Mercy Disability Services
Brisbane Queensland

Submission to Senate Inquiry Into The Funding and Operation Of the Commonwealth State Territory Disability Agreement (CSTDA)

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INTRODUCTION:

Mercy Disability Services are pleased to provide a submission on the future complexion of the Commonwealth State Territory Disability Agreement, from the perspective of the ageing/disability interface.

1.01 The main focus of this submission is in relation to responding paragraphs (c) & (d) of the Terms of Reference: 'An examination of the ageing/disability interface with respect to health, aged care and other services, including the problems of jurisdictional overlap and inefficiency'.

1.02 Our response also relates to paragraph 3(1) of the *Queensland Bilateral Agreement*: **Strengthening cross government linkages, particularly at critical life stages and transition point.**

1.03 In this submission, we respectfully invite the Senate Committee to consider even more flexible approaches to funding provided to meet the support needs of those with a disability who are ageing.

1.04 We further encourage the Committee to explore the concept of a 'Continuum of Care' model as detailed in our response to Jurisdiction and Funding.

OUR SERVICE:

2.01 Congregate facility for ladies residing in individual rooms and sharing common cooking, bathing facilities, and a common large lounge dining room, typically four ladies share such a facility. A slightly more independent level of living is provided by individual flats connected to the units Support is provided on a 365 day basis with sleepover support. Service users are supported in life skills, activities, attendance at work, and involvement with the community/

2.02 We support a number of persons to live in the community in Group homes co tenancy arrangements and independently many of these have transitioned from institutional or congregate care and required substantial initial training to make the transition. With appropriate case management and reinforcement of skills the only returns to higher level support being the deterioration of their health.

2.03 We provide one of the few services that provide targeted support to persons exited from SACS business services to access alternative support. Those obligations are successfully integrated into a program serving congregate care and in community support service users requiring valued and appropriate community access opportunities.

2.04 Through a long association with Holy Cross Laundry (Commonwealth funded Business service) we operate a training and commercial kitchen catering to baked Goods, basic commercial catering a training both persons with a disability and young people seeking to enter the workforce or acquire competency based qualifications in basic catering.

2.05 We are Quality Accredited under both Commonwealth and State Disability Service Standards

OUR CLIENTS:

Our client group (whom we describe as Service Users), possesses the following characteristics:
3.01 Our four programs serve 57 people;
3.02 Most of our Service Users are female;
3.03 All have a mild to moderate intellectual disability;
3.04 Some have dual diagnosis;
3.05 The age range in our population is 20 to 73years;
3.06 Some have Adult Guardians and Financial Administrators appointed;
3.07 Approximately one half live in the community with moderate to minimal support

MDS in a spirit of partnership withy the community and families provides an on site and community based accommodation and lifestyle support service. Targeting Brisbane's inner north and persons 18 to 65 (some up to 75) with an intellectual disability who require frequent support. In terms of persons requiring frequent support with daily living tasks we target the low to medium part of that spectrum. We do not target acquired disabilities or high behavioral support persons as we hold obligations to existing populations,

We have and continue to respond to crisis situations and provide individualized case management support to clients with unique needs requiring intensive support enabling a positive and valued life experience.

We are active in offering mentoring and support to smaller services and in the Acrod unmet needs campaign.

Mercy Disability Services (MDS) and Aged Care.

The Sisters of Mercy's have provided service ministries on the Wooloowin site for 117 years. Mercy Disability Services grew in the 1970's from the Sister's desire to respond in a practical way to the needs of women, especially young women, who had an intellectual disability.

MDS was originally an accommodation support service responding to the emerging needs of these women. As sector practice has developed the service types provided by MDS have kept pace with initiatives to meet the ongoing needs of service users.

The service types as outlined in paragraph 2 reflect the practical response to meeting needs.

Service user, family preference and funding constraints have combined to develop a population with long term trust in our support and strong family links. One of the major issues facing our organization is the ageing of our client group.

As an approach to responding to support needs of the Service Users, our sister organization, Mercy Aged Care Services Brisbane, was invited, some six years ago to set up an annex to their aged care service adjacent to our on-site accommodation service in Wooloowin. A specialist 15 bed facility was provided, to serve women with a disability, who were ageing.

Fifteen women with a disability, who were former Mercy Disability Services Service Users, still reside in this facility.

Mercy sponsored ministries are able to provide a seamless service provision as people progress through the stages of ageing with an intellectual disability.

Our 'dream' for our Service Users is outlined below. This concept gives to people with an intellectual disability, the opportunity to age in the place of their choice; a choice which should be available to all members of the community.

Jurisdiction and Funding

Mercy Disability Services presently has seven (7) service users who are in need of assessment for some form of aged care or pre transition to aged care assessment.

Mercy Disability Services has transitioned several service users to aged care.

Mercy Disability Services has direct experience of service users whose need to transfer to aged support is independent of their age.

We presently provide support to three (3) young women who are in transition from foster care, crisis housing and family care respectively.

We have two (2) service users who have either entered or re entered our support through ageing carers. On of those and one of the young women have no life skills or ability to self support.

The issues surrounding disability / aged care, youth care / disability support, family / service provider support progression and transitions are not potentialities to us but current realities but current problems.

We enjoy access to the skills and knowledge of our sister ministries, the empathy and support of public servants with whom we deal and the unstinting support of families the basic system has flaws.

Issues we identify

Eligibility criteria based on age are inappropriate as a tool to determine the source and nature of funding for persons with disabilities.

Developmental issues, Downs syndrome, Autism, Foetal alcohol syndrome, Cerebral Palsy and many other disabilities do not conform to a time based developmental pattern. They do progress or plateau in individual cases in individual ways.

Both Family and Community services and the Queensland Government impose on service providers a quality system establishing the primacy of resourcing the needs of the person within available resource constraints.

The principal agreement between the States and Commonwealth Governments on how disability support should be funded, managed and out comes measured then adopts an outdated and irrelevant structure for the basis of transition from one form of support to another.

Developing Crises

Many politicians have spoken on the inappropriate placement of people with disabilities in inappropriate aged car facilities. Those occurrences are detrimental to the person and a waste of aged care resources.

Coming over the horizon is the first wave of people with disabilities who have been supported by their families, in an appropriate caring environment, at great financial and personal cost to the families. This support has resulted in an almost exponentially greater saving to government. As family carers age the number of persons with a disability who, because of a loving and supportive family, have not been trained in independent living skills are going to need extensive support for the balance of their lives until they reach a high care residential aged facility.

Submission

The Commonwealth State Territory Disability Agreement must move to an approach consistent with the governments concerned Disability Service Standards.

Care and the points at which services are available together with transition points between funding types must be moved to a basis consistent with providing appropriate care for each person with a disability.

We refer from this point to a support continuum. Simply put it is that a person with a disability congenital or acquired, who requires support in basic living, requires that support for the balance of their life. No likely cure, possible remissions and relapses, achievements and failures.

The most appropriate model is the least intrusive support that allows the person with the disability as full, normal and valued an experience of life as is consistent with their abilities.

Support of disabilities is intrusive, it reduces the exercise of choice by the individual, and it is fraught with communication difficulties for the person with a disability in expressing their likes, dislikes and choices.

The person with a disability is entitled to a full experience of the dignity of risk. Support in their life is necessary, they should not be set up to fail but equally it must be recognized that they face challenges each day, fail yet try again and again.

State Governments provide 12 years of schooling free to all children. We are not aware of any State that imposes a fee on a bright student re sitting a final year (and so accessing thirteen years of schooling) to improve their university prospects, yet no State provides for a student with high needs development issues to remain in the schooling system an extra year to enable reinforcing some lately learned skills.

State Governments provide large packages to support profoundly disabled until the age of 18. At that point the person has to transfer on to family, post school, or service provider support. Not only does the person with a disability face the challenge of finding employment or activities in a tightly restricted market place, not only do they face the challenges , physical , emotional and in lifestyle of the move from school but a dramatic change in how they are supported.

At age 65, irrespective of their ability to live independently, they must move from the disability support they have known (possibly for 40+) years to a new environment because the CSDTA enforces it. No other Australian faces such a deliberate and calculated disruption in their life.

If the person with a disability does deteriorate in their late 40's as with some conditions and exhibit ageing related disorders they are not eligible for aged care until 65. ACAT assessments and the efforts of Service Providers may get some special consideration. Support when given is often in spite of the system rather than because of it.

Under Disability legislation, through Centrelink, FoFms and the CSDTA data collection, State based client management systems much information is known about supported persons with a disability and is readily shared where appropriate. A disability profile based on primary/ secondary diagnosis of conditions could be used to set a review and monitoring process in place for the support continuum.

Those conditions that exhibit early onset of aged related conditions would have the case flagged for earlier review. Those with no significant deterioration could continue in disability support beyond 65 with adequate monitoring.

Funding

Funding is a resource allocation exercise. It is probable that funding will never match need. It is incumbent upon the funding providers to fund as many persons with a disability to an appropriate level as constraints allow. It is incumbent upon service user to maximize the service delivery they provide for those funds.

That families bear an enormous burden must be recognised. That this burden is a fraction of the cost of providing trained support is also self evident. Families suffer giving rise to flow on costs such as family collapse, loss of family carers as contributors to the "normal" economy, increasing needs for respite etc.

The Crises anticipated by us in the requirement to support unskilled non independent persons with a disability must also be addressed,

Cost is a function of the needs and the method of support, low skills translate to higher support needs, greater family and ancillary costs and ever greater support staff costs.

Early intervention and continued support works, is an investment that begins to repay itself almost immediately and reduces the possible long term costs of care. There are a number of illustrative figures attached to this submission that assist with this concept.

The basic continuum can be stated as:

- **Provision of support early to parents so they persist with maximising the ability of the child to be independent,**
- **persisting with support with the parent, special school or integrated special ed unit,**
- **introduction of future support methods while still at school, encourage parents to allow young adults maximising independence,**
- **training parents to accept that the independence is good not abandonment or restriction of love,**
- **Providing support to allow life in an independent or appropriate form of accommodation so that the person has maximum learned, reinforced and used skills so if a t 40 the parent care dies much lower support needs are evidenced.**
- **Supporting the independent living past a notional age of 65 so the eventual cost of aged care is reduced.**

Commonwealth State Functional interaction

At the point of initial support from Centrelink or a Disability Service Department the primary diagnosis needs to be assessed and the person assigned a particular Continuum of Support plan e.g.

- will the person be non verbal for the entirety of their life
- is a normal prognosis that a person will be self supporting in hygiene issues
- does the condition degenerate or accelerate ageing
- What is a normal development prognosis for a person with that diagnosis?

This will assist in identifying where and the type of early intervention, training and support of parents can be aimed, the required review time frames can be assessed.

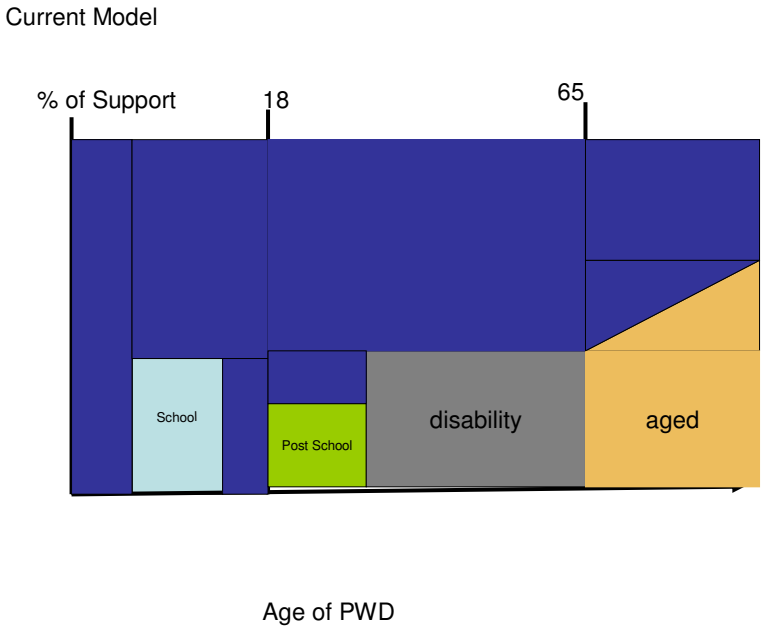
States have the responsibility for children, schooling and disability support, Commonwealth for employment and ageing

Management of the cases should rest with the principal funding body and principal carer with those acting as agencies or broker for the lower proportion services.
Review dates will be closer together at transition points and further apart during life intervals of minimum change in underlying conditions,

The emphasis has to be ion skilling families and individuals to extend the time span of family or independent living as afar as possible through the life of a person with a disability.

Illustrative Figures

Figure 1

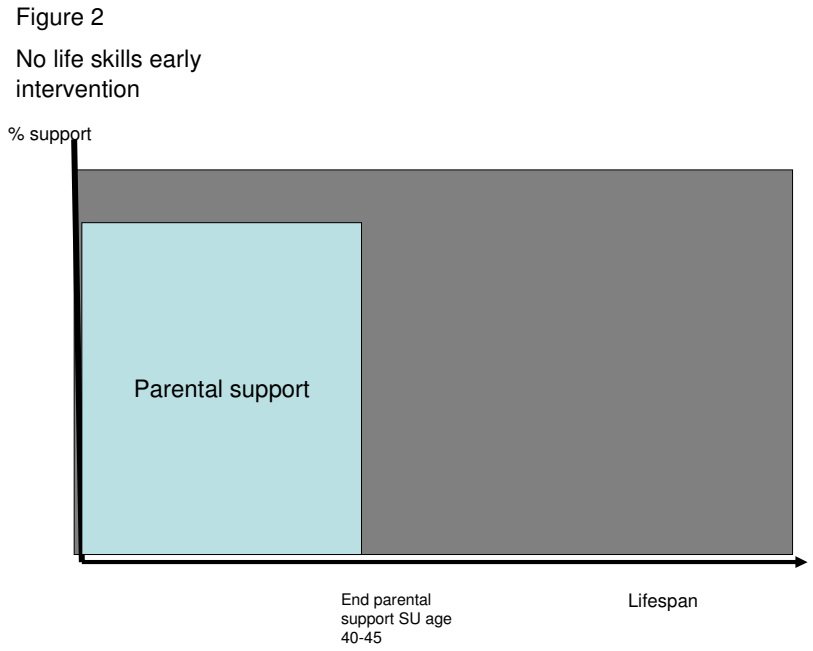


The dark blue area is family and self support. The costs to community are training respite and other indirect support. Even where the carer is Centrelink supported the cost per hour of support provided is at its lowest.

Early intervention and training support will increase the proportion of required support available here.

The more costly funded hours of school post school, disability and aged support are minimizes

Figure 2

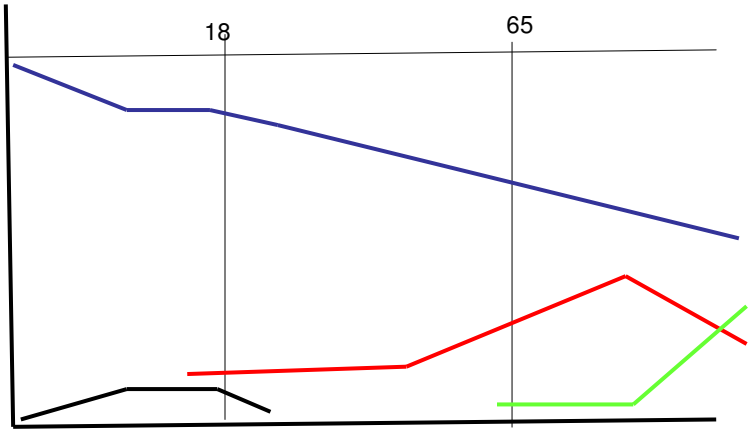


Clearly the burden of support is transferred to the disability support sector and a much greater lifetime cost incurred.

Figure 3

Figure 3

Continuum Concept



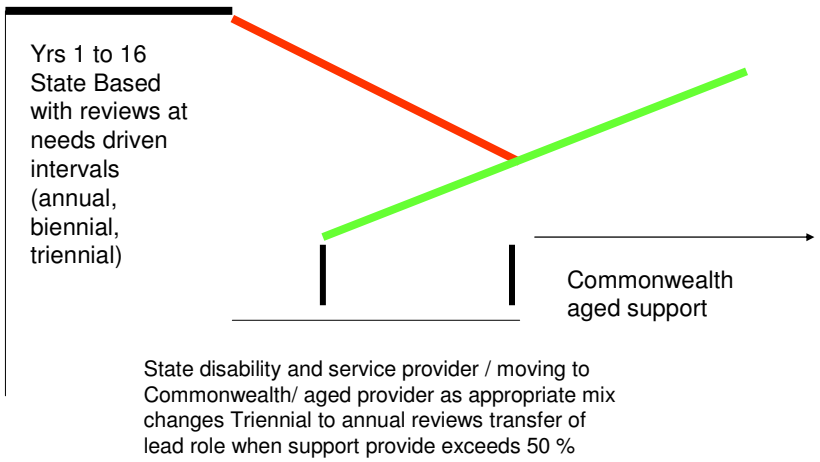
Blue again indicates the family independent support, **Black** School years, Red and green Disability / ageing respectively.

Our belief is that and early intervention and skilling by skills at each transition point enable a longer maintenance period at a lower intensity and hence cost.

Figure 4

Figure 4

Jurisdiction through the continuum



In short jurisdiction should follow primacy of support. As the appropriate mix of support moves from State to Commonwealth so the major funding agency takes primacy. It sub contracts with the correspondent or secondary funding body to fund and acquit grants. The primary service provider receives and then disburses the secondary service providers funding under on of the established and proven sub contract or fee for service models. As the service users needs progress the roles are reversed,

Service users benefit as there is certainty of t6heir forward support plan, there is a clear passage of all appropriate knowledge between funding bodies and successive service providers,

Service providers benefit as there is a clear plan for the service user progression and they do not need to divert resources into locating services and accessing them, they have the benefit of being able to plan future resources based on assessments on a regular basis.

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Funding bodies benefit from the extension of independent living as long is possible, a lesser demand for high cost high level accommodation and application of resources where needed.

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