

DISABILITY CARE AND SUPPORT

SEPTEMBER 2010



Children
with **Disability**
AUSTRALIA

A bigger voice for kids

Contact:

Stephanie Gotlib

Executive Officer

Suite 2, 98 Morang Road, Hawthorn 3122

Phone (03) 9815 1094 or 0425 724 230

www.cda.org.au

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Executive Summary

Children with disability and their families are amongst our country's leading experts on the challenges of the current disability system. It is with this long history of intimate knowledge of the disability service system that CDA greatly welcomes the present inquiry by the Productivity Commission regarding the feasibility of a Disability Care and Support Scheme. The idea of a national scheme which has the fundamental aims of improving long-term care and support services for people with disability is applauded.

Comment provided in this submission has a primary focus on issues of particular relevance to children and young people with disability and their families.

A national scheme has the potential to create real and much needed change to our disability service system. As indicated in the terms of reference and the issues paper it could address many of the key concerns that have been long recognised in the disability sector. It is imperative that its implementation occurs in conjunction with other key actions and reforms considered as vital to ensure the full recognition and realisation of rights and equal opportunities for people with disability, including children.

CDA considers it imperative that the introduction of a disability care and support scheme occurs as part of the broader implementation of a national disability strategy. This strategy must accurately identify the wider areas and actions involved to create a more equitable and accessible community for people with disability and compel the Australian society to action.

CDA recognises the feasibility and viability challenges in the implementation of the proposed scheme, and that it is important that the Commission recommend a scheme that meets and addresses both the fiscal and political imperatives of this reference. Ultimately it must be ensured that a viable scheme emerges. To this end CDA agrees with a limited target group initially for the scheme, and would recommend that the scheme begins with people with a severe or profound level of disability AND all children and young people with a recognised disability, aged 0-21. The scheme would be a no fault need based scheme that looks at functional needs due to the impact of disability.

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 5000¹ 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 with disability and their families.
2. **Advocating** on behalf of children 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 with disability to services and support.
4. **Celebrating** the successes and achievements of children with disability.

CDA acknowledges the critical role that families play in providing the necessary care and support to children 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 with disability is paramount and consistent with Australia's obligations under the Convention on the Rights of the Child and the Convention of the Rights of Persons with Disabilities.

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

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

Inclusion: to ensure that children 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 with disability.

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

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

¹ 70% families and 30% organisational

Background

A VOICE FOR CHILDREN WITH DISABILITY

Children with Disability Australia was officially incorporated as a company limited by guarantee with ASIC in November 2009. CDA however is not a new organisation. The initial seeds of the organization were planted in the 1990's. At that time, parents of children with disability were very concerned that they had no national voice. There was recognition that there was limited community awareness of children and young people with disability and that they were an insignificant part of the national political agenda.

A meeting of parent representatives from all states and territories was held in Melbourne in 2002. A decision was taken to proceed in establishing a national organisation. CDA was established because of the recognition of the real need to clearly and collectively communicate the lived experience of children and young people with disability.

This united voice is seen as an invaluable component to achieve:

- greater recognition of rights and equal opportunities for children and young people with disability
- increased community awareness of disability
- better coordinated and consistent levels and quality of service across different service jurisdictions
- provision of a vital link between the direct experiences of children with disability and their families to federal government and other key stakeholders
- acknowledgement of the significant role and importance of families in relation to children with disability

THE EXPERIENCE OF CHILDREN WITH DISABILITY AND THEIR FAMILIES

Many of the key issues for children with disability and their families are aptly documented in the 'Shut Out' (2009) report by the National People with Disabilities and Carers Council. These include fragmentation and complexity of the service system, frequent inability to obtain appropriate levels and quality of service, inadequate access to aids and equipment, appropriate training of service providers and the need for family centred and informed practice for children with disability.

The lived experience of disability for children and their families involves a service maze which has developed over time into an ad hoc and crisis driven system. The focus of services is ostensibly on the individual whereas for children it is essential that a service system supports them not only as individuals but also in the context of their family.

It is important to note that the absence of functional service delivery for children with disabilities in 2010 will have impacts on their quality of life, and level of dependence on the welfare system and others, for the rest of their lives. The Commission is required to take account of the value of early intervention. This is an essential feature of an investment in support for children that will last a lifetime.

Future demographic pressures on the Australian economy illustrate an economic need to ensure maximum workforce and community involvement for all who are able – strengthening the participatory capacity of our children with disability, makes sense for the community. It is also a basic human right that is clearly expressed in the UN Convention of the Rights of Persons with Disabilities.

Member Feedback for this Submission

Advocacy for a Disability Care and Support Scheme (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.

In this context, informing and involving families in the discourse about a national scheme is imperative. Over the past two years CDA has made the progression of a scheme a key focus of its work. The organisation's national publication 'Family Voices' has been utilised to inform readership, of approximately 15,000. Contact with members has also occurred through community engagements and personal contact. During this period, many families reported that they were unaware of the proposal of such a scheme.

CDA received funding in June 2010 from FaHCSIA to consult with its members regarding the implementation of a disability care and support scheme. A survey² was posted to all members in July 2010 to obtain feedback to inform the preparation of this initial submission to the Productivity Commission. The survey contained the questions contained in the 'key questions summary' provided by the Productivity Commission. It also invited members to provide feedback on issues which they believed were pertinent to children with disability and their families. Approximately 150 responses were received by mail, email, and telephone interview.

Key features of member feedback

Member feedback mostly identified the inadequacies of the existing service system. Families expressed difficulty contemplating the significant challenges associated with establishing a more equitable and practical new long term care and support system. They described a struggle to maintain stability and optimism on a day to day basis, many noting that they do not have the emotional energy or time to imagine a different outcome. They are exhausted, and their focus is their children.

Members reported that their children were often unable to access supports when they need them and that the costs to families are too high. They expressed their concerns about their own ability to parent effectively in the current system – and what happens to their children if they can't. Many felt hopeless about their ability to affect change in this context. They felt that the change often resulted in a more complex, unfair, and administrative outcome which did not materially affect the situation for their children.

There were families that have managed to achieve a workable service delivery arrangement however that were reluctant to contemplate anything that could potentially diminish their current level of support; scepticism that they would be supported through a change process was significant.

Many families spoke of the need for a one stop shop reflecting a requirement to obtain accurate information about services, resources and support available.

² See Appendix A for copy of survey

Our Vision for a new Disability Care and Support Scheme

GUIDING PRINCIPLES

Convention of the Rights of Persons with Disabilities

The introduction and ratification of the Convention of the Rights of the Persons with Disability in Australia in 2008 must be reflected in all relevant policy including the significant initiative of a disability care and support scheme. Accordingly Australia must tackle the environmental and social barriers which affect full and equal participation and the scheme must be modelled according to the principles enshrined in the convention.

It is noted that specific reference is made to children in Article 3 stating 'respect for the evolving capacities of children with disabilities and respect for the right of children to preserve their identities'. Article 23 further states that 'State Parties shall ensure that children with disabilities have equal rights with respect to family life'.

Convention of the Rights of the Child

Consideration of the specific issues pertaining to children with disability is essential in the establishment of a disability care and support scheme. Accordingly the relevant principles of the Convention of the Rights of the Child (CROC) should be reflected in the Scheme. These include recognition that 'childhood is entitled to special care and assistance'.

CROC recognizes the role of family as the environment for the growth and wellbeing of children and the role of parents in acting to protect, care and take legislative and administrative measures on behalf of their children.

Family centred practice

A central focus of CDA has been the importance of ensuring that family experience informs policy and practice. Service provision for children with disability must take into account the expert knowledge and preference families have in relation to their children and also support and progress the right of children to family life. Best practice in relation to children with disability is viewed as a collaborative approach between children and young people with disability, families, service providers and health professionals.

Long term planning

It is imperative that a scheme allows for long term planning. The person with a disability, particularly the older child or young person, has the right to transition from their family.

A key issue which arises for families and carers is in relation to people with disability, particularly adult children with high support needs, is the extremely significant reliance and dependence on families and carers.

The person with a disability and their family must have reassurance and a clear means of ensuring that appropriate supports and resources can be accessed independent of their provision of these when the desire or need arises.

Prerequisites to a Disability Care and Support Scheme

The following sections consider the context in which the Scheme would be effective and efficient. Whilst a Scheme could commence in the absence of these systemic transformations, CDA believes a scheme introduced in isolation would substantially increase the risk of increasing the overall cost of disability services, without achieving improvements in delivery or outcome.

A WHOLE OF GOVERNMENT APPROACH

The Draft National Disability Strategy setting out 'a ten year plan for improving lives for Australians with disability, their families and carers' was released in August 2010 as an election policy.

The strategy is an ambitious plan. It is a roadmap for action that guides public policy across governments, change in all mainstream services and programs as well as community infrastructure. It hopes to ensure people with disability have the same opportunities as other Australians – to a quality education, to health care, to have a job where possible and to access buildings, transport and social activities.

The strategy notes the importance of:

- changing policy;
- improving mainstream response;
- an inclusive and shared agenda;
- understanding and changing attitudes and practices that disable;
- advocacy;
- improving productivity; and
- looking to the long term

CDA confirms the relevance of each of these directions in a national disability strategy, including the identified outcome areas of inclusive and accessible communities, rights protection, justice and legislation, economic security, personal and community support, learning and skills, health and wellbeing.

There was considerable work done by many over years to complete the strategy and significant consultation occurred with people with disability, families and carers. It must be ensured that this substantial and essential contribution is not lost in the political fallout of the recent federal election.

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 pre-requisite to effectiveness and cost efficiency of the Scheme considered in this submission.

A BASELINE OF OPPORTUNITY AND STABILITY

The Disability Investment Group Report – The Way Forward - (DIG Report) recommends a number of structural transformations that are outside of the scope of this Scheme:

- better employment opportunities
- meeting housing needs
- investing in a centre of excellence for disability research

This submission does not contemplate these items, however it is critical to note the reliance of any scheme on a functional infrastructure accessible to people with disability.

If the costs of a Scheme are to be offset by the long term workplace and community involvement of people with a disability, employment opportunities are required. If the costs of accessing the community are to be minimised, a stable and appropriate home base is required.

DATA AND RESEARCH

Whilst outside of the scope of this submission in general terms, the DIG Report refers to data capture required to build the evidence base for good practice. The Draft National Disability Strategy goes further, noting the level of data required in order to effectively deliver services:

"A key part of the Strategy will be the development of a nationally agreed approach to research on disability issues that can inform research priorities across both mainstream and disability service systems. It will identify gaps in information, and where data definitions, collections and reporting are inconsistent. Moreover, it will consider the frequency and scope of the range of national data collections, including the ABS Survey of Disability and Carers, the ABS General Social Survey and the ABS Household Expenditure Survey, the ABS Australian Health Survey (which includes the National Health Survey and the National Health Measures Survey). The agenda will identify areas of particular interest across jurisdictions, complement existing research activity at Commonwealth, State and Territory levels, and identify where research activity specified in relevant National Partnerships and National Agreements needs to take account of disability."

Such activities are beyond the scope of this Scheme. The data collected will be invaluable in providing effective and efficient service delivery and in evaluating the implementation of a disability care and support scheme.

Only access to real, timely, accurate and transparent data about people with disability and their involvement in, or exclusion from, the community can inform appropriate service delivery at a national and individual level.

A BETTER MAP

CDA submits that prior to the implementation of a scheme there is a national requirement to detail and co-ordinate the current services. Put very basically, we need a better map which details existing services, schemes, pathways and funding options.

It is the usual experience of children with disability and families that negotiating the service system is fairly random. If they are fortunate families may access effective case management or come into contact with someone who has a thorough knowledge of the service system. It is common place however that families just stumble upon services.

Local contacts can have very detailed knowledge of services in particular areas but there is no comprehensive collection of information. As the national peak body for children and young people with disability we are continuously learning of new services and resources for children and young people with disability.

CDA has been contacted numerous times with inquiries from government departments, members of parliament, families, and services to ascertain if we could provide a listing of services available for children or young people with disability. Information is often sought regarding the usual pathway families take to obtain

assistance. How do you provide a road map to the jungle?

There is a significant need for a clearer and more comprehensive understanding of the aids and equipment schemes available and a centralised database to contain this information.

The requirement for information on services would significantly increase in the event of individualised funding for a large number of people with disability. Individuals are more likely to experience difficulty sourcing reliable information, and the ability to make informed choices is dependant on this information.

The real value of a long term care scheme for children is that it would replace the current 'jungle' with a single point of reference and responsibility for support services over a lifetime. While multiple services and providers would be involved, the fact that there is ultimate authority for decisions and management in one place means greater attention to individual needs. It would avoid cost and responsibility shifting that currently characterises our system. Children with disability don't get a second chance for early intervention if they miss out so it is absolutely essential to make it available and manage it thoroughly through a coordinated 'investment' approach.

Eligibility

Ideally a scheme would provide for all recognised needs of people with disability irrespective of cause. It is however recognised that it is not practical or feasible to establish such an extensive long term disability care and support scheme in the first instance. CDA submits that there are significant eligibility categories to consider and prioritise.

It is proposed those eligible for the scheme would be people with a severe or profound disability regardless of age AND all children with a recognised disability. Further eligibility categories could be considered in the future if deemed feasible.

The scheme should be a no-fault scheme which looks at functional needs due to impact of disability. Initially this would be people who fit this definition who need lifetime care and cannot get their needs met through the existing disability system.

SEVERE OR PROFOUND DISABILITY

There is a strong argument for individuals with severe or profound disability to be automatically eligible for the Scheme.

These individuals experience extremely significant challenges in achieving quality of life and experience inequitable access to the current system.

Individuals with very high needs often utilise existing services at a much higher rate than others, although this does not always lead to improved outcomes due to inability to target supports appropriately. A streamlining and funding boost of the supports available to these individuals should have a flow on effect of relieving pressure on the services currently being accessed, and allowing greater access for others. This would be expressed through offsets in healthcare, income support, education and also in more stability in families with a child with a disability.

By creating a scheme for this discrete group CDA can only assume this means a two-tiered system in the initial stages. As long as the scheme and the existing system have porous boundaries and are linked through improved lifetime care management systems, this may be feasible. CDA notes Anna Howe's submission and her proposition that the development of a 'CAT' scheme would release an additional 20% capacity in the existing disability system. Depending on the eligibility range this may be more or less in reality, but if more services became available overall, more people would have their needs met across the community, which is the desired outcome.

CHILDREN WITH DISABILITY

The first few years of life are critical in development terms of emotional and social development, learning of skills and greatly impact on the success a child has in formal learning environments.

Jordan and Sketchley (2009) report that "Infancy is a time of rapid physical, cognitive, language, social and emotional development. ...Although genetic potential predisposes an individual to develop certain abilities and skills, environmental influences determine the ultimate expression of these potentials. Future development beyond the infancy period is based on experiences and relationships in the early years. These early experiences affect physical health, emotional regulation (including the stress response system) and mental health across the life course, cognitive development, learning and the capacity for full engagement and participation in and thus access to social resources (eg.

education, employment, relationships)" .

Further the Centre for Community Child Health (CCCH) state that studies of good quality early intervention programs have shown that:

- they lead to improved psychosocial and health outcomes in the long-term
- they are particularly effective with children from disadvantaged backgrounds
- the earlier the intervention begins (and the longer it lasts), the more effective it is likely to be
- interventions need to address multiple environmental risk factors simultaneously rather than focusing on single issues. Intervention programs that address a single aspect of child and family functioning are likely to fail by ignoring other factors that can undermine family functioning and child development
- sustained intervention over time (rather than intervention at a single time point) is most likely to be effective
- the nature and intensity of the intervention may vary over time because of changing circumstances and developmental needs, and needs to be flexible

Based on these findings the CCCH recommended that "expenditure in the early years should be regarded as an investment and is analogous to investing in physical infrastructure for the long term. Investment in early childhood needs to be incorporated into the economic debate about other forms of infrastructure."

Beyond 21?

It is proposed that the year between 20 and 21 is a period of review where an assessment occurs to ascertain whether the young person should remain on the Scheme as they have profound or severe disability, or whether services and support should be obtained from other avenues.

ELIGIBILITY CRITERIA AND ASSESSMENT

Severe and profound disability

It is proposed that severe and profound disability be defined using the Survey of Disability, Ageing and Carers (SDAC). It refers to limitations, restrictions or impairments that have lasted or are likely to last for longer than 6 months and restrict everyday activities. Severe or core activity limitation is defined as sometimes or always requiring personal assistance or supervision with self-care, mobility or communication. A person with a profound level of disability always needs assistance from another person to perform a core activity. A person with a severe level of disability sometimes needs assistance from another person to perform a core activity; or has difficulty understanding or being understood by family or friends; or can communicate more easily using sign language or other non-spoken forms of communication.

Children and young people with disability

It is suggested that eligibility be established using a like model to that used in relation to the Child Carer Payment. This approach has categories of recognised disabilities and capacity to measure the child's functional ability according to standards appropriate to their age and is based on information provided by a treating health professional and their carer. This would avert placing pressure to obtain premature diagnosis to ensure access to appropriate services, support, aids and equipment.

Assessment of need/level of support required

Needs establishment must be based on a measure of the functional impact of disability of the person concerned. It is envisaged that a comprehensive needs assessment could occur throughout the assessment for eligibility. Eligibility would be defined by an established criteria set by the Scheme which would direct the information which need to be obtained. The assessment process should be establishment with consideration of the model contained in the ICD 10 classification by the World Health Organisation. This allows the breadth of factors to be taken into account which shape how disability impacts on an individual.

The needs assessment will then inform the formation of an individual service plan and goal setting process. The other crucial component of the care plan being the central involvement of people with disability and their families.

Assessment, Review and Lifetime Care Management

Regular review is necessary. It is particularly pertinent in relation to a child with disability, as is flexibility in service and resource provision, as needs will be constantly changing due to development, life circumstances, environmental factors and other changes which are common place in life.

A specialised lifetime care management function needs to be funded by the scheme and put in place in community organisations to manage the support services, negotiate with providers and community providers, manage reviews and assessments and support decision making.

Critical times for children and young people with disability are identified by families, health professionals and service providers as frequently requiring more intense supports. These periods are typically at the time of diagnosis or emergence of disability, entry to early childhood care or kindergarten, commencement of primary school, transition from primary to secondary education, adolescence and the post school period.

Model of Service Delivery

INDIVIDUAL FUNDING MODEL

A critical component of the CDA vision for a new Scheme is the use of individual funding. Individual funding (also referred to as individualised funding) is a model of organising consumer directed care. Fisher et al (2009) describe it as "a defined package of funding that is allocated to be spent on the disability support services of a particular person in the way that best suits them, including the disability support type and who provides the support". The study by Fisher et al examines the effectiveness of individual funding. The study examined personal wellbeing in relation to the use of an individual funding model. The better control people have in organising their disability support was found to contribute to positive outcomes in different domains of personal wellbeing (standard of living, achievements in life, personal relationships, personal safety and community connectedness) All respondents said that individual funding had improved their control, choice, independence and self determination in their lives.

It was also found that people with disability and their families commented on how changing to individual funding had improved the wellbeing of family members because they could share the responsibilities. Concern however was expressed about what would happen in the future when the family members could not help manage the individual funding.

It is believed that there should be flexibility in the models of individual funding used to allow a wide range of purchasing options in relation to service and care provision, obtaining of aids and equipment and coordination of individual care plans. CDA considers this approach the most appropriate in order to allow families to make appropriate choices regarding the wishes and needs of their child, and considers their family context.

An individual funding model provides participants with the ability to determine the best mix of aids and services to suit their current context. Three factors are critical to the success of this approach in ensuring fair, equitable and cost effective outcomes.

Reasonableness

Insurance schemes such as the TAC or WorkCover have a ready benchmark of the level of support required by an individual, as there was an existing level of function prior to the incident.

A Scheme which applies to individuals who are born with, or acquire a disability requires certain parameters around the reasonableness of support required. CDA submits that the preliminary test of reasonableness is that the support is required because of the disability, i.e. that another person of the same age, family structure, location, etc would not need this support if they did not have a disability.

The second level of reasonableness is the cost of a specific service or support item, which will be dependant on the market cost of equivalent products or services in that location.

Where there is uncertainty, and especially where the cost of support is high, a decision panel is recommended. Any such panel should be comprised of health professionals, service providers, people with disability, families or carers and community members. Such a process would lead to consistency and transparency, and allow the decisions made to be used as precedent for subsequent questions of

a similar nature.

Complaint/Appeal Mechanisms

In order to ensure accessibility to the Scheme, decision making delegations will need to be fairly broad and rely significantly on the decision of one individual in a case coordinator or management model. In order to avoid inconsistency of outcome, bias or other corruptions of the decision making process, an effective complaint and appeal mechanism will be required.

SCHEME COVERAGE

It is anticipated that the following broad categories of support would be covered by the Scheme:

- Care – personal and community
- Aids and equipment. The submission by National Aids and Equipment Reform Alliance's (NEARA) is believed to articulate well the considerations which need to be taken into account when looking at the provision of aids and equipment in relation to a disability care and support scheme.
- Recognised therapies (provision of actual therapy)
- Lifetime care coordination - specialised professional advice (provision of support to develop plans, access services, review, negotiate with providers, and financial, legal, or other advice required to effectively manage affairs) and report to the scheme
- Community access (may include support for transport, modifications, guide dogs, attendance at specialised programs, skills development etc)
- Assessment services (to provide ongoing assessment and review as required by the Scheme, may include costs of medical reports, case manager time, etc)
- Where regulation carries a compliance cost (eg administration cost of requirement to complete reports etc), this should be borne by the Scheme. Any other arrangement will not provide an incentive to reduce existing red-tape and provide streamlined and sensible processes.
- Administrative processes including payment for services, accounting for funds allocation and expenditure. This should be retained by the Scheme for both accountability and efficiency purposes. Delegation of these functions to case managers is an inappropriate use of the case manager skill set.

Out of Scope

The supports available under the Scheme would not include:

- Infrastructure, apart from modifications
- Income support, apart from professional support in sourcing and managing income support
- Education, apart from provision of support services and therapies to increase the effectiveness of the education received
- Medical costs, apart from approved therapies not covered under Medicare
- Labour market programs for carers and individuals
- Pharmaceutical Benefits Scheme

SPECIFIC ISSUES FOR CHILDREN

Families

It is imperative that a child's right to family is respected and supported through the operation of a disability care and support scheme. The role of the family and the usual role of parents as decision makers for their children should not be compromised because a child has a disability. Typically the level of decision making reduces as the child develops and ages. This trajectory can vary when a child has disability depending on the impact of their disability.

As with all children, unless there is evidence to the contrary, it must be acknowledged that parents are the legal decision makers for their children and as such respect that decisions will be made based on their beliefs, desires, preferences, knowledge and access to information. It is imperative that a situation is not created where a scheme decides what is in the best interest of a child rather than parents.

Families of children with disability have a key role to play in relation to providing information regarding eligibility of the scheme, assessment of needs, formulating individual care plans and the provision of care and support.

Education

Should integration support be in or out?

Existing education support services funded by State and Territory education departments (commonly called 'Integration programs') should be left outside the scheme. While the Scheme would have interaction with these programs through the lifetime care coordination function and at a policy level, it is important that the education system continue to take ultimate responsibility for the education of all children, and not be given the opportunity to 'cash out' their obligation in this area for children with disability.

The Scheme could pay for specific goal based therapy programs that would complement the in-school education system. It is important that the community institutions used by children with disability (health services, schools, transport systems) maintain their role for all citizens, and are not taken over by a discrete funding source. This runs the risk the clients of the Scheme being turned into market commodities.

Where there are deficiencies in their program for people with disabilities it is the responsibilities of the relevant Government jurisdiction to address these gaps, and there should be a mechanism alongside the introduction of a long term care scheme to ensure that this effort is made so that undue pressure is not placed on the scheme to duplicate their fundamental responsibilities. This would need to have the backing of a COAG directive to this effect, related to the National Disability Strategy.

In cases where children are eligible for the Scheme but ineligible for a State or Territory education support program then the scheme should seek recovery of costs from the program. This would avoid the potential for cost shifting.

SPECIFIC ISSUES FOR RURAL AREAS

Remote accessibility issues would potentially have the benefit of more innovative approaches under a national scheme. Looking more broadly, some possible improvements could include:

- Understanding the impact of internet access – if this is critical to service

delivery and information provision it is a basic requirement for people with disability in rural areas

- Online management, scheduling and mobilisation of equipment on a national basis. This would allow the most cost effective usage, and budgeting for purchase of significant additional equipment
- A national incentive scheme for medical practitioners to visit remote areas. Reward those prepared to relocate or at least rotate.
- A national scheme to improve the basic training levels of therapists and rehabilitation staff in remote areas, potentially using online training, travelling or lecturers.
- New methods of creating community links between remote and urban communities to support smaller organisations.
- Scheme to cover necessary costs of airlines for carrying beds, stretchers etc where necessary. Where a Scheme is making such payments, opportunities for efficiency will be more visible.
- Negotiate with transport authorities to provide like access – so if other residents can pay \$30 for a bus fare to a major rural centre, those with a disability should be able to use available transport (eg private taxi) at the same cost.

Funding Model

The scheme is conceptualised as a funding program which works in cooperation with broader disability services. It would utilize the same pool of service providers but would have a specific funding source. The relationship would be similar to that which exists currently between generic disability services and the WorkCover and Victorian TAC system.

The scheme would be funded through a tax levy similar to that used by Medicare which is applicable to all.

Funding to States and Territories to provide services for people with profound and significant disability and children would be directed to the Scheme. Further, States and Territories without no-fault catastrophic schemes would be required to provide a greater financial contribution to a national Scheme.

It is envisaged that income to the Scheme can be pooled in an insurance type model to create capacity to meet future costs or increased eligibility for the scheme.

The need for data and research is clearly identified which needs to identify the potential future economic advantages of the introduction of a scheme as envisaged.

Other Comments

During the planning phase, it will be critical that projected service levels be modelled accurately to determine skill and workforce gaps.

A Scheme that relies on the market availability of services will need to have a sound understanding of what the services are, and who needs them, and where. Professional associations may need to be formed to advise government on skills gaps and appropriate policy initiatives to overcome these. Such activities take time, and the earlier this information is gathered, the lower the likelihood that implementation of the Scheme would immediately result in the highly undesirable outcome of extensive waiting lists for service for eligible individuals.

Finally, there is significant work to be done on communicating and promoting a Scheme to the broader public.

Thank you for the opportunity to comment on this framework.



Stephanie Gotlib
Executive Officer

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Appendix A

Survey provided to all CDA members for comment is attached.