



Disability Care and Support Productivity Commission Draft Report

**Submission
May 2011**

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Executive Summary

Children with Disability Australia (CDA) welcomes the Productivity Commission's Draft Report on Disability Care and Support. The Draft Report identifies that the current disability support system is unsustainable and recommends that a new national system be implemented to provide long term disability care and support for all Australians with significant disability. The proposed new system aims to ensure people with disability and their families have more choice and control over their lives. It aims to provide the supports and services required to enable people with disability to live and enjoy their lives on equal terms to others in the community, as is their right. The Commission has also proposed that significant additional funding be allocated to the new system and has provided detailed information in support of the feasibility and sustainability of their proposal.

Children and young people with disability and their families are amongst our country's leading experts on the challenges of the current disability system. For many years a primary concern reported to CDA by families has been the failure of the disability support system to adequately meet the current and future needs of their children. CDA congratulates the Commission on their recognition of the inadequacies of the current disability care and support system and their recommendation that a new national system be established.

CDA supports the overall recommendations for reform proposed in the Draft Report but has identified areas of the proposed system that it believes require further clarification or refinement. The recommendation that people with disability outside the proposed tier 3 category would be able to obtain support and assistance from generic services is viewed as unfeasible. The role and importance of families in the lives of children with disability is also one significant area that CDA believes has not been adequately addressed. The comments and recommendations provided in the submission are primarily focused on issues of particular relevance to children and young people with disability and their families.

Children with Disability Australia

Children with Disability Australia (CDA) is the national peak body that represents children and young people with disability and their families. The organisation is primarily funded through the Department of Families, Housing, Communities and Indigenous Affairs (FaHCSIA) and is a not for profit, community based organisation.

The organisation represents children and young people aged 0–25 as an advocacy body with the mandate of building respect, recognition and inclusion for ‘kids’ with disability. CDA works alongside families of children and young people with disability and has a membership of approximately 5000 members nationally.

Vision

To provide children with disability the opportunity to live meaningful and fulfilling lives within safe, supportive and appropriate environments. CDA achieves this vision by:

1. **Educating** national public policy-makers and the broader community about the needs of children and young people with disability and their families.
2. **Advocating** on behalf of children and young people with disability to ensure individual choices and the best possible support and services are available to them from government and the community.
3. **Informing** families about the rights and entitlements of the child and young person with disability to services and support.
4. **Celebrating** the successes and achievements of children and young people with disability.

CDA acknowledges the critical role that families play in providing the necessary care and support to children and young people with disability and recognises their need to be supported in this role.

Guiding principles

Children the priority: that the safety and well-being of children and young people with disability is paramount and consistent with Australia’s obligations under the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities.

Respect: for the views and interests of children and young people with disability and their families.

Recognition: for contributions made by families to ensure the safety and well being of children and young people with disability.

Inclusion: to ensure that children and young people with all types of disability, from all cultural and religious backgrounds and different family structures are supported by the work of CDA.

Responsiveness: to ensure that full advantage is taken of strategic opportunities that arise from the political and social policy environment that benefit children and young people with disability.

Collaboration: with relevant non-government, government and private sector partners to promote the interests of children and young people with disability.

Transparency: within CDA's governance structures, decision-making processes, financial expenditure and reporting activities.

Introduction

As part of the Australian Government's commitment to find the best solutions to improve care and support services for people with disability, the Productivity Commission (Commission) was asked to assess the costs, cost effectiveness, benefits and feasibility of a National Disability Care and Support Scheme. After significant public consultations in 2010 the Productivity Commission released a draft report (Report) on its findings in February 2011. The Report identified that "the disability support 'system' overall is inequitable, underfunded, fragmented, and inefficient and gives people with a disability little choice." The Report also provides substantial recommendations for a new national framework for disability care and support that would reform the present system and address its current inadequacies.

CDA congratulates the Commission on their recognition of the inadequacies of the current disability care and support system and their recommendation for reform and the establishment of a new system to provide long term care and support for all Australians with significant disability. Designing a new national system to meet the long term care and support needs of people with disability is a challenging and complex undertaking. CDA supports the Commission's major recommendations for reform but has identified aspects of the proposed scheme that it believes need further clarification or refinement prior to the Commission releasing its final report.

CDA welcomes this opportunity to provide a submission to the Commission's Draft Report on Disability Care and Support. This submission aims to address issues that have been raised in the Report with particular emphasis on those that impact on children and young people with disability and their families. It provides discussion and recommendations on key areas of the Report that CDA believes need to be considered when introducing a new system for disability care and support.

Response to the Draft Report

General comments

The Report proposes two schemes, a National Disability Insurance Scheme (NDIS) and a National Injury Insurance Scheme (NIIS). Whilst the Report provides strong arguments for the need to have two schemes, CDA has some concerns that this could lead to inconsistencies or inequality in funding between the two schemes. If two separate schemes are implemented then it is imperative that community awareness about the proposed schemes should clearly indicate the need for two schemes and the reasoning behind this decision. The schemes should also be aligned so that funding arrangements between the schemes are transparent.

A strong emphasis in the Report is the need for the person with disability to play a central role in decision making about their support needs within the scheme. Whilst the level of decision making of a person with disability will depend upon the impact of their disability, it must be recognised that for children with disability, families have a key role to play in relation to providing information regarding assessments and individual care plans. In most cases the role of a parent/carer in decision making declines as the child ages, but some children with disability continue to rely on family support for decision making even when they are adults. The scheme must acknowledge that families are the experts on their child's needs and it is imperative that these needs be considered in the context of the whole family. This is particularly relevant to families with young children or children who are unable to articulate their own needs independently and require assistance to contribute to the decision making process.

CDA believes that a child or young person's right to a family must be respected and supported through the entire operation of a disability care and support scheme and that family and not the scheme should decide what is in the best interest of the child.

The Report is a substantial document that recommends significant changes to the current disability care and support system and will potentially transform the lives of millions of people living with disability in Australia. The Report was released on 29 February 2011 with final submissions due on 29 April 2011. Whilst CDA received an extension until May 18 for providing its final submission, we would like it noted that this is a very short time frame for providing feedback on such a significant and detailed report.

44% of respondents to CDA's member survey stated they had very little knowledge of the proposed scheme and only 50% were aware of the Report (see below). This suggests a need for organisations such as CDA to properly inform and consult with members on this significant proposal. CDA received \$30,000 from FaHCSIA in July 2010 to provide input into both the Productivity Commission's initial inquiry into Disability Care and Support and the draft report based on feedback from its members. Whilst CDA has endeavoured to do so, the short time frame and amount of funding provided to inform and consult with members throughout Australia has resulted in direct member feedback for this submission being limited.

CDA would also like to note that Appendix A.2 in the Report wrongly refers to CDA as Children with Disabilities Australia when it should read Children with Disability Australia.

Member Feedback for this submission

Advocacy for a Disability Care and Support Scheme has been an organisational priority for CDA. The need for reform of disability services is recognised as a critical component of the CDA vision for children to live meaningful and fulfilling lives within safe, supportive and appropriate environments.

CDA sought feedback from its members on the recommendations of the Report through an online survey¹. Members were notified about the survey via email. Survey questions included an overview of some of the Report's recommendations viewed as most relevant to children and young people with disabilities and their families.

Over 200 members viewed the survey, 155 members started the survey and 43 members provided feedback. 85% of survey respondents were parents and the remaining respondents were organisations (6%), grandparents (3%) and other (6%). Knowledge of the proposed disability care and support scheme by respondents ranged from 44% stating they had very little knowledge, 47% some knowledge and 9% good knowledge. Only 50% of survey respondents were aware that the draft report had been released prior to completing the survey.

Key features of member feedback

Member feedback was predominantly positive for the implementation of both a National Disability Insurance Scheme (NDIS) and a National Injury Insurance Scheme (NIIS), although many members were unsure about the need for two schemes. Some respondents expressed the view that the reforms proposed are long overdue whilst others still remain sceptical that it will ever eventuate. A major concern to a number of respondents was the uncertainty about who would fund services and supports for people who are ineligible for support in tier 3 and whether they would fall through the cracks. The community awareness component of the scheme, in addition to the provision of services and supports, was considered by many members to be vital.

Member responses also highlighted the vital role that families play in the life of a child with disability. It was seen as imperative that in any new system, families of children and young people with disability are supported and their views respected in order to ensure the needs of their children are adequately considered.

Other views expressed by members through both the survey and ongoing member feedback has been incorporated in the following sections of the submission.

Chapter 3 — Who is the NDIS for?

Tier 1

The Report recommends that an important role of the NDIS would be to create awareness within the general community of the issues that affect people with disability and promote social inclusion. CDA recognises the wide breadth of the total response required by the community to address the systemic barriers and challenges faced today by people with disability in Australia. Such an approach is a significant prerequisite to the effectiveness and cost efficiency of the NDIS, as without it people with disability will continue to be marginalised regardless of the supports they receive. CDA strongly

¹ See Appendix 1 for a copy of the survey

supports the Report's recommendation for the NDIS to perform this role. However our organisation disagrees with the assumption that current awareness campaigns will be able to provide a significant proportion of this initiative and that the costs associated with this function would be a very small part of the NDIS budget. The Report refers to the National Disability Strategy (NDS) and the social inclusion initiatives it proposes. It should be noted that no funding is provided by the Australian Government for these initiatives under the NDS.

CDA recommends that a national initiative for promoting disability awareness and the social inclusion of people with disability should be developed and funded.

Tier 2

CDA supports the proposal in the Report for the establishment of an information and referral service under the NDIS that will ensure that all people with disability access appropriate support from any system. However it is unclear in the Report exactly how the NDIS is going to ensure that people with disability who are not eligible for tier 3 funding will access supports and services. This is particularly concerning if all current disability funding is to be incorporated into the NDIS. It cannot be assumed that other services such as health services or generic services have the necessary expertise and will provide these supports.

Currently many people with disability, including children, fall between the cracks as they are unable to access or afford the supports they need. For example some children with learning disabilities often require support at school and other therapies but cannot access assistance. These issues are often not identified until children are at school and are too old to qualify for early childhood intervention services. In addition, these children are often ineligible for assistance through the education system.

In 2007 the Australian Government reported that 129,298 children received care from a carer allowance recipient². Some of these children would have medical conditions and can be mainly supported through the health system. However, the majority would require therapy or other disability supports and services and some of these would not be eligible for tier 3 funding. There are also many other children who do not receive support from a carer allowance recipient who need support. Clearly funding needs to be available to these individuals to ensure they do not fall through the cracks or become disadvantaged.

CDA recommends that the Commission clarify how the role of referrals under tier 2 of the NDIS will be managed to ensure that everyone is able to access the supports they require.

Tier 3

CDA recognises the feasibility and viability challenges in the implementation of the proposed NDIS. CDA agrees with the proposal in the Report that individual support through the NDIS is provided to a limited target group. However CDA is concerned that the criteria provided in recommendation 3.2 for receiving individual supports could result in many children with disability not accessing necessary early intervention services. It indicates that a person must "have a permanent disability" and "be in an early intervention group". There are many children, particularly infants and young children, who have developmental delays or undiagnosed disability where the long term prognosis is unclear.

² Australian Government 2007, Review of Carer Payment (Child) Statistical Compendium, Australian Government.

Early intervention is essential for this group of children in order to reduce the social, emotional and physical impact of the disability on the child as well as supporting families. Without early intervention, care and support requirements and reliance on the service system is likely to increase. Currently in most States and Territories this group of children have access to early intervention support, which is often inadequate. CDA believes that it is critical that these children access adequate early intervention under any new system. It should not be assumed the support required could be obtained through another system such as the health system.

CDA recommends that all children and young people with a recognised disability, developmental delay or impairment that would benefit from early intervention should be eligible for individual support under the NDIS. The requirement for continued support under the NDIS can then be evaluated during future assessments.

The Report also recommends that individualised support will be provided for all persons diagnosed with an intellectual disability. Whilst CDA supports the recommendation that people with intellectual disability should be supported, it has concerns about the use of a specific diagnosis as a criteria for receiving support.

In the past few years, with the introduction of the Federal Government's Helping Children with Autism Package and the soon to commence Better Start initiative, CDA has received many calls and complaints about these initiatives. There are concerns that these support schemes appear to favour some disabilities over others and are discriminatory. It has also led to some parents feeling so desperate to obtain access to therapies for their child that they push to get a diagnosis of autism for their child.

CDA believes that in order to avert placing pressure on families to obtain an inaccurate or premature diagnosis, that the impact of an impairment and not the diagnosis or cause of the impairment, should be used as criteria for receiving individualised support. This is in line with the World Health Organisation framework for measuring health and disability.

CDA recommends that eligibility for individualised support should be based on the impact of the impairment and not a specific diagnosis. It is proposed that the Commission adapts criteria based on functional need that would encompass intellectual disability.

Chapter 4 — What individualised supports will the NDIS provide?

Aids and equipment

CDA is in agreement with the Commission's proposal that under an NDIS the full range of aids and appliances including home and vehicle modifications and artificial limbs will be provided based on an assessment of individual need. The draft report discusses the importance of the NDIS in delivering quality supports (including aids and equipment) and that these should be provided in a timely manner with minimal or no waiting times. CDA views these aspects as being extremely important particularly in relation to providing support for children and young people with disability where early intervention can have a significant impact on future outcomes.

The Report mentions rolling the many current aids and equipment programs into one program (pg 14.26), however there is little detail regarding how the NDIS will administer the provision of aids and equipment including information on ownership, purchasing,

distribution and recycling issues. There is also little information provided on how assessments will take into account the provision of aids and equipment that might require a specialist assessor (e.g. a speech therapist for communication aids). CDA regards these as important issues that need further clarification.

CDA would also like to ensure that the NDIS takes into account the changing needs of children and young people with disability in relation to the provision of aids and equipment (e.g. changing the sizes of supports as the child grows or develops).

CDA recommends that there be flexibility for exchanging, upsizing or upgrading aids and appliances without the need for a new assessment (unless there are other reasons for doing so). CDA also acknowledges the need for national reform with regards to the provision of aids and equipment and endorses the proposal by the National Aids and Equipment Reform Alliance for the implementation of a national aids and equipment policy framework and strategy.

Community access

It is essential that children and young people with disability are able to access their communities with their families. Currently families of children and young people with disability report that their ability to socialise as a family with the broader community can often be limited. This puts significant pressure on families and often results in the child with disability being left out of family based community activities. Whilst a major aspect of this can be the physical and social barriers that often exist in communities, for some families the barrier is as simple as needing an extra pair of hands to assist the child with disability.

CDA believes that community access supports provided through the NDIS for children and young people with disability should include supports for family based community activities. CDA is also aware that a priority under the National Disability Strategy is to create accessible communities to enable greater social inclusion. It is envisaged that this will provide more opportunities for children and young people with disability to enjoy and access communities with their families, their friends or on their own.

CDA recommends that under the NDIS, community access supports should include providing support for children and young people with disability to enjoy and participate in community based activities with their families.

Respite

At the time of writing this submission the Australian Government is finalising its National Carers Strategy which is aimed at shaping the long-term agenda for government policies and services for carers. It will form part of the National Carer Recognition Framework that also includes national carer recognition legislation. CDA was involved in consultations with families and carers of children with disability on the development of this strategy. Respite for families and carers of children with disability was one of the most significant issues raised. As respite is essentially considered to be a “carer” support, CDA is unsure of how the National Carer’s Strategy will align with the NDIS and would like the Commission to clarify this relationship.

The comments and recommendations below for respite are based on member feedback on both the National Carer Strategy and the Report.

Caring for a child with disability can be overwhelming and stressful for some families and respite is considered to be an essential support for families. For many families respite is not used as “a break” from their caring role but allows them to carry out everyday activities such as cleaning or shopping. Many families report that they need more respite hours, and flexibility in how and when it can be used. However, many families also acknowledge that improved disability support and care options for their child under an NDIS are likely to reduce the need for both respite and other carer supports.

CDA understands that the impact of disability on a family can vary greatly and that in many cases respite is essential. However, to be effective, respite needs to be flexible and families should be allowed to make decisions on what respite options are most suitable for their child and their family. The role of family in making decisions for their child with disability should be respected in the same way that decisions made by parents of children without disability are. The scheme or the service provider should not interfere with that role.

CDA recommends that a family’s needs are respected when providing respite options for children and young people with disability and that flexible respite options are available.

Many families of children with disability also report that they need to access childcare to enable them to undertake employment. This includes outside school hours care; holiday care; in-home childcare; support for children to attend mainstream childcare and pre-school, and specialised childcare and pre-school for children with disability. This is similar to care that all children access, but for children with disability care is less available, less flexible and more expensive.

Currently the provision and support for children with disability to access care is largely the responsibility of childcare policy and disability policy. The difficulty in accessing care has resulted in respite becoming the default care option for many families and has blurred the distinction between these two different supports. The need for care options also increases and becomes more difficult to access as children enter secondary school or leave school and families rely more on respite services to provide this care. Most formal respite for carers cannot be used to enable paid employment. Hence for some parents of children and young people with disability the barriers to undertaking paid employment are simply impenetrable.

This situation not only restricts families from entering paid employment, it results in other perverse outcomes such as some families relying on school buses, on which children attending special schools can spend up to four hours a day, becoming the default care provider.

CDA recommends that the NDIS provides support for families to access “care options” (in home or centre-based) for their children with disability so that parents or carers can undertake paid employment. This support should be distinct from “respite” and a co-payment or fee could be charged for families accessing this support.

Specialist accommodation support

The Report discusses the diversity of housing needs for people with disability and that the NDIS will employ a range of options to address those needs. However CDA is concerned that the Report is scant on details about how exactly the NDIS will provide the infrastructure for some of these options, particularly supported accommodation. In order to address this issue it would be necessary to commence locating and building homes now to ensure that the NDIS meets the demand if the scheme is to commence in 2015.

CDA proposes that the Commission recommend that funding should be made available immediately to plan and build the infrastructure to provide accommodation options for people with disability by 2015.

The Report also proposes that people with disability or their families/carers would have the option to cash out specialist disability housing support and use it towards renting or purchasing accommodation. It is unclear from the Report as to whether families who choose this option for an adult child, who is unable to live independently and needs supported accommodation on a 24 hour basis, will be provided with that level of support.

CDA recommends that the Commission provide further details on how the cashing out of specialist disability housing support and the provision of in-home support would occur under an NDIS.

A significant concern reported by many families of children and young people with disability is the inability to plan for the future needs of their child when they are no longer able to care for them. This is particularly the case for families of children or young people with significant disability who it is envisaged will be unable to live independently and require considerable assistance to communicate their own needs.

CDA recommends that families are provided with support and advice on accommodation options available for their child to allow them to plan for the future.

Means testing

CDA strongly agrees with the Commission's proposal that the NDIS would not include an income or assets test.

Front end deductibles

CDA acknowledges the rationale for the Commission's recommendation that front end deductibles apply for individuals accessing support through the NDIS. Our organisation also strongly supports the recommendation that these should be waived depending on income and impact of disability on families. Given that the impact of disability on the majority of tier 3 recipients and their families is likely to be high, the probability is that this payment would be waived for many recipients.

Other services

CDA supports the recommendation that other services such as health, public housing, public transport and education and employment services should remain outside the NDIS. CDA believes that it is important that these services continue to take responsibility for delivering their services to all Australians and not be given the opportunity to "cash out" their obligations for people with disability. For children and young people with

disability this is particularly relevant to the education system, both mainstream and specialist. For example many students with disability are ineligible for support or obtain inadequate support in schools. This is due to the narrow eligibility criteria that currently apply in many states which are often dictated by funding constraints. These students should all be able to access the educational supports they need.

CDA recommends that the NDIS interacts proactively with all areas of government and community services to ensure that children and young people with disability access adequate support, assistance and equal opportunities to participate.

Centrelink payments

The Commission has asked for feedback on whether the value of current Centrelink payments such as Carer Payment and Carer Allowance should be included in an individual's support package under the NDIS or whether they should still apply as a separate payment.

CDA acknowledges that under the proposed NDIS, people with disability who qualify for tier 3 funding might no longer require these Centrelink payments as they would ostensibly be included in the support package. This is seen as applicable to Carer payment where the payment is provided as income support for the carer. However CDA would like to note that Carer Allowance is not solely intended to be a reimbursement for providing support to a child with disability. Whilst it provides some financial assistance, it is viewed more as recognition of the daily additional care and support required for children with disability. For example, parents of a teenage child who is incontinent and requires assistance with toileting. The proposed NDIS will go a long way toward alleviating some but not the entire extra care that families provide in caring for a child with disability.

CDA recommends that Centrelink payments such as Carer Payment and Carer Allowance remain outside of the scheme initially and that a review of how these payments are made to tier 3 recipients should be undertaken 2 years after the scheme commences. The payments should still remain for all families/carers caring for someone who is ineligible for tier 3 support.

Chapter 5 — Assessing care and support needs

CDA supports the Commission's proposal to use the International Classification of Functioning, Disability and Health as the framework for the assessment process. CDA however has some concerns that the recommendations do not include or discuss adequately the role of families in assessments for children and young people with disability. Whilst CDA supports the person with a disability-centred approach that the Commission is proposing, it must be acknowledged that families should play a central role in assessments for children with disability (particularly very young children). It is also important that the assessments focus on strengthening the capacity of families to support their child or young person with disability. Families need to be provided with information about the types of supports and services available, or that are specifically recommended, so that they can make informed decisions. By assessing children and young people with disability in the context of the family there is also less likely to be a requirement for family members to undergo their own assessment as proposed in the Report.

CDA recommends that the significant role of families in the assessment of children and young people with disability under the NDIS be acknowledged and included. Families should also be provided with adequate information about supports and services to enable them to make informed decisions on what is best for their child.

The Report recommends that in order to promote independent outcomes, assessors should not have a longstanding connection to the person they are assessing. Whilst CDA understands the reasoning behind this recommendation it is concerned that for some children and young people with disability this could lead to inaccurate assessments. Some children and young people will not engage in an assessment process unless they are familiar with or have an established relationship with the assessor.

CDA recommends that assessments for children and young people with disability are conducted by a professional who will ensure accurate presentation of abilities and needs. Alternatively these professionals should be allowed to contribute to the assessment process.

CDA welcomes the Report's proposal to minimise waiting times for assessments. This is particularly relevant to children and young people with disability where timely early intervention is key to improving outcomes for both the child and the family.

CDA recommends that waiting periods for child assessments are minimal and that essential therapies be provided whilst a child is waiting for a full assessment.

Chapter 6 — Who has the decision-making power?

CDA supports and welcomes the Commission's recommendation that people with disability or their families/carers will have the power to choose service providers and that some will have the opportunity to take up self directed funding. CDA also supports the proposal to allow flexibility within the system so that individuals can either administer their own support packages or they can engage a disability support organisation to do this. This approach will allow families to make appropriate choices and decisions regarding the wishes and needs of their child within the context of their family.

The following are some issues regarding aspects of self directed funding discussed in chapter 6 of the Report that CDA would like to raise with the Commission.

1. It has not been made clear in the Report how individualised support packages and self directed funding will work for people with disability requiring support to make decisions or express their needs and do not have a family/carer. Who will support this group of people in making choices and decisions that will allow them to "achieve their potential in social and economic participation" and how will support packages be administered? CDA is concerned that this could result in an increase in appointments of administrators and guardians.

CDA recommends that the Commission address the issue of how the NDIS will best support the needs of people with disability who require support to make decisions or express their needs and do not have a family/carer to assist in this capacity.

2. Families have reported that they need to be provided with appropriate information, advice and support to enable them to make informed decisions about supports and services for their child. This would be particularly relevant for families of a child with a newly diagnosed, acquired disability or with a developmental delay. In these cases the future impact of the disability is often unknown and the needs of the child are frequently changing. Most of these children require a coordinated approach to their care such as those provided through an early intervention agency. Accordingly CDA supports the proposal in the Report that early intervention therapies will not be able to be 'cashed out' by people with self-directed care packages. Families also require advice and support with dealing with the impact of the disability on the family in general.

CDA recommends that the Commission evaluates whether self-directed funding for children or young people with a newly diagnosed or acquired disability is appropriate.

3. Page 6.37 of the Report discusses using currently available practical information and guidelines for applying self-directed funding to develop a similar handbook for the NDIS. Whilst CDA recognises the need for such documents it is important that the NDIS ensures that everyone is aware of the existence of these guidelines and that they are put into practice. Too often government departments and agencies develop guidelines such as these and yet the policies therein are not widely implemented. In many cases the people who they are aimed at are unaware of their existence. For example, CDA is currently providing a submission to the Department of Education, Employment and Workplace Relations on a review of the Disability Standards for Education 2005. These Standards aim to ensure students with disability access and participate in education on the same basis as other students. CDA's experience is that many families, school principals and others working in the education sector are unaware of the existence of these legislative requirements.

CDA recommends that the NDIA ensures that practical guidelines under the NDIS are made available to everyone who will benefit from them. Part of the NDIS' monitoring role should be to ensure that policies and practices are implemented.

4. The Report proposes that people with disability and their families/carers should have easy and cheap access to police checks of employees particularly for vulnerable people such as children or adults with intellectual disability. CDA fully supports this recommendation.

Chapter 7 — Governance of the NDIS

Advocacy

The Report proposes that under the NDIS, Disability Support Organisations (DSOs) could provide a range of services including brokering services for individual support packages, personal planning services and advocacy services. These organisations will be providing individualised services and advice to clients in relation to the NDIS. The Report implies that this proposed advocacy role would be on an individual basis and related to the NDIS.

CDA believes this could result in a possible conflict of interest. For example, where a DSO provides advice that leads to a problem or issue arising for the client. CDA believes that advocacy services need to be able to provide independent information and advice and should not provide other services such as those proposed for DSOs.

Systemic advocacy through disability peak organisations has also not been adequately addressed in the Report. A key role of systemic advocacy for peak disability organisations in Australia is to identify and address inadequacies within national systems by pursuing positive changes to legislation, policy and service practices. It is extremely important that individual advocacy informs systemic advocacy. It is believed that there should be formal communication mechanisms established between providers of individual and systemic advocacy. This mechanism needs to be inclusive of the advocacy needs of children and young people. It must also recognise the role of families of children and young people with disability. Hence peak disability organisations such as CDA will have a significant role to play in the NDIS at both the implementation and establishment stages. Peak organisations need to be independent of the NDIA.

It is vital that adequate funding is committed to enable these organisations to perform the essential service they provide.

CDA recommends that the Commission considers advocacy agencies as independent to the proposed DSOs under an NDIS and that funding be provided for this role. CDA also recommends that peak disability organisations are included in the implementation taskforce consultations for the NDIS.

Complaint resolution

CDA supports the proposal that the NDIA should include an internal complaints office that would provide an independent process to review appeals. It has been the experience of many CDA members that the current process for hearing complaints in justice systems, such as the Victorian Civil and Administrative Tribunal, takes too long. It is also often reported that the people involved lack experience with disability. A system that will allow complaints to be resolved quickly and is cost effective will be well received.

CDA recommends that the establishment of an internal complaints office is cost efficient and that persons making complaints should be provided with support such as advocacy or interpreter services if required.

Case managers

The Report recommends that NDIA local case managers would play a key role under the NDIS and be the primary point of contact for people with disability and their families. Many families report that they would welcome a case manager to help co-ordinate services and reduce their administrative burden but that this should be an optional choice for families. It is envisaged that they would only be useful if they were trained and qualified for the role they perform. For example many families who currently have access to a case manager report that it can be ineffective. One parent commented that 'our key worker is always a 21 year old social worker who knows stuff all, works for six months and then gets pregnant and leaves'. Hence CDA welcomes the recommendation in the Report that case managers will be trained for their role and come from a range of specialised backgrounds.

CDA recommends that people with disability and/or their families/carers should be able to choose whether they require a case manager.

CDA also has concerns about how the increased capacity for case managers will be addressed under the NDIS. CDA's discussion on this issue is provided below under Chapter 13 — Workforce Issues.

Chapter 8 — Delivering disability services

CDA supports the Commission's recommendations for centralised databases to provide advice and information about service providers and to store client details and information. CDA is in agreement with the Commission that safeguarding privacy must be a priority when developing electronic client records. CDA also welcomes the Report's recommendation that the NDIA should develop and implement a quality framework for disability providers.

CDA does have concerns about how people with disability and their families/carers that do not have access to or are unable to afford a computer and/or internet access will be able to benefit from the database.

CDA recommends that the Commission consider whether the NDIS will provide funding for computers and internet access where necessary. This will ensure that everyone receiving funding under the NDIS has access to the NDIS database and electronic systems.

Chapter 9 — Disability within the Indigenous community

CDA supports the Report's recommendations that disability supports and services are offered to Aboriginal and Torres Strait Islanders through community based operations that offer culturally sensitive and appropriate support.

The Report discusses the high rates of Aboriginal and Torres Strait Islander disability. The most recent data shows that Aboriginal and Torres Strait Islanders aged 0–64 years are 2.4 times as likely to need assistance with the core activities of daily living than non-Aboriginal and Torres Strait Islander people³. For Aboriginal and Torres Strait Islanders under the age of 25 this rate ranges from 1.3 to 1.7 times more likely to need assistance.

The Report also identifies that a paucity of available data makes it difficult to obtain an accurate depiction of disability within the Aboriginal and Torres Strait Islander community and that the extent of disability amongst Aboriginal and Torres Strait Islander people is likely to be underestimated. CDA agrees with this assessment and would like to add that accurate data on Aboriginal and Torres Strait Islander children under 15 is even harder to obtain and is often recorded as “not collected” or “not available”. As the Report identifies, a significant reason for this lack of data is likely to be related to cultural issues about disability. However it is important that these children are identified and that they and their families are provided with culturally appropriate supports. CDA believes that a significant role of the NDIA would be to collect accurate data on Aboriginal and Torres Strait Islander children and young people with disability.

³ Australian Institute of Health and Welfare (AIHW) 2011, Making Progress: Aboriginal and Torres Strait Islander people with disability-Wellbeing, participation and support, May 2011, AIHW, Canberra.

The Report also makes mention of initiatives such as Closing the Gap that have been implemented by the Australian Government to address Aboriginal and Torres Strait Islander disadvantage. The Report recommends that delivering disability supports to Aboriginal and Torres Strait Islander people would be mindful of these initiatives. Many of the specific targets of the Closing the Gap initiative are focused on Aboriginal and Torres Strait Islander children and young people. However initiatives such as the Draft Indigenous Education Action Plan failed to include how the needs of Aboriginal and Torres Strait Islander children and young people with disability would be identified and met. There also tends to be a focus on medical interventions rather than disability related interventions.

CDA recommends that the NDIA should engage in extensive consultation with First Peoples Disability Network Australia to plan appropriate strategies for identifying and supporting Aboriginal and Torres Strait Islander children and young people with disability.

Chapter 10 — Collecting and using data under the NDIS

CDA strongly supports the Commission's recommendations that a robust data system is designed and established to provide an effective evidence base under the NDIS. CDA agrees with the Report that this data system must be established prior to the implementation of the NDIS.

Chapter 11 — Early intervention

CDA's recommendation that the NDIS supports all children and young people who require early intervention is discussed above (Chapter 3 who the NDIS is for — tier 3)

Chapter 12 — Where should the money come from? Financing the NDIS

CDA supports the Commission's recommendations that the NDIS is funded from consolidated revenue.

Chapter 13 — Workforce issues

The Report correctly identifies that workforce issues could potentially undermine the core objectives of the proposed NDIS. CDA agrees with the Commission that in light of the proposed expansion of the disability sector under an NDIS that this issue must be addressed. It is essential that various means of attracting, training and retaining these staff in the sector are established.

The Report discusses a number of strategies for attracting and retaining non-professional staff into the sector. However, the issue of the shortage of professional staff such as therapists is not discussed in the Report. This issue impacts on the whole community and as such is seen as "beyond the scope of this inquiry". Whilst CDA understands this rationale, it believes that this is a very significant issue and that it must be addressed prior to the implementation of the NDIS. In recent years the introduction of the "Helping Children with Autism" initiative led to an increased demand for early intervention services. Many families report that this has resulted in a shortage of therapists and long waiting lists in many areas. The importance of timely early

intervention is discussed in the Report as a priority area for the NDIS. However unless trained professional staff are available to provide these services this initiative will not achieve the intended outcomes.

The Report also discusses the use of allied health professionals in other roles in the NDIS such as case management and assessment. Clearly initiatives are required to address the current shortages of these professionals to ensure the success of the scheme.

CDA proposes that the Commission recommends that initiatives to attract and train both professional and non-professional staff to work in the Disability Sector are established and commenced immediately.

CDA supports the Report's recommendation that workers for children with disability who are employed using NDIA funding should all have a police check and/or working with children check.

CDA members have also indicated that they would prefer care workers to have qualifications in a disability related area and that these workers should be offered specific training if required e.g. lifting or feeding. First aid training was considered to be essential.

CDA supports the Commission's recommendation that parents of children with disability over 18 can access flexible leave from their employer.

Chapter 16 — A national injury insurance scheme

CDA discusses the rationale for having a separate scheme for catastrophic injury under general comments above.

Chapter 17 — Implementation

The Report proposes that the NDIS should commence in stages from 2014, be rolled out nationally in 2015 and be fully operational by 2018. It also proposes that the NIIS should be in place to cover catastrophic injuries from motor vehicle accidents and medical accidents in all jurisdictions by 2013 and all other forms of catastrophic injury by at least 2015.

CDA acknowledges that the current system is unsustainable and that people are eager for change as soon as possible. However, given the complexities involved in establishing and implementing the proposed new schemes CDA is concerned that rushed implementation could compromise aspects of a new scheme. Our organisation does however support the Commission's recommendation that full-time high level taskforces from all jurisdictions are established as soon as possible to work on the detailed implementation of the schemes.

The Report discusses the need for the NDIS and NIIS implementation taskforces to consult with key groups to inform the planning and implementation of the schemes.

CDA recommends that representatives of people with disability, families and carers are included in the consultation process for the planning and implementation of the new schemes.

CDA supports the recommendation that prior to the full introduction of the NDIS that the Australian Government should supplement funding under the National Disability Agreement to reduce some of the worst rationing of support services.

CONCLUSION

CDA supports the Commission's proposal for a new national system to be established and the recommendation for a substantial increase in the quantum of funding for disability supports and services. The proposal has the potential to significantly change the lives of millions of Australians. It is critical that we develop a feasible scheme that takes into account the complexity of providing disability supports and services. This is a mammoth task and the need for change is indisputable. A new scheme must ensure people with disability have access to a fair and workable disability service system.

Thank you for the opportunity to comment on the Draft Report.

Stephanie Gotlib

Executive Officer

SUMMARY OF RECOMMENDATIONS

1. CDA recommends that a national initiative for promoting disability awareness and the social inclusion of people with disability should be developed and funded.
2. CDA recommends that the Commission clarify how the role of referrals under tier 2 of the NDIS will be managed to ensure that everyone is able to access the supports they require.
3. CDA recommends that all children and young people with a recognised disability, developmental delay or impairment that would benefit from early intervention should be eligible for individual support under the NDIS.
4. CDA recommends that eligibility for individualised support should be based on the impact of the impairment and not a specific diagnosis.
5. CDA recommends that there be flexibility for exchanging, upsizing or upgrading aids and appliances without the need for a new assessment (unless there are other reasons for doing so). CDA also acknowledges the need for national reform with regards to the provision of aids and equipment and endorses the proposal by the National Aids and Equipment Reform Alliance (NAERA) for the implementation of a national aids and equipment policy framework and strategy.
6. CDA recommends that under the NDIS, community access supports should include providing support for children and young people with disability to enjoy and participate in community based activities with their families.
7. CDA recommends that a family's needs are respected when providing respite options for children and young people with disability and that flexible respite options are available.
8. CDA recommends that the NDIS provides support for families to access "care options" (in home or centre-based) for their children with disability so that parents or carers can undertake paid employment. This support should be distinct from "respite" and a co-payment or fee could be charged for families accessing this support. .
9. CDA proposes that the Commission recommend that funding should be made available immediately to plan and build the infrastructure to provide accommodation options for people with disability by 2015.
10. CDA recommends that families are provided with support and advice on accommodation options available for their child to allow them to plan for the future.
11. CDA recommends that families are provided with support and advice on accommodation options available so that they can plan for the future and have some security that their child will be cared for when they are no longer able to or when their child decides to leave home.

12. CDA recommends that the NDIS interacts proactively with all areas of government and community services to ensure that children and young people with disability access adequate support, assistance and equal opportunities to participate.
13. CDA recommends that Centrelink payments such as Carer Payment and Carer Allowance remain outside of the scheme initially and that a review of how these payments are made to tier 3 recipients should be undertaken 2 years after the scheme commences. The payments should still remain for all families/carers caring for someone who is ineligible for tier 3 support.
14. CDA recommends that the significant role of families in the assessment of children and young people with disability under the NDIS be acknowledged and included. Families should also be provided with adequate information about supports and services to enable them to make informed decisions on what is best for their child.
15. CDA recommends that assessments for children and young people with disability are conducted by a professional who will ensure accurate presentation of abilities and needs. Alternatively these professionals should be allowed to contribute to or play a role in the assessment.
16. CDA recommends that waiting periods for child assessments are minimal and that essential therapies be provided whilst a child is waiting for a full assessment.
17. CDA recommends that the Commission address the issue of how the NDIS will best support the needs of people with disability who require support to make decisions or express their needs and do not have a family/carer to assist in this capacity.
18. CDA recommends that the Commission evaluates whether self-directed funding for children or young people with a newly diagnosed or acquired disability is appropriate.
19. CDA recommends that the NDIA ensures that practical guidelines under the NDIS are made available to everyone who will benefit from them. Part of the NDIS' monitoring role should be to ensure that policies and practices are implemented.
20. CDA recommends that the Commission considers advocacy agencies as independent to the proposed DSOs under an NDIS and that funding be provided for this role. CDA also recommends that disability peak organisations are included in the implementation taskforce consultations for the NDIS.
21. CDA recommends that the establishment of an internal complaints office is cost efficient and that persons making complaints should be provided with support such as advocacy or interpreter services if required.
22. CDA recommends that people with disability and/or their families/carers should be able to choose whether they require a case manager.
23. CDA recommends that the Commission consider whether the NDIS will provide funding for computers and internet access where necessary.

24. CDA recommends that the NDIA should engage in extensive consultation with First Peoples Disability Network Australia to plan appropriate strategies for identifying and supporting Aboriginal and Torres Strait Islander children and young people with disability.
25. CDA proposes that the Commission recommends that initiatives to attract and train both professional and non-professional staff to work in the Disability Sector are established and commenced immediately.
26. CDA recommends that representatives of people with disability, families and carers are included in the consultation process for the planning and implementation of the new schemes.

APPENDIX 1 — Disability Care and Support Survey



Children with Disability Australia
Suite 2, 98 Morang Road, Hawthorn VIC 3122

MEMBER FEEDBACK

12 July 2010

FEATURES OF A NEW NATIONAL DISABILITY CARE AND SUPPORT SCHEME

Dear Members,

I write to ask your assistance with informing the submission which Children with Disability Australia (CDA) is currently preparing regarding the need for National Disability Care and Support.

The typical plight of families of children with disability is that they fight for basic rights and services from the moment their child is born and throughout their life. The under-resourced service system is a complex maze. Presently many children and young people with disability are not able to obtain the type and level of service they need. CDA supports the introduction of a National Long Term Care and Support Scheme. It is seen as an essential part of the reform needed in this country to address this national crisis.

CDA believes this is a 'once-in-a-lifetime' opportunity to overhaul our disability system. This is a unique opportunity to advocate for appropriate levels and quality of service for children and young people with disability. It is imperative that families voice strongly and loudly what type of system they want for their children in the future and how it would work. Most of you will know only too well what doesn't work and now is the chance to contribute ideas as to how a new system could work.

CDA is strongly of the belief that real experiences must inform policy. CDA provides a link between the direct experiences of children with disability and their families to federal government and other key stakeholders. This link is viewed as essential for the creation of a true appreciation of the experiences and challenges that make up the lives of children with disability and their families. **It is thus vital that we receive your feedback about a National Long Term Care and Support Scheme. Please provide feedback by no later than Friday, 6 August, 2010.**

There are a number of ways to contribute:

1. Complete and return the attached feedback form.
2. Request an electronic version of the feedback sheet and email response. The email address is info@cda.org.au
3. Ring CDA on (03) 9815 1094 or on 1800 222 660 and provide feedback. Please note that calls can be scheduled for outside of regular office hours on request.

Your contribution will be greatly appreciated and will ensure that CDA provides advice regarding the National Disability Care and Support Scheme which is based on the real experiences of children and young people with disability and their families.

Thank you for your assistance.

STEPHANIE GOTLIB
Executive Officer



MEMBER FEEDBACK

FEATURES OF A NEW DISABILITY CARE AND SUPPORT SCHEME

Thank you for providing feedback to assist with the submission being prepared for presentation to the inquiry being conducted by the Productivity Commission into Disability Care and Support. The information provided will be used to inform our submission and may be quoted in to the final document presented to the Productivity Commission.

The questions cover the range of issues being addressed by the inquiry. These have been included so you can have an understanding of the broad nature of the issues being considered.

You do not need to answer every question if you do not wish to do so. If it is easier for you to ring and tell us your answers then we can record your feedback. Members need to use the survey so it works for them. CDA wants members to have every opportunity to tell us what you think is important about a new Disability Care and Support Scheme.

Further information about the Disability Care and Support Inquiry can be obtained by contacting the Productivity Commission on (02) 6240 3221 or freecall number 1800 080 083 or at <http://www.pc.gov.au/projects/inquiry/disability-support>

1. BACKGROUND INFO (OPTIONAL)

Home State/Territory _____ Age of Child/Children with Disability _____

Type of Disability _____

Non-English Speaking Background? Yes No

Organisational Member? Yes No

2. ELIGIBILITY

POSSIBLE CONSIDERATIONS: Types of disability, impact of disability, level of need, needs that change over time, needs for early intervention.

Who should be in the new scheme and how could they be practically and reliably identified?

What should be the process for entering the scheme?

Which groups are most in need of additional support and help?

What could be done about reducing unfairness, so that people with similar levels of need get similar levels of support?

3. DECISION MAKING/POWER

POSSIBLE CONSIDERATIONS: The right for people with disability to have control over their own lives, the role of families or carers, individualised funding models, the ability to have greater choice of services, the obligation of service providers to take greater account of people's individual needs, stages of acquiring knowledge by families i.e. initial awareness of children's disability compared to later years

How could people with disability or their families/carers have more power to make their own decisions (and how could they appeal against decisions by others that they think are wrong)?

How should the amount of financial support and service entitlements of people be decided (and by whom)?

4. SERVICES NEEDED

What kind of services particularly need to be increased or created?

POSSIBLE CONSIDERATIONS: Aids and equipment, transport assistance, vehicle modification, accommodation, respite, care.

How could the ways in which services are delivered be improved?

POSSIBLE CONSIDERATIONS: Coordination, costs, timeliness and innovation, needs for assessments, duplication of paperwork.

**Are there ways of intervening early to get improved outcomes over people's lifetimes?
How could this be done?**

How could a new scheme encourage the full participation by people with disability and their carers in the community and work?

How can a new system ensure that any good aspects of current approaches are preserved?

What should be done in rural and remote areas where it is harder to get services?

5. FUNDING

POSSIBLE CONSIDERATIONS: Through existing taxes, a new Medicare type levy, other ways.

How could a new scheme be financed?

How can it be ensured that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future?

6. ORGANISING AND IMPLEMENTING

POSSIBLE CONSIDERATIONS: The roles of service providers, people with disability, their family or carers and governments (local, state and national), how existing arrangements will fit in with a new scheme, how risks and costs would be managed to make a scheme sustainable in the future, workers for the new scheme (who, training, recruitment, boosting the workforce), transitions to a new scheme.

What are your views about the 'nitty-gritty' aspects of a scheme that will make it work practically?

How long would be needed to start a new scheme, and what should happen in the interim?

7. SPECIFIC ISSUES OF RELEVANCE REGARDING CHILDREN WITH DISABILITY AND THEIR FAMILIES

Do you think a Disability Care and Support Scheme should include educational funding needs for students with disability or should there be separate system? How do you envisage this working?

What other specific considerations do you believe need to be made regarding children with disability and their families?

8. OTHER COMMENTS



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