparent that governments are developing concepts of psychiatric disability, with associated policies, funding and practice developments; however, there is concern about this trend and Novita is aware of other agencies and experts who hold apprehensions about it.

The history of disability services for children and adults in South Australia has close parallels with other Australian States and with historical movements over the last century in other western countries. It has been briefly summarised earlier in this submission. Until the 1970's there were frequent overlaps between the disability sector and the mental health sector, with differing levels of government action and inaction. By the 1970's, governments began to develop public sector facilities for residential care of children with disabilities, with a primary objective of separating disability from mental health.

The critical point is that the history of disability and mental health shows with abundant clarity that a blurring of the lines between the two sectors has led to abuse, neglect through misdiagnosis, or neglect because of no diagnosis. The consequences have been frequently shameful and degrading for citizens who have been subjected to treatment regimes that are wholly inappropriate for their circumstances.

Although confinement of children into institutions is, thankfully, no longer a reality, the mis-direction of children (and adults) into the wrong service system is potentially a problem. A child with an intellectual disability should not be "treated" as a child with a mental health issue, and vice versa.

The concept of psychiatric disability can lead to a disturbing mismatch of mental health and developmental disability. It is urged that the NDIS acknowledge the border between mental health and disability, so that both are funded, developed, improved and sustained separately. In individual instances, there will be crossovers to which both systems should respond collaboratively.

#### 4.1.17 Novita Equipment Service

The Equipment Service (ES) provides services to all eligible clients of Novita who require specialised equipment to assist them with mobility, communication, education and daily living.

Referrals are received for provision of complex items of equipment and associated services (eg power wheelchair driving training, bed reviews, complex technology prescription, long term planning for Augmentative or Alternative Communication (AAC) use). ES therapists establish goals for equipment provision; complete assessments and prescriptions; provide intervention programs, and liaise with suppliers and the South Australian Government's Domiciliary Equipment Service (DES) regarding provision of equipment for clients.

ES established 'Walker Clinics' in 2008 which, in addition to walking frames, now includes advice to therapists regarding standing frames. ES works closely with the Australian Lions' Children's Mobility Foundation (ALCMF) with the ALCMF providing considerable funding for walkers.

ES has established a Short Term Loan Equipment pool, enabling items of equipment to be booked for short term use (eg during active rehabilitation interventions or for trial).

In addition to the direct services that ES provide to clients, ES staff provide consultancy and advice to therapists within the client's primary service area (metropolitan and regional) by:

- co-coordinating modifications and repair and delivery of equipment
- providing clinical sign off of complex equipment prescriptions for clients living in regional areas
- providing training and development for all Novita therapists regarding equipment, the provision of up-to-date resources; and clinical guidelines
- providing the administration support for all service areas to keep waiting lists up-to-date; ensuring procurement of new standard and complex equipment; and the tracking of recycled equipment.

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#### **COMMENT:**

For children and adults with physical and/or severe multiple disabilities, the provision of aids and equipment to assist their mobility, independence and community participation is essential to improving their wellbeing. The provision of equipment can be life changing.

However, often equipment for children requires more frequent replacement or modification than it does for adults, while each child progresses into and through adolescence. In addition, children rely on different types of equipment in different settings (eg school, home, playground, social settings) that requires flexibility and planning when selecting and implementing equipment solutions. There are increased costs associated with physical growth and achievement of developmental milestones that should be recognised as an essential element regarding equipment.

Equipment is often used as a component of, or as an enhancement to, therapeutic intervention. Therapy and equipment are critically interrelated in successfully supporting mobility and independence as well as enhancing capacity to participate in the community.

Under the current arrangements the provision of equipment across jurisdictions is often sporadically funded, there are huge waiting lists, and as a consequence, the ability to achieve social inclusion is often denied.

In recent developments, the South Australian Government Department for Families and Communities (DFC) has established a single equipment scheme through the combination of the previous Independent Living Equipment Program (ILEP) and the Domiciliary Care Equipment Program. The DFC Equipment Program is managed by the South Australian Government Domiciliary Equipment Services (DES).

Novita has confirmed its intent to develop systems and procedures that will enable the inclusion of the children's component of the previous ILEP scheme into the procedural framework of the DFC Equipment Program, while retaining Novita's role as an essential partner in the DFC Equipment Program.

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#### **4.1.18 Novita Assistive Technology Services (NovitaTech)**

As the technology division of Novita, NovitaTech assists people with a disability to lead fuller and more satisfying lives with the help of aids and equipment. NovitaTech (previously called Regency Park Rehabilitation Engineering) was established in 1976.

NovitaTech provides services for people of all ages, all disabilities and all locations within Australia, and is a quality-accredited supplier, reflecting a commitment to continually strive to be an Australian specialist centre that benefits customers and professionals.

NovitaTech staff regularly find solutions to the most challenging technology-related problems people with disabilities face, and draw on the skills of a diverse professional team that includes researchers and testing engineers. NovitaTech has links and agreements with specialist centres nationally and internationally to enable staff to draw on, and contribute to, worldwide expertise for the benefit of Australians with disabilities. NovitaTech works in partnership with clients, customers and those on whom they rely for professional advice.

NovitaTech provides equipment, support and training for people living with disabilities who require complex technical solutions. NovitaTech's areas of expertise include assistive technology, complex mobility and seating, orthotics and Australia's only disability equipment standards facility accredited under the National Association of Testing Authorities (NATA). NATA accreditation provides a means of determining, recognising and promoting the competence of facilities to perform specific types of testing, measurement, inspection and calibration.

The NovitaTech test laboratory began in 1989. It was created to assist the International Standards Organisation (ISO) and Standards Australia produce a

range of quality and performance standards for wheelchairs and other rehabilitation equipment. These standards are now published and the Novita Tech Laboratory is available to carry out commercial testing and product development for clients and customers locally, interstate and overseas.

For several years, NovitaTech has expanded its business operations overseas. Currently, for example, NovitaTech has distributor agreements in place with companies in the UK, USA and Canada in relation to assistive technology products, devices, research contracts and projects relating to services, equipment, aids and technology in the disability sector.

NovitaTech has been active in establishing partnerships with national and international universities and companies to provide training opportunities for staff and research pathways which could not be undertaken on their own.

From 2005, NovitaTech has continued to develop its role in the Asia-Pacific region through the establishment of partnership agreements with organisations in both Singapore and Taiwan. Specifically, NovitaTech has helped to establish an assistive technology advisory service in Singapore. Through this project, NovitaTech has worked in collaboration with strategic partners in Singapore and the USA to develop communication solutions for people who speak Mandarin.

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### **COMMENT:**

Over recent years, rapid advances in assistive technology for people with a disability have become available. However, timely access to this technology is limited, due primarily to funding constraints and the lack of a nationally consistent approach. For some people, assistive technology provides life changing opportunities – for example the ability to communicate, which is a basic human right.

In 2007, the South Australian Government provided funding for the State-Wide Complex Communication Needs (SCCN) Project which provided individual communication solutions, training, education, and professional development in augmentative and alternative communication. The innovative and distinctive aspect of this Project was its holistic approach to services for people with complex communication needs. It drew together resources and services targeted at addressing the outcome for those with a communication disability – namely an effective means to communicate and increased opportunities to successfully do so. However, funding for this project ceased, despite protest and rallies at South Australia's Parliament House. Accordingly, the right to communicate must be recognised.

Both the Commonwealth and State/Territory Governments administer schemes that provide some essential aids cost-free or at low-cost to people with disability. In addition, a number of Non-Government organisations provide aids and equipment.

However, the process of equipment provision is underpinned by a rationing model. Thus it rarely meets the needs of children and adults in a timely way, often leading to lengthy delays in the issue of prescribed items.

In several reports related to equipment provision published by the Australian Institute of Health and Welfare (AIHW), these delays were shown to lead to significantly higher costs of subsequent hospitalisation and lost function, in addition to the personal cost to the individual. Due to the high costs associated with some equipment (or restrictions on types of equipment available), families may need to supplement (personally or through fund raising) government funding to purchase essential equipment items.

Overall, in a study of aids and equipment, the Australian Institute of Health and Welfare (AIHW) reported in 2003 that there was a limited range of equipment; issues with cost and availability; a shortage of referral services in remote areas of Australia; and a decline in equipment supply from traditional dispensing units such as hospitals. Systems for the provision of equipment are fragmented both across state borders and on diagnostic and item grounds.

In addition, equipment, assistive technology and therapy are critically interrelated. Therapy encompasses a wide range of interventions which aim to improve the wellbeing of an individual in society. Families commonly attribute their child's improved levels of functioning to therapy, and consider therapy and equipment as crucial to supporting independence, participation and contributing to a child's overall wellbeing.

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#### **4.1.19 Novita Research and Innovation**

Novita's Research and Innovation Division (Novita R&I) conducts clinical and product-related research, to maximise relevant technology and evidence-based outcomes for people with disabilities.

Novita R&I has research experience in many areas, including physiotherapy, speech pathology, occupational therapy, psychology and engineering (rehabilitation, mechanical, biomedical, electrical and electronic).

Novita's history of research includes:

- clinical research (associated with conditions such as poliomyelitis, cerebral palsy, spina bifida, and muscular dystrophy, etc);
- technical research and development (such as access and wheelchair standards, product designs, and accessible telecommunications); and
- the impact of disability and ageing (such as participation, the burden and impact of disability on families, and the economics of disability and assistive technologies).

Novita's work appears in national and international standards, publications, conference presentations and reports.

In 2005, Novita R&I completed a trial of the use of communication devices with mobile telephones. The trial, funded by the Australian Government Department of Communications, Information Technology and the Arts, was highly successful and led to additional funding applications, which gained further funding to expand the project to trials using Telerehabilitation.

#### 4.1.20 Novita Central Intake

All new client applications and enquiries are handled by Novita Central Intake. Eligible clients are then assigned to the most appropriate primary service area.

Central Intake processes include information provision, information gathering, initial consent for eligibility, decision making regarding eligibility, further information provision for eligible clients, advice for non-eligible clients, client information set up (hard copy and electronic), alerting/informing service areas of potential and eligible clients.

Strategies have been developed to promote collaboration around intake/eligibility between Novita and the South Australian Government's Disability SA. The focus includes a joint approach to new referrals for which eligibility is unclear (ie which agency would be the most appropriate for the client). The aim is that ideally clients are accepted by the most appropriate agency right from the initial referral.

#### 4.1.21 Novita Life Needs Model of Service

In 2007 Novita endorsed the 'Life Needs Model'<sup>7</sup> to guide the organisation's present and future work. This model is considered the world's best practice in supporting children with disabilities, emphasising age-appropriate services, support across key transition stages in a child's life and increased focus on the needs of children, families and the wider community.

The Life Needs Model of service delivery incorporates what is known about children's development and resilience, family relationships, community involvement, and the ways these processes and relationships influence participation and quality of life. Key themes of the Life Needs Model, when applied to service delivery, are:

- the importance of focusing on the strengths of children and families
- the focus on children's real-world function and participation in addition to intervening on the level of impairment
- the importance of providing service options at transition points in people's lives, and
- the importance of fostering, nurturing and accepting environments to support community participation and quality of life (King et al, 2002).

The Life Needs Model is a trans-disciplinary, evidence-based model that guides:

- paediatric service delivery to meet the long-range goals of community participation and quality of life for children and youth with disabilities.

The model integrates a family-centred approach to service delivery, with the idea that services should be delivered through programs structured to meet the child's age-specific needs. The model also focuses on key transitions in children's lives and is community-based. The key aim of the model is to support children's participation in all areas of life.

The emphasis in the service delivery model is Novita's Client Centred Practice which involves a strong focus on:

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<sup>7</sup> Gillian King, Thames Valley Children's Centre, Ontario, Canada

- the needs and the wishes of children in the context of the family
- advocating to support children
- helping children to develop skills to achieve greater personal control and understanding in their lives
- assisting children to have a greater role in decision-making
- communication opportunities for children
- planning for and implementation of interventions with families
- evaluation of intervention effectiveness.

According to the Life Needs Model, communities should provide a spectrum of paediatric rehabilitation services, based on the needs of the child and family and the developmental status of the community with respect to attitudes, policies, and practices that support inclusion (King et al, 2002). The assumption that underpins the model is that services structured to address children's needs and the needs of those around them will maximise opportunities in areas of life that are important to children and thereby will contribute to their quality of life.

In the Life Needs Model, services should be provided to intervene in all spheres of life and should address:

- impairments, by assisting children to develop foundational skills (e.g. assisting children in terms of mobility, physical strength, etc.)
- activity limitations, by assisting children to develop applied skill sets (e.g. assisting children in their day-to-day function at home, at school, and in the community)
- interpersonal factors (family needs) and reduce participation restrictions by encouraging positive and welcoming community attitudes and policies that facilitate inclusion.

The model was initially developed to extend the organisational vision of the Thames Valley Children's Centre, a regional children's rehabilitation centre, which provides a range of multidisciplinary services to children with physical, communication, and/or developmental needs and their families in the South-western region of the province of Ontario, Canada. At Thames Valley Children's Centre, the model has been used to identify service areas of greater or lesser need, to provide direction for the development of new clinical programs and research initiatives, and to develop community awareness of the needs of children and youth with disabilities.

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### **COMMENT:**

Under current arrangements, a number of shortcomings have been consistently identified across the disability sector, both from a national and local perspective. Key issues that the NDIS needs to address include:

- Equity and consistency of access to Early Intervention Services:
  - Lengthy gaps exist between referral for early intervention, assessment and action. Delays are frequently in the order of one to two years, by which time the diagnosis may have changed and the original need for the service is superseded by another need; and

- There is fragmentation of early intervention, frequently between private providers, non-government services and Government agencies.
- Therapy Services:  
Arrangements for therapy services to school aged children are another consistently identified issue of concern. Issues which families often raise include:
  - Reduction in hours of service being provided when the child's needs have not changed;
  - Hours provided are significantly less than those required for the child to obtain benefit; and
  - Fragmentation of service across different types of therapy when a coordinated approach was required for the child to get the best outcome from the services available.
- Services for Adolescents and their Families:  
Families of older children and adolescents with disabilities often indicate that, at the time when the care of their child is becoming challenging, both behaviourally and physically as they grow into adulthood, the support services available to help them are severely reduced. For example, across the nation, therapy services become less available, recreational opportunities diminish, and specialist counselling services do not exist to meet the needs of older children.

There is a demand for all of the services that Novita currently provides, and waiting lists for the majority of them. The inability to meet demand is a long term resource issue about lack of government funds to supplement charitable fund raising, and in some specialised areas of service the inability to attract and retain qualified, professional staff is a major problem.

The NDIS must ensure that current service provision is sustained and not diminished in any way at all. Government subsidies to Novita come from diverse areas of government. The diversity of funding services must not be a barrier within the NDIS to provision of specialist disability services to children and young people with disabilities.

Furthermore, Novita provides critical disability care and support in collaboration with mainstream agencies. The NDIS must not leave the responsibility, funding and provision of that disability component to the mainstream agencies. History is perfectly clear in its lesson that mainstream systems will not recognise and fund vital disability support. The funding initiative must come from disability.

Lack of workforce capacity to meet the demand for disability services, in particular the recruitment and retention of staff, is also a key concern for Novita and is a common issue for many non-government disability services providers. It will be critical for the NDIS to recognise and address the challenges created by a labour shortage and limited funding to meet market level remuneration.

A KPMG report<sup>8</sup> commissioned by National Disability Administrators, recommended the development of a national 15-20 year disability workforce plan. This report recommended that 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; and to influence academic curricula to promote disability awareness.

At this time, Novita is not aware of any nationally coordinated effort. This should be a concern for the NDIS.

In addition, the NDIS should recognise that there are many varied skills required to deliver the range of services required by children with disabilities. Some of these service types demand highly trained allied health professionals to enable effective delivery of services to children with disabilities. In South Australia, for example, there is a high demand for allied health care professionals, in particular, those employed to deliver essential therapy services required by children and young people living with disability such as speech pathology, psychology, occupational therapy and physiotherapy.

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<sup>8</sup> Investigation into Workforce Capacity Issues: Research Report, prepared by KPMG for the National Disability Administrators, April 2006

## Funding Issues

The range of Novita's funding sources has expanded significantly beyond a subsidy base provided by successive South Australian Governments. It now includes national based funding in a number of service areas, private fundraising activities, and funds generated in trading activities in technology, specialist aids and equipment for people with disabilities.

In the 2007/2008 financial year, funding from the Australian and South Australian Governments equated to 56.54% of Novita's total income.

NovitaTech has for many years operated without government funding. As a consequence, its operations depend on sound business practices to ensure the division's capability is marketed well and that it can deliver effectively and efficiently.

In addition, NovitaTech has, for over thirty years, provided technology solutions to individuals and organisations across Australia, generating much needed revenue to supplement other Novita services.

Every year, Novita Children's Services must raise millions of dollars to meet the ongoing requirements of its clients. Novita relies heavily on public donations and grants to survive, and Novita assesses and avails itself of fundraising opportunities locally and nationally.

For decades, Novita's marketing and fundraising activities have been a vital part of its operational activities. They include major events such as the annual Convoy for Kids, a large network of fundraising auxiliaries and committees in metropolitan Adelaide and regional South Australia, regular Bingo sessions, corporate sponsorships and partnerships, donations and bequests.

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### **COMMENT:**

Long term reliance by government on Novita fundraising and philanthropy brings risks, particularly in an environment where funding increases do not match the cost of maintaining current service levels or addressing new demand. This trend has developed for at least a decade and is unsustainable. It is a trend that will be common to other non-government disability agencies. With a widespread move towards greater scope and flexibility in individualised funding, the NDIS will have to account for the shortfall in government funding to sustain even current levels of services to people with disabilities.

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## Rights of Children and Adults with Disabilities

In Australia, there is a longstanding and demonstrable need for a human rights approach to addressing the needs of people with disability. This submission recommends the development of a legislative framework that recognises the right to equality for people with disabilities, which should include the right to participate in the NDIS.

The Australian Government and State Governments must ensure that citizens who cannot, through disability, adequately exercise their rights to equality are not overlooked or marginalised in the broader social context. Ideally, there should be congruent legislation nationally and within each State and Territory that recognises the right of a person with a disability to equality that is enjoyed by the rest of the community.

There must now be a paradigm shift if the Australian Government is committed to achieving legislative and social justice for all people with disabilities, in the short, medium and longer terms. Current Legislation, such as equal opportunity laws and anti-discrimination laws, are available to redress discrimination only after it has occurred.

In the Australian Human Rights Commission, half of the 998 of the total 2077 complaints that were made last year were on disability grounds.

Strong and effective rights based legislation for people with disabilities would provide an essential, proactive, cost-effective way to address the full range of barriers to people with disabilities. It would also provide a more effective means for the Australian Government to meet its obligations to people with disabilities under existing obligations, through ratification of the United Nations Convention on the Rights of People with Disabilities (CRPD).

It is therefore anticipated and hoped that the CRPD will both prompt and guide the passage and reform of domestic legislation, ensuring substantive equality and non-discrimination for persons with disabilities.

The CRPD describes the detailed obligations for States, with information about fundamental freedoms and the specific human rights which are enshrined in the Convention. These obligations provide for the protection of civil and political rights, economic, social and cultural rights, and rights to development.

While the CRPD contains traditional human rights concepts, it has modified and added traditional rights concepts to provide them with a specific disability focus. It has also included comprehensive, disability specific interpretations to some of these 'traditional' human rights concepts. As such, the effect is the transformation of the protections against interference with disability rights into positive State obligations. Accordingly, Novita's submission reinforces the importance for the Australian Government in addressing and meeting this commitment through legislation.

It is important to highlight that CRPD Article 4.1(a) commits parties to adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognised in the present Convention.

Article 4.1(c) says parties will take into account the protection and promotion of the human rights of persons with disabilities in all policies and programs.

The principles, as outlined in Article 3, include the following:

- (a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- (b) Non-discrimination;
- (c) Full and effective participation and inclusion in society;
- (d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- (e) Equality of opportunity;
- (f) Accessibility;
- (g) Equality between men and women; and
- (h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Article 12 of the CRPD addresses issues related to the legal capacity of persons with disabilities. Specifically, it clarifies that persons with disabilities not only have the "right to recognition everywhere as persons before the law", but that "persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life," and that "States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity."

## 4.2 Domestic Context

In Australia, there exists a considerable body of evidence that demonstrates conclusively that persons with disabilities are over-represented in categories such as unemployment, poverty and homelessness. At the federal and state level, the under-development of buildings and transport accessibility and disability supports are strong indicators of the gap that exists between the promise of equal rights for persons with disabilities and the reality of the challenges experienced on a daily basis.

Over past decades, Governments around Australia have made commitments to social inclusion for people with disabilities. This has led to considerable advances in tackling many areas of disadvantage among vulnerable people. However, there remains an urgent need for an ongoing commitment to achieving cohesion and a sense of purpose between Commonwealth, State and Local Governments which must be underpinned by disability rights legislation lying as a centre point of a longer term strategy for people with disability, inclusive of a NDIS.

Commonwealth and State legislation contains important provisions about disability services, equal opportunity for Australian citizens and protection from discrimination. However, Governments have not enacted legislation to provide for long-term guarantees of the human rights of children and adults with disabilities. Legislation on disability at Commonwealth and State levels primarily makes provision for the establishment and funding of services. Legislation regarding discrimination and equal opportunity generally provides for complaints-based mechanisms as a means to apply for a remedy. The critical component that is missing commitment is rights-based legislation. It would go further than service-based and complaints-based

legislation, by preserving and protecting in law, the fundamental human rights of people with disability.

### 4.3 Disability Legislation

Even in countries in which disability-related legislation exists (such as non-discrimination legislation), the efficacy of such legislation is often hindered by public assumptions, outdated attitudes and stereotypes of persons with disabilities.

Despite some positive benefits, it is widely accepted within the disability community that current legislation, the means of enforcement and current resources are insufficient in removing existing barriers or in the prevention of new ones.

The main Commonwealth legislation addressing the rights of people with a disability is the Disability Discrimination Act 1992 and Human Rights and Equal Opportunity Commission (HREOC) acts as the main body responsible for protecting the rights of people with disabilities and advocating on their behalf.

Currently, discrimination on the basis of disability is unlawful under the legislation in relation to work, access to premises, provision of goods, education, services and facilities, disposal of an estate or interest in land, accommodation, membership of clubs and incorporated associations, sport and the administration of Commonwealth laws and programs. In addition, state and territory Anti-Discrimination and Equal Opportunity Acts also prohibit discrimination on the basis of disability in a range of areas.

Currently, individuals can lodge complaints with HREOC regarding discrimination and harassment, or can do so under jurisdictional specific anti-discrimination or equal opportunity boards or commissions. Under the federal system, HREOC has power to investigate and conciliate complaints of discrimination based on disability. If the conciliation does not succeed, the complainant has the right to take legal action in the Federal Magistrates Court or in the Federal Court.

The Disability Services Act 1986 aims “to assist persons with disabilities to receive services necessary to enable them to work towards full participation as members of the community” as well as outlining arrangements for the provision of services for people with disability.

The National Disability Agreement is the current inter-governmental agreement in place that supersedes the previous Commonwealth State and Territories Agreements (CSTDA). It is not an Agreement that is concerned with the rights of people with disabilities. The focus is the demarcation of roles and responsibilities in relation to services, performance and policy. Its scope is set out in the preliminary statement which is as follows:

“The new National Disability Reform Agenda will introduce national tools to identify service benchmarks: plan for changing needs; identify people at risk and work towards program and service delivery consistency across jurisdictions.”<sup>9</sup>

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<sup>9</sup> National Disability Agreement 2009 – Council of Australian Governments (COAG) pg. 3

## 4.4 Disability Standards

Under the Disability Discrimination Act (DDA), the Attorney-General may make Disability Standards to specify rights and responsibilities about equal access and opportunity for people with a disability, in more detail and with more certainty than the DDA itself provides. Currently, standards can be made in the areas of employment, education, public transport services, and access to premises, accommodation and the administration of Commonwealth laws and programs.

National Disability Service Standards are developed under the Disability Services Act 1986 and apply to all service types funded through the NDA. These standards complement the provision of services for people with disability under the Commonwealth Disability Services Act 1986 and the Disability Discrimination Act 1992, along with related Australian legislation, such as laws relating to discrimination, guardianship provisions, equal employment opportunity, occupational health and safety, and freedom of information.

## 4.5 Effect of Legislation

While these various Acts have provided significant advances in the protection of rights and provision of services to people with disabilities, they do not provide the necessary paradigm shift that is required to guarantee equal rights for people with disabilities and to empower citizens with disabilities.

The primary reason for this is that complaints-based bodies cannot of their own volition resolve the numerous issues faced by persons with disabilities. Individual investigation and litigation of complaints is, even at its most effective, a lengthy process and costly for all involved. Individual complaints may raise industry or system-wide issues that require a coordinated approach beyond the scope of any single complaint. Many complaints raise broad systemic issues, such as access to public transit and educational services, or lack of captioning at movie theatres.

Tribunal decisions can potentially clarify human rights principles, and do have an educational (and perhaps a deterrent) effect; however, they are not binding beyond the parties to the particular complaint. Individual complaints are therefore a slow, cumbersome and arguably not always effective means for resolving the systemic barriers facing persons with disabilities.

Despite this legislative context, exclusion of persons with disabilities, and barriers impeding them, remain widespread and largely unaddressed. This is reflected in the high rates of unemployment, and socio-economic disadvantages experienced by people with a disability, across the nation.

## 4.6 Current Situation

Novita's submission includes a range of assumptions that, through its collective experiences and knowledge, has been accumulated over decades of service provision to children and young people with disabilities. Accordingly, Novita is of the view that children and adults with disabilities want:

- An environment that makes it possible for all to achieve dignity and a decent standard of living, and which addresses the social causes of disadvantage related to disability.

- National and State Governments to adopt a common and cohesive approach to disability issues across all jurisdictions that is sensitive to individual differences and needs; that guarantees access to similar disability related supports in all regions, and that holds governments accountable to ensure this occurs.
- Governments to commit to disability program arrangements that are secure and predictable; that ensure that core funding and other financial supports are available for disability-related organisations.

Currently for people with disabilities there is a lack of guarantees to:

- Legal Equality
- Social Equality
- Assistive technology
- Aids and Equipment
- Protection from abuse
- Services
- Education
- Employment, and
- Equipment.

## 4.7 Rights based Legislation

Novita believes that there is a solution which will deal effectively with the barriers facing people with disabilities, and at the same time will prevent the creation of new barriers, whilst minimising the cost and administrative procedures needed to achieve these goals. It is to enact a strong and effective rights based legislation, in which the objective is to identify, remove and prevent barriers which keep people with disabilities from fully participating in society.

Such legislation would be a vital tool to help achieve a barrier-free society. It would not only provide remedies where exclusion of people with disabilities occurs, but would provide the type of consistent guidelines that will allow employers and others to plan effectively a way that will prevent new barriers from being created.

The development and enactment of a strong and effective rights based legislation must not result in less protection than is currently available. It must at a minimum provide comprehensive removal and prevention of barriers for people with disabilities.

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### **COMMENT:**

Australian legislation has not addressed a number of issues of systemic discrimination, that is, discrimination that is the unintended effect of a program, policy or law that otherwise appears to treat everyone equally.

Rights based legislation should provide for the appointment of a Minister (not a Parliamentary Secretary) with responsibility for disability issues, and should enumerate the principles and values to be embodied in the relationship between persons with disabilities and Government.

To address disability issues in everyday government business, the legislation should also require the Commonwealth Government to set out the powers,

duties, and functions of federal institutions, including private-sector organisations delivering public services, on disability issues.

Rights based legislation should also establish an independent office with the power to monitor compliance, report to the public, and advocate within Government on behalf of the disability community. The legislation could also require the Government to consult regularly with the disability community and to conduct specific studies.

The purpose of the legislation should be to effectively ensure to persons with disabilities in Australia the equal opportunity to fully and meaningfully participate in all aspects of life, based on their individual merit, by removing existing barriers confronting them and by preventing the creation of new barriers.

The legislation should require companies, organisations, government entities and public premises to be made physically accessible to all persons with disabilities through the removal of existing physical barriers and the prevention of the creation of new barriers, within strict time frames to be prescribed in the legislation or regulations.

The legislation should also require the Government to take affirmative steps to promote the development and distribution in Australia of new adaptive technologies and services for persons with disabilities.

The legislation should mandate the Government to provide education and other information resources to companies, individuals and groups who seek to comply with the requirements of the Act.

The legislation should require the providers of goods, services and facilities to the public to ensure that their goods, services and facilities are fully accessible to and usable by persons with disabilities. Included among services, goods and facilities are all aspects of education, including primary, secondary and post-secondary education, as well as providers of transportation, communication facilities and public sector providers of information to the public. Providers of these goods, services and facilities should be required to devise and implement detailed plans to remove existing barriers within legislated timetables.

The legislation should require public and private sector employers to take proactive steps to achieve barrier-free workplaces within prescribed time limits. Among other things, employers should be required to identify existing barriers which impede persons with disabilities, and then to devise and implement plans for the removal of these barriers, and for the prevention of new barriers in the workplace.

The legislation should provide for a prompt and effective process for enforcement. As part of its enforcement process, the legislation should provide for a process of regulation-making, to define with clarity the steps required for compliance. It should be open for such regulations to be made on an industry-by-industry basis, or sector-by-sector basis. This should include a requirement that input be obtained from affected groups, such as persons with disabilities, before such regulations are enacted. It should also provide persons with

disabilities with the opportunity to apply to have regulations made in specific sectors of the economy.

The legislation should require Governments to make it a strict condition of funding any program, or of purchasing any services, goods or facilities, that they be designed to be fully accessible to and usable by persons with disabilities with the government in question.

The rights based legislation should contribute meaningfully to the improvement of the position of persons with disabilities. It must have real force and effect.

Novita looks forward to a time when the rights of persons with disabilities do not have to be advanced one complaint at a time, so that persons with disabilities will enjoy the substantial changes for which they have waited for so long.

Through a legislative commitment to equal rights, there can be a long-term guarantee that the disability community will be directly consulted and empowered to shape the policies, initiatives and funding that affects their daily lives, including the provision of a NDIS.

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