Productivity Commission
Inquiry into
A National Long Term Disability Care and Support Scheme
Submission - August 2010

Association for Children with a Disability

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Introduction

Established 30 years ago, the Association for Children with a Disability is a non-profit community State-based organisation representing children with a disability and their families living in Victoria. Our current membership includes over 2,000 families.

Purpose and Principles

Our Association exists to assist children with a disability and their families through the provision of information, support and advocacy.

Statement of Purpose

- To empower parents of children with a disability to be as self-sufficient as possible in advocating on behalf of their child and family.
- To promote and advance the rights of children with a disability and their families.
- To advocate on behalf of children with a disability and their families to ensure the best possible support and services are available.
- To work collaboratively with other organisations to improve the service system for children with a disability and their families.

Guiding Principles

- To be responsive to the needs of children with a disability and their families.
- To provide a professional, quality service.
- To be proactive by raising issues with government and build awareness in the community about the rights of children with a disability and their families.

Introduction

Our Association applauds the decision to examine the feasibility of a National Long Term Disability Care and Support Scheme and for the opportunity to provide comment on how such a scheme could support our constituency.

Like many others who have provided submissions our Association also is of the opinion that the Scheme should be underpinned by the principles and priorities of the Convention of the Rights of Persons with Disabilities and be based on the principle of entitlement rather than a welfare approach to supporting people with a disability and their families.

For our constituency, the United National Convention on the Rights of the Child is equally as important as the Convention on the Rights of Persons with Disability and therefore any service delivery framework governing policy and practice should incorporate both human rights frameworks. The rights of children and the responsibilities that parents carry to ensure that their children are given the best opportunities to realise their full potential need to be supported by the National Long Term Disability Care and Support Scheme.

Many other submissions to the Productivity Commission provide in greater detail the theoretical argument for the Scheme. Rather than expand on or duplicate the writings of others, our submission is focussed on the "nuts and bolts" components of a scheme that we believe would work in the best interests of those being supported whilst at the same time, demonstrating an a more streamlined approach to service system delivery.

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

Our Association is of the view that children and young people with a disability (0-25) requiring support to reach their key milestones should be supported. Overwhelming evidence in recent years confirms broad practice wisdom that early intervention works, providing the best opportunity for children to realise their full potential and dramatically reduces the level of intervention required to support over the long term – it makes sound economic sense.

Therefore the eligibility definition for the scheme is based on the definition contained in Australia's Disability Discrimination Act, together with an assessment of need for support by both the person with a disability and those who support them.

Over the age of 25, individuals with an ongoing long term need for care and support that directly relates to their disability should also be covered by the Scheme.

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

When appropriately supported in the early years many of the challenges children face, could be either eliminated or reduced by the time they reach adulthood. It is also important to recognise the context in which a child with a disability is developing and the level of support required to meet their needs (e.g. large families, single parent families, other caring responsibilities – ageing parents). Often children with a disability have siblings and the overall caring responsibilities are usually greatest in young families. Key life transitions can also be accompanied by a spike in need for support – e.g. transition from early childhood settings to school, the onset of puberty, transition to post school options.

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

An assessment tool that incorporates individual weightings for –
level of need
caring context
geographical location

A Scheme based on entitlement, should not be means tested.

An appeal process both at the point of eligibility and review, needs to be independent and not embedded within the scheme's framework, to maintain transparency and ensure that decisions are not driven by service capacity but by the expressed needs of those using the Scheme.

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

In assessing the level of support needed, an allocation to cover either self managed or provider managed service co-ordination is required. Families of children with a disability can choose which type of service co-ordination best suits their needs.

As outlined above, an appeal process needs to be developed for initial assessment, service monitoring and evaluation, to ensure that those using services funded under the Scheme are satisfied with the quality of support provided.

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

A panel of independent registered assessors should evaluate the submission for support under the Scheme. Relevant documentation will provide evidence of eligibility which together with the identification of required levels of support would constitute the provision of service.

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

Support available through the Scheme should include –

Support Co-ordination (self-managed or provider purchased)
Personal Care
Aids and Equipment
Respite and Carer Support
Home and Vehicle Modifications
Therapies – speech, OT, physio, music, play
Community Access

How could the ways in which services are delivered — including their coordination, costs, timeliness and innovation — be improved?

Assessment and resource allocation needs to occur in a manner that eliminates waiting times, especially for children. The service coordination component of the Scheme is critical to maximise service continuity. A disability care and support card is issued with the notional allocation attached to it. All payments for services occur through an electronic payment system, similar to Medicare.

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

Early assessment for children requiring support should be encouraged, through traditional health related pathways – e.g. GPs, health centres, early childhood settings – thus generating a submission to the Scheme.

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

Providing access to resources when and where children require individual support and where added supports would ensure that families can continue their caring role. The traditional barriers to community participation would be either removed or significantly reduced.

The Scheme also needs to have the capacity to respond to emergency situations outside of the current notional allocation. Costs incurred prior to determining the notional allocation can be reimbursed as expenses under the Scheme.

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

The primary strength of current systems is their flexibility to meet individual need. Practice approaches need to be person-centred and family-centred, to ensure that the Scheme is driven by the need for support, rather than the capacity of the service system to deliver.

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

Geographical weighting to account for remoteness – incorporating travel expenses relating to service delivery, extra costs for services such as travel and accommodation required to access treatment.

Flexibility as to who can be engaged to provide support (family members if paid staff are not available).

Information technology provided for remote areas – video conferencing for some supports e.g. therapy

How could a new system get rid of wasteful paper burdens, overlapping assessments (the ‘run around’) and duplication in the system?

One eligibility and submission process provides pathway to all services. Managed through one electronic payment system.

How should a new scheme be financed?

Introduction of a levy on all eligible income earners. Standardised costs will mean registered providers will need to adhere to a set schedule of indexed fees.

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?

The current funding provided by individual jurisdictions needs to be maintained through the National Disability Agreement and would be used to contribute to the cost of service deliver. Current programs provided under the NDA could still deliver the range of supports required by eligible individuals.

Services that sit outside the Scheme will still need to be adequately supported = education, employment services, supported accommodation. Income support and disability related allowances currently administered through Centrelink should operate outside the Scheme.

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

See our Association’s model for a National Long Term Disability Care and Support Scheme, designed around individual need.

Once a submission is processed and the notional allocation determined, a Support Card is issued to process all services engaged. Key categories of support include – Therapy, Equipment, Support and Access.

As well as the traditional services available under each category, carer support should include a type of work-cover arrangement so that family carers injured while undertaking caring activities are not financially disadvantaged if they are unable to maintain paid employment.

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

Begin pro-active recruitment initiatives to attract workers to disability related professions – waive tuition fees; provide scholarships; increase workforce pay and conditions.

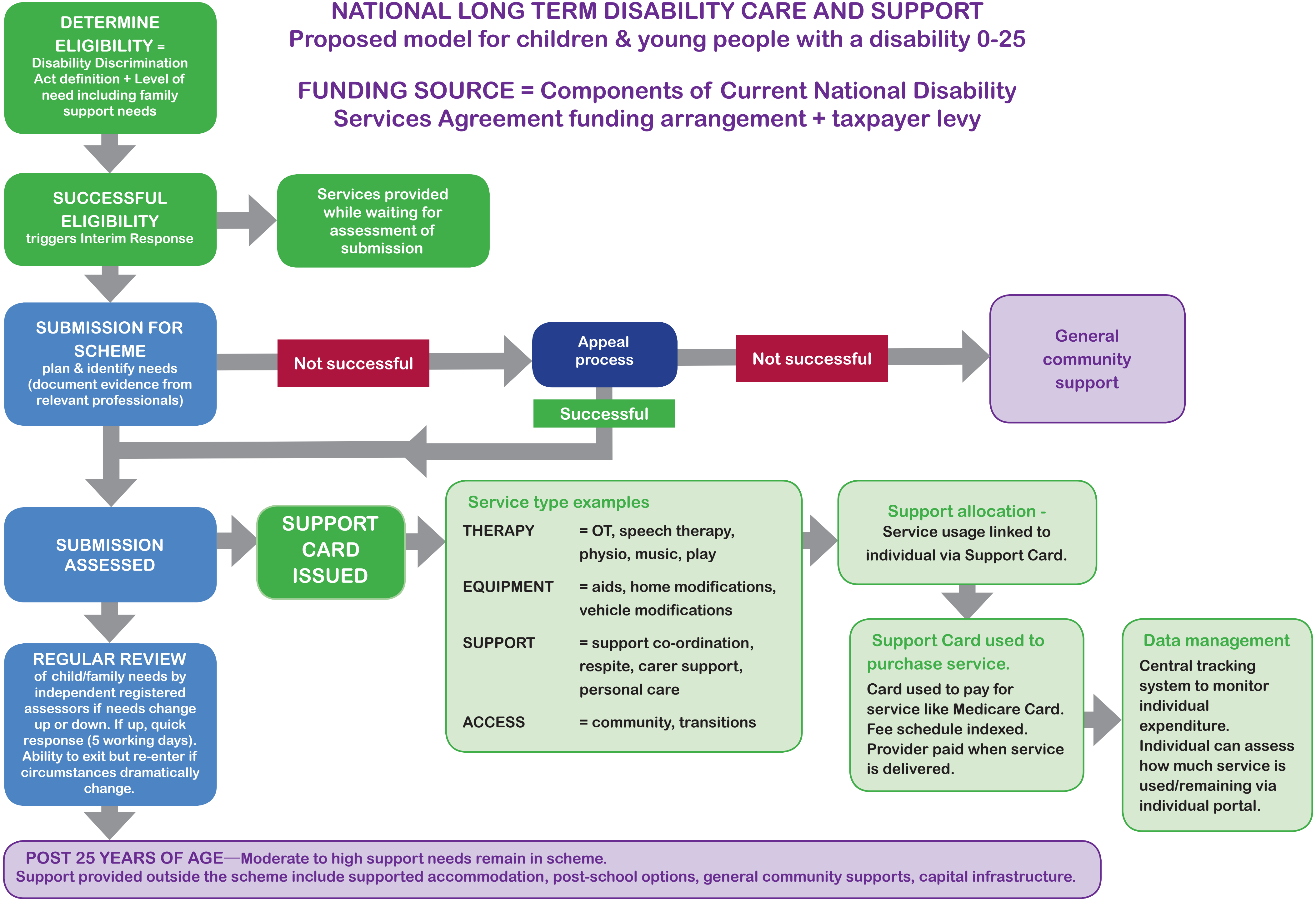
Maintain current entitlements through transition to the Scheme. People already assessed within state jurisdiction as requiring significant ongoing levels of support should not need to undergo another assessment to be eligible for the Scheme.

Other ideas for a good scheme

Our Association has developed a service model for the National Long Term Disability Care and Support Scheme, which is attached. It tracks the access, and implementation processes for a child requiring support to meet their developmental needs.

NATIONAL LONG TERM DISABILITY CARE AND SUPPORT
Proposed model for children & young people with a disability 0-25

FUNDING SOURCE = Components of Current National Disability Services Agreement funding arrangement + taxpayer levy



DETERMINE ELIGIBILITY =
Disability Discrimination Act definition + Level of need including family support needs

SUCCESSFUL ELIGIBILITY
triggers Interim Response

Services provided while waiting for assessment of submission

SUBMISSION FOR SCHEME
plan & identify needs (document evidence from relevant professionals)

Not successful

Appeal process

Not successful

General community support

Successful

SUBMISSION ASSESSED

SUPPORT CARD ISSUED

Service type examples

THERAPY = OT, speech therapy, physio, music, play

EQUIPMENT = aids, home modifications, vehicle modifications

SUPPORT = support co-ordination, respite, carer support, personal care

ACCESS = community, transitions

Support allocation -
Service usage linked to individual via Support Card.

Support Card used to purchase service.
Card used to pay for service like Medicare Card. Fee schedule indexed. Provider paid when service is delivered.

Data management
Central tracking system to monitor individual expenditure. Individual can assess how much service is used/remaining via individual portal.

REGULAR REVIEW
of child/family needs by independent registered assessors if needs change up or down. If up, quick response (5 working days). Ability to exit but re-enter if circumstances dramatically change.

POST 25 YEARS OF AGE—Moderate to high support needs remain in scheme.
Support provided outside the scheme include supported accommodation, post-school options, general community supports, capital infrastructure.