Submission to the Senate Community Affairs References Committee

Inquiry into the Funding and Operation of the Commonwealth State/Territory Disability Agreement

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Terms of Reference

An examination of the funding and operation of the CSTDA, including:
a) an examination of the intent and the effect of the three CSTDAs to date;
b) the appropriateness or otherwise of current arrangements, including an analysis of levels of unmet needs and, in particular, the unmet need for accommodation services and support;
c) an examination of the ageing/disability interface with respect to health, aged care and other services, including the problems of jurisdictional overlap and inefficiency; and
d) an examination of alternative funding, jurisdiction and administrative arrangements, including relevant examples from overseas.

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Introduction

The Disability Advocacy and Complaints Service of South Australia Inc. is a Commonwealth funded disability advocacy agency, which is managed by a Board of Management of people with disabilities.

Disability Advocacy and Complaints Service of South Australia Inc. is currently funded to deliver individual advocacy to people with disabilities and their families. Our clients come from all socio-economic backgrounds. Anyone with a disability, including someone with a mental health problem, can access our services, if they have a complaints or grievance related to their disability.

We act on the expressed wishes of the person with a disability wherever possible.

Advocates at the Disability Advocacy and Complaints Service of South Australia Inc. experience every day the effects of the Commonwealth State Territory Disability Agreement. Unfortunately we hear the sad stories only, the critical need of some people to access services or equipment, the lack of accommodation for younger people with disabilities to move out from their parents and create their own lives, the younger people forced to live in Nursing Homes, the lack of accessible transport and most of all the discrimination people experience as a result of living with a disability.

Discrimination happens at school, TAFE, universities, in employment, in employment services of the Job Network, and most institutionalized in the service provision of home based care, and specialist disability services.

Unfortunately we can only work on one issue after the other. We are not funded to provide systemic advocacy. As a result of the de-funding of a major disability advocacy program, Disability Action Inc., we have lost South Australia’s only overarching systemic advocacy program.

This is most tragic as we currently experience a reform in the disability services sector which may have far reaching consequences for our clients.

We do our best to communicate our concerns in regard to the reform, but we can not do this by using our staff during working hours.

The importance of strong and efficient advocacy services

5(2) The Commonwealth and the States/Territories acknowledge that, at the time of signing this Agreement the specialist disability services to which this Agreement relates are -

(a) accommodation support;
(b) community support;
(c) community access;
(d) respite;
(e) employment;
(f) advocacy;
(g) information; and
(h) print disability.

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About three years ago Disability Advocacy and Complaints Service of South Australia Inc. was approached by 76 individuals who had severe shortages in their care hours and urgently needed aids and equipment. We sent 76 individual letters to the Minister, the Premier and the Treasurer of South Australia. Three years on half of the urgent needs have been picked up, the other half are still waiting.

A systemic advocacy program could unite other disability groups and run a more efficient campaign. The systemic advocacy program would monitor service standards and raise issues about how to improve the delivery of services based on consumer consultation.

As defined in the Disability Services Act and the Commonwealth State Territory Disability Agreement advocacy plays an important role and the segregation of the disability services sector was overcome to a degree by having an overarching systemic advocacy program, even though the program was chronically under-resourced in South Australia.

We need a strong systemic advocacy program and our agency is willing and ready to deliver such a program to standards and with key performance indicators and outcomes.

Recommendation 1

Disability Advocacy and Complaints Service of South Australia Inc. recommends that the funding for a strong, independent, overarching systemic advocacy program is restored to South Australia.

Our current funding does not really cover our potential to reach out to all country areas, although we are the only disability advocacy agency working on behalf of all people with disabilities and of all ages. The demand on our services from clients with mental health problems has grown strongly and it would be greater if we were to make ourselves available at times to the patients of the mental health wards.

We urgently need more personnel to meet the demand in the mental health sector. We could promote our services better, and visit people in Boarding Houses and institutions to offer our services there. However, we cannot afford an increase in client load.

Every year our costs of insurance and rent, telephone and communications increase and we have to cut hours of our staff. We are working with a very small budget considering we are also delivering a five days, eight hours advocacy service in Whyalla with outreach to the whole Eyre Peninsula.

Recommendation 2:
The Disability Advocacy and Complaints Service of South Australia Inc. recommend that the State and Territory governments agree on a definition of advocacy services, and either negotiate an increase from the Commonwealth Government to the existing advocacy program in South Australia, or to consider investing into a new professional disability advocacy service to respond to the needs of mental health clients.

1.) An examination of the intent and the effect of the three CSTDAs to date

Objective: The objective of the CSTDAs was to “strive to enhance the quality of life experienced by people with disabilities through assisting them to live as valued and participating members of the community.” (CSTDA, Part 4 – National Framework)

Policy priorities of the last CSTDA were to

a) strengthen access to generic services for people with disabilities by:

- fostering a whole-of-government approach to maximise the opportunity for people with disabilities to participate socially and economically in the community; and
- explicitly recognising access to, and the role of, generic services as a complement to the focus on the funding and delivery of specialist disability services and supports.

b) strengthen across government linkages by:

- positively influencing the service system within and external to the Agreement to ensure that access to appropriate services is supported and strengthened; and
- improving collaboration, co-ordination across programs and governments to ensure that people with disabilities have fair opportunities to access and transition between services at all stages of their lives.

c) strengthen individuals, families and carers by:

- developing supports and services based on individual needs and outcomes, which enhance the well-being, contribution, capacity and inclusion of individuals, families and carers; and
- increasing their opportunities to influence the development and implementation of supports and service at all levels.

d) improve long-term strategies to respond to and manage demand for specialist disability services through:

- a strategic approach to broad national and local/jurisdictional planning to underpin the determination and allocation of equitable funding to respond to unmet demand, growth in demand and cost increases; and
- approaches which enhance prevention and early intervention outcomes, the effective co-ordination across service systems and clear and transparent decision making.

e) improve accountability, performance reporting and quality by:

- improving accountability and transparency for specialist disability services funded under this Agreement; and
- incrementally developing, implementing and reporting progress on the aforementioned national policy priorities.

These policy priorities were reflected in the Bilateral Agreement between the Commonwealth and South Australia.

The South Australian Government has pursued the objective and policy priorities of the last four years. The latest development heralds a complete reform of the disability services sector in order to improve access to specialist disability services.

Unfortunately funding allocated to disability services, respite, day care services, and accommodation services is not meeting the most essential needs of people with disabilities.

Many of our clients in need of personal care do not receive a daily shower. Many of our clients cannot get a meal or drink during the day without calling friends, family members, neighbors, or even cab drivers to deliver lunches.

Families with children with disabilities wait until the parents turn 75 before their ‘children’ find independent accommodation and care.

People with intellectual disabilities and mental health problems do not receive any service at all, they are the forgotten people, in need of weekly assistance with cleaning and maybe shopping, and most importantly, at least one weekly visit from another person.

There are no statistics about unmet need. Our agency received 76 client referrals from APN (Adult Physical and Neurological Disabilities) Options Coordination agency two years ago. We are still waiting for 36 of these clients to get extra hours or their equipment, they are so urgently need.

We are also aware that in 2006 the Intellectual Disability Services Council had a waiting list for urgent accommodation for 2200 people with intellectual disabilities. Every year around 20 – 30 places become available as a result of ‘attrition’, however, last year there were around 50 people with disabilities who urgently needed accommodation and care, partially because they would otherwise be jailed, or alternatively, they would be homeless and abandoned.

Very little new accommodation is made available. This year’s allocation of funding for accommodation is dedicated to get 165 Strathmont residents into the community.

Even if the State Government would fund 300 new places each year in addition to the Strathmont project, the need would not be met. The need grows every year with new young people wanting to live independently.

It is questionable whether the new arrangements between Housing SA and Disability Services SA will improve the situation for these 2200 people on the waiting list. These people will not be able to live on their own. Some may have tried but have returned to their parents.

Each Options Coordination service has waiting lists, but even if the waiting lists were published as an indication of the extent of unmet need in this State, they would not provide a reliable indication of the full extent of unmet need.

Many people have given up asking. Many people with intellectual disabilities do not know how to ask, they have been on the list for many years, without needing any service. When they get in the situation where they would need a service, they often do not know how to ask.

Many carers have given up asking. Due to chronic underfunding of Day Care Options, lack of access to employment and respite, they may have organized their lives around the needs of the person with a disability without relying on services. We have spoken to several people who simply do not want anything to do with the Options system. Many of these people live in regional and remote areas where services are particularly scarce.

Unless a comprehensive unmet need analysis is undertaken, and adequate services are put in place, no amount of information and data sharing will improve the situation of people with disabilities waiting for a second shower per week, or a cushion for their wheelchair for eighteen months. During their ‘waiting time’ these people cannot access employment. They can hardly get out of bed, even though they may be highly employable.

Recommendation 3:

Disability Advocacy and Complaints Service of South Australia Inc. recommends that a thorough study is conducted by the Senate Community Affairs Committee about the true level of unmet needs for disability services, accommodation, respite services and day care programs, including for people with mental health problems.

Not only is there a lack of statistics about unmet needs, there is a lack of funding for services in all areas to meet ongoing needs.

Funding is approved by the Commonwealth Government and the States four years ahead, based on statistics which reflect the reality five years back. This makes a time gap of nine years. This is a gap, which is hard to fill.

Governments on all levels need to start planning for the future, based on statistics of today. The last accepted statistics of unmet need in Australia came from the Australian Institute of Health and was based on statistics collected in 1994. In 1998 they called for an additional $93 Million to address the existing unmet need. This call has never been responded to.

Recommendation 4:

Disability Advocacy and Complaints Service of South Australia Inc. recommends that following the results of the study about unmet needs, the Commonwealth and States agree to address the unmet need over the following four years, while increasing the ongoing service delivery to a level which will meet ongoing demand.

1.1 Whole of Government Approach to maximize participation

The bi-lateral agreement between the Commonwealth and South Australia identified a range of outcomes to be achieved during the latest CSTDA.

Whether progress has been made or not, the impact on most people with disabilities has not been significant. The full impact of the latest round of Welfare to Work has not yet come to pass. Our greatest fear is that those young people, no longer eligible for the DSP, yet living with a disability, will be removed from the eligibility list of the State for disability services as well.

This may lead to people with invisible disabilities not receiving the support they need to participate fully in the social and economic life of our nation. In particular people with intellectual disabilities and other mental incapacities will be hard hit.

In this context the cooperation between Centrelink and SA's disability services may have the opposite effect of the main objective of the CSTDA. It may significantly worsen the situation for some people with disabilities.

In regard to data collection, neither the Commonwealth Government nor South Australia have been able to publish statistics of the unmet need in the disability sector (see recommendations 3 and 4).

One of the positive outcomes of the Whole of Government approach is the work undertaken by Maurice Corcoran, who is a public servant employed by the Office of Disability and Client Services assisting all South Australian government departments to comply with disability access standards. This work has increased accessibility for people with disabilities to government services, websites and documents. There is still room for improvement but progress so far has removed barriers for people with disabilities.

Unfortunately many opportunities to work cooperatively with other departments to encourage inclusion of person with a disability in their consideration of service planning and delivery, as well as in regard to consumer representation, have been sadly missed.

Some lost opportunities are outlined in the following parts of our submission.

1.2 Access to generic services: Education

Despite extra funding for children with disabilities to the Education system, discrimination against children and young people with disabilities is still an issue in the Primary, Secondary, Tertiary and Vocational sector.

The Disability Advocacy and Complaints Service of South Australia Inc. regularly receives calls from desperate parents, whose children have been removed from class, locked into padded rooms for hours, are kept busy without learning, or are excluded from partaking in sport activities or from excursions. In addition, many children and young people report excessive bullying because they have a disability.

The Autism Association SA reported the results of a survey of parents with children with autism range disorders in 2005. The results showed that up to 80% of the students were regularly bullied at school. Children with autism will get very distressed and often develop behavior problems, which interfere with their ability to learn, and often that of other students as well.

Students at TAFE with hearing impairments still complain about the lack of access to AUSLAN interpreters. Other students with disabilities are discriminated against when they are placed in the field for work experience, or if they have special needs when it comes to assessment of their competency.

Overall access to TAFE has declined by 1.4%, according to the National Centre for Vocational Education Research (NCVER). Their Pocket Guide for 2005 shows an overall decline of 1.4 % of students with a disability in the 2003/04 year in comparison to the previous year. The overall participation rate is 5.7%. (NCVER Pocket Guide 2005, page 4, found at http://www.ncver.edu.au/statistics/vet/pocketgd/pocket05/pocketguide.pdf)

Important projects which may have led to an improvement, such as Bridging Pathways have been discontinued. The participation rate of people with disabilities has not markedly improved.

University students with psychiatric disabilities have made complaints against some South Australian universities. The disability liaison officers seem at times to be inexperienced and lack disability awareness. The participation rate of students with disabilities could certainly increase.

According to the Department for Education Science and Technology's own statistics there were 671 492 students enrolled at Higher Education institutes. Of these students 23871 had a disability. (Students 2003 Tables: Selected Higher Education Statistics, appendix 3: Equity Groups, found at http://www.dest.gov.au/NR/rdonlyres/245A689B-996A-4C1E-A577-972E7664F664/1004/appendices.xls#'App 3.2'!A1)

This means that 3.5% of all students have a disability, which shows that studying at a university may pose too many barriers for people with disabilities.

Flinders University must be recommended with a unique program for people with intellectual disabilities. The ‘Up the Hill’ program allows people with intellectual disabilities to participate in university life, visit lectures, and to learn about learning. Students are assisted and encouraged to participate in courses they are interested in.

1.3 Access to generic services: Health services

The South Australian Government undertook significant reforms to the health system since 2004. Despite input from disability advocacy groups, the new decision making structures have had some difficulties recognizing their duties in regard to including people with disabilities in their planning and decision making bodies, and in their consideration of delivery of health care to some people with disabilities.

People with intellectual disabilities have a similar health status as indigenous people. Women in wheelchairs still cannot be transferred onto examination tables, many private practitioners and allied health services such as chiropractors, do not provide wheelchair access. Private psychiatrists refuse to treat people with intellectual disabilities and paranoid schizophrenia. A leading scientist indicated that his cancer screening test does not need to be available to people with disabilities, as ‘they do not have a good quality of life and it would be a waste of resources’.

The South Australian Government has missed an important opportunity to address the needs of people with disabilities in the establishment of their reformed health system. Despite of input of advocacy groups it seemed to be all too hard to address some of the systemic issues pointed out to the Office of Health Reform. There is hope that in future the newly established consumer advisory groups will include people with disabilities who can further the cause of accessibility. Yet the onus is once again on people with disabilities to fight for inclusion.

1.4 Access to generic services: Transport

While South Australia was one of the first States to purchase an accessible bus fleet for its public transport system, the transport system has many time gaps and does not cover all areas.

The new trams are wheelchair accessible, but some of the tram and train stations are not very accessible.

There is a constant lack of access cabs and the taxi system is well known to cause a lot of problems and generate many complaints from people with disabilities. These range from clear discrimination to exploitation of people with intellectual disabilities.

Accessibility for people with limited capacities is limited, there is little understanding of the issues people with intellectual disabilities face when bus lines change, the buses change their displays too quickly, or when they fall asleep and wake up not knowing where they are.

1.5 Access to generic services: Legal system

Accessibility for people with disabilities to the legal system is often difficult and very stressful.

During the past year we assisted around 77 of 478 of our clients through processes which involved a variety of tribunals or Courts.

Our applications to the Human Rights and Equal Opportunity Commission on behalf of our clients were mostly successful, as our clients were able to conciliate in this stage. However, there were some cases where the respondent refused to mediate. In many of these cases the clients would have a very good chance to win their case in the Magistrate Court.

Unfortunately on four occasions our referral to the only disability discrimination legal service was refused on the grounds of conflict of interest. A charity which delivers a variety of services, including disability services, manages the Disability Discrimination Legal Centre as part of a Community Legal Centre. They employ one lawyer and another staff member.

When they refuse to take on a client, our previous work is rendered ineffective, as there are no other lawyers in South Australia who are willing to work pro bono or on a retainer on these cases. Justice has not been done. Two cases concerned employees or clients of the charity. The Disability Discrimination Legal Service is unable to act against their employer.

People with mental health problems and intellectual disabilities are able to access a diversionary court, which in cases of several of our clients were very helpful.

We worked for many people with mental health problems who were detained or under a Community Treatment Order and wanted to appeal their orders. Currently we are in the process of negotiating a Memorandum of Understanding with the Mental Health Services to establish a protocol for referral, access, and grievances of clients. However, we are powerless in getting services for people with mental health problems who are living in the community.

Many hospital submissions could be prevented if people with psychiatric disabilities were able to receive social work and home care services. This would also break the cycle of isolation, which does inhibit the recovery process. More funding must be made available to meet this huge unmet need, which may, if met, add up to 20% onto the currently existing Disability Services budget.

1.6 Access to generic services: Housing

This is one of the greatest problems in this State.

People still live in large institutions with similarly large stigmas attached. Many people with disabilities are forced to live in substandard Boarding Houses and Hostels. Although many residents enjoy the company of the other residents, and fear homelessness, and therefore choose to live in these places, they do not deserve to be exploited, harassed, imprisoned, nor starved.

Residents with Acquired Brain injuries in group homes have complained about being told which GP to attend, what to eat (although they pay for their food), and what clothes they can wear. Their phone calls were ‘supervised’, they were told who could be their friends and who could not, and they were forced to play pokies in a pub, or stay home alone at risk of suffering a seizure.

People with disabilities living in public housing experience isolation, harassment from neighbours, and often sheer fear of being assaulted and taunted. Many have no access to any other services, their flats decay, many feel too embarrassed to ask for help. These are the forgotten, but accommodated people with intellectual disabilities, for example, or recovering from mental health problems.

People with disabilities whose disabilities have worsened and require wheelchair accessible housing after an accident or an MS attack wait for up to eighteen months for wheelchair accessible accommodation. While Housing SA builds a considerable number of accessible new units and flats, they are often not well designed and pose serious problems for some people with disabilities. There should be far more consultation of people with disabilities in the planning of new accessible new homes.

2. Role of Disability Advisory Bodies

6 (7) The Commonwealth and the States/Territories acknowledge that the Disability Advisory Bodies of the Commonwealth and States/Territories will:
(a) provide a conduit for people with disabilities, their families, carers and other people with knowledge of, or experience in, matters relevant to the disability sector to provide advice regarding the planning, delivery and evaluation of services;
(b) advise their respective Ministers on progress against meeting the CSTDA objectives and priorities from the point of view of the disability sector;
(c) provide a mechanism for the provision of advice on directions for research and development under this Agreement to their jurisdictions;
(d) consult with the National Disability Advisory Council (NDAC) on matters of broader national significance that impact on people with disabilities, their families and carers.

The Disability Advisory Councils can perform a very important role if people with disabilities are appointed to serve, and if they are appropriately resourced.

One of our current advocates has served on the Disability Advisory Council over the last three years. Her experience is reflected in the following.

Members on the Disability Advisory Council have two to three hours monthly to meet and exchange their views, decide on actions, receive invitations to offer their views on issues raised by the Minister, listen to plans of the Disability Services Office, and report their findings resulting from consultations with people with disabilities. It is not possible to do the work outlined in the Commonwealth State Territory Disability Agreement in two hours monthly.

The level of experience and exposure to a variety of people with disabilities varies greatly among the members of the Disability Advisory Council. Hence there can be no expectation of the members to work intensively outside of Disability Advisory Council attendance times. Most members are either full time employed or parents of children or young people with disabilities.

Undertaking research or consultations with a wider group of people with disabilities and their families requires adequate resources. The members of the Disability Advisory Council were able to assist with one consultation undertaken by the Office of Disability in 2003/04. Since that time there have been no opportunities to actually reach out to people with disabilities and provide a conduit to the Minister.

Unless the Disability Advisory Council is better resourced, possibly with an Executive Officer from the Minister's Office, and funding to travel to country locations and consult throughout South Australia, the members will not be able to achieve what the Commonwealth State Territory Disability Agreement outlines.

It is important for the members of the Disability Advisory Council where funding and administrative support for the Disability Advisory Council is coming from. While in South Australia the cooperation between the Disability Advisory Council and the Office of Disability and Client Services has worked well, it also leads to a filtering of information through the department. The Executive Officer for the Disability Advisory Council is working in the Office of Disability and Client Services, but only for a few hours.

As the Minister is already continuously informed and advised by the head of his department, there is a problem when the information from the Disability Advisory Council is also taken to the Minister by the head of the department. It would be preferable to establish a line of communication which provides an independent alternative to the views of the head of his disability department.

Recommendation 5:
Disability Advocacy and Complaints Service of South Australia Inc. recommends that the Disability Advisory Council be appropriately resourced by the Minister's office, not by the Department for Disability Services, to fulfill the role assigned by the Commonwealth State Territory Disability Agreement.

b) the appropriateness or otherwise of current arrangements, including an analysis of levels of unmet needs and, in particular, the unmet need for accommodation services and support;

Unmet Need in Accommodation

All people with disabilities have great difficulties accessing independent living accommodation or supported residential facilities.

The waiting list for public housing is huge, only those at risk of becoming homeless, or being unable to live any longer in their current inaccessible accommodation, are eligible to be on the Category 1 waiting list. This means having to wait on average about 18 months.

There are few community housing options, in housing cooperatives or housing associations.

Supported accommodation in group homes is scarce, for people with intellectual disabilities around 20 places become available per year. 2200 are on the waiting list. Parents have taken the initiative and financed the building of a group home, and in partnership with the government other parents developed a model for a variety of accommodation in a regional centre.

These partnerships may indicate a future trend where the government uses resources provided by parents to ensure the future accommodation needs of their children with disabilities.

Where parents offer support in the building of accommodation the government must ensure adequate care packages for the long term. This will mean that already thinly stretched services will have to stretch even thinner. Before the accommodation was built, parents and family members used to care for the person with a disability, who is now living with others, who also need care. This care will have to be provided by the government.

The South Australian Government is currently reforming the disability and housing departments and we only hope that this reform may lead to increased accommodation for people with disabilities. Yet there will not be enough saved by simply rearranging the administration of the sector to address the immense unmet need in the accommodation area.

Public Private Partnerships may provide an increase in accommodation, once again, it needs to be accompanied by adequate funding for support services.

Finally, parents may be willing to rearrange their family home to provide a semi-attached more independent unit for their family member with a disability. With additional home support services many more people with disabilities may be able to lead a more independent and private life, while still being able to access family support when needed.

Units and flat arrangements also offer opportunities for independent living with one or two community carer families living among the units and providing care where needed. One could call it the caretaker model, where a carer/support person visits people with disabilities during the day where needed and provides services where needed.

Supported Residential Facilities such as Boarding Houses are often overcrowded and people with disabilities are at times exploited and their needs neglected. New standards for Supported Residential Facilities should limit the number of residents to the number of rooms available, so that residents do not have to share their room with another person.

Standards, such as the Disability Services Standard, should apply and be enforced to any accommodation supporting people with disabilities and mental health problems. This standards should apply over and above fair residential rights legislation and Supported Residential Facility standards outlined in the South Australian Supported Residential Facility Act.

South Australia has no Official or Community Visitors Program such as all other States in Australia. Disability Advocacy and Complaints Service of South Australia Inc. highly recommends that progress should be made speedily. Advocates have campaigned for such a program for longer than ten years. South Australian people with disabilities deserve the same right to have their human rights observed in their accommodation or in the institution they are forced to live in.

Unmet Needs Support Services

The Disability Advocacy and Complaints Service of South Australia Inc. is not in a position to ascertain how much unmet need exists in South Australia.

We have some indications from our clients. Of 389 clients Disability Advocacy and Complaints Service of South Australia Inc. represented over the last financial year, 130 clients had issues around unmet need. This included unmet needs for aids and equipment, personal care, independent living and access to disability services. This represents one third of our clients. Discrimination on the grounds of disability and all our clients' legal issues constitute another 28% of our clients' issues. The rest of the issues include issues in employment, education, transport, recreation and mainly physical access to services in the community (16%).

With a third of our clients waiting for a long time for services every human being has a right to access, such as daily showers, food, ability to access health and recreational services, we have tried to lobby for our clients collectively and individually, with very little success. We know that for every good outcome for one client another client looses services.

We have participated in several community consultations where clients have shared their shame and embarrassment to have to come to a meeting without having had a shower for three days. We have heard from clients who were asked to agree to have a catheter or a stoma inserted because there were not enough home care hours to take the client to the toilet during the day. These clients had nothing wrong with their digestive system, this proposal was made for the sake of saving money, and these procedures are not without risk to the clients.

The current Executive Officer of the Multiple Sclerosis Society explained to us that two social worker look after 1600 people with varying degrees of MS. Many have complex needs and sudden onsets of the disease can create a huge crisis in the lives of MS sufferers. Surely this case load is unmanageable, hence only those who are severely impaired by their MS receive services. In the meantime families break down because they are unable to care for their impaired and scared family member.

One of our clients is a single mum with two sons just entering puberty. This is a difficult for any family and it demands a strong mum, if she is a single mum. This mum is using a wheelchair, has no strength in her arms, and is fighting for her independence. She needs much more than assistance with cleaning the house and cooking for her children. She and her children need assistance with facing her illness, with developing positive and strong relationships, with establishing a balance between the role of the boys as carers and being boys. Very few people will have to face what the children will have to face with their mother’s downhill journey. How will this family be supported?

People with intellectual disabilities receive most of the funding of the Commonwealth State Territory Disability Agreement in South Australia. This is despite many people with intellectual disabilities living an independent and often very lonesome life.

The Disability Advocacy and Complaints Service of South Australia Inc. supports a group of people with intellectual disabilities who want to speak up about issues of concern to them, and who want to be involved in the planning and decision making of services delivered to other people with intellectual disabilities.

Many members of the OUR VOICE SA Committee grew up in institutions, several work in Business Services, and most live on their own. Some are quite capable of leading an independent live, others are less able to perform all the daily chores needed to look after a home and oneself. Several members receive no services at all, although they urgently need maybe six hours per week to maintain their homes and look after their own health.

While the unmet need list of the IDSC includes all clients of the IDSC on waiting lists for a variety of services, it does not include those who are deemed to be ok, but are not really coping. It does not include all those who have given up asking for services, and those who did not 'get on' with the local Options Coordinator. It does not include all those, parents and individuals, who do not want to disclose their family member's or their own disability for fear of discrimination.

Unmet Needs of People with Mental Health Problems

People with mental health problems have had almost no access to home care, respite or other community based services. The Mental Health system is administered and managed by the Health Department and the Minister for Health.

Over the last two years some innovative and very successful trials have been established in South Australia, in particular for residents of Supported Residential Facilities. Last year $2.5 Million were added to the disability services budget which will slightly increase over the next three years.

Considering the immense unmet need of people with mental health problems who live in isolated public housing accommodation, this is a beginning but the amount needs probably be increased tenfold to begin top address the needs of people with mental health problems.

Carers and Family Members versus People with Disabilities

Family members of children and adults with a disability certainly deserve to be consulted in all decisions concerning their family member with a disability. Where the capacity of the person with a disability is severely limited family members may be the only persons able to make decisions.

Family members and carers of people with disabilities certainly deserve recognition and some form of compensation for their service, which otherwise would be the responsibility of the government at much higher cost.

However, we have experienced many times that the interests of family members and carers opposed the interests of the person with a disability. Our model of advocacy demands that we ensure that we are not acting against the expressed wishes of the person with a disability mostly affected by our advocacy intervention. We will always speak and act on the expressed wishes of the person with a disability. We refer family members to Family Advocacy in cases where family members wish to access an advocacy agency, while we will represent the person with a disability and ensure that the expressed wishes of the person with a disability are heard.

Recommendation

Disability Advocacy and Complaints Service of South Australia Inc. recommends that the participation of people with disabilities in the decision making and evaluation processes of all service levels is supported by extra funding. All services must be enabled to encourage and assist all people with disabilities to participate in the planning and evaluation of their service provision. This is especially important for people with intellectual disabilities, who require a different kind of assistance than other people with disabilities may need.

Appropriateness of Current Arrangements

Our submission demonstrates that the current arrangements are not meeting the needs of people with disabilities in South Australia.

Yet we do not believe that the arrangement between the Commonwealth and States, and Territories ought to be changed.

If the Commonwealth were to solely fund and be accountable for disability services, there would still not be enough funding to bring services to a level where unmet need disappears to a manageable level. Housing would still be a State issue, cooperation between departments would become even rarer, and the blame shifting would still exist.

The State Government also does not enough money to provide appropriate levels of disability services. There may even be a risk of less funding if the State would solely be responsible for the funding of disability services.

While the current arrangement may seem to be cumbersome at times and distributes responsibility to both Commonwealth and States, it guarantees a better deal for people with disabilities. Both the Commonwealth and the States need to provide the resources needed by people with disabilities to live their life as part of the wider community.

Recommendation

Disability Advocacy and Complaints Service of South Australia Inc. recommends that the current arrangements between the Commonwealth and the States and Territories should be maintained, however, generally funding needs to be increased to meet the high levels of unmet need in all areas of disability service provision.

c) an examination of the ageing/disability interface with respect to health, aged care and other services, including the problems of jurisdictional overlap and inefficiency;

Transition – disability services should be able to access aged care funding, where they deliver services at home to over 65 year olds. Service providers should only change when circumstances no longer allow independent living, no different to able bodied people

Nursing homes need training in disability awareness, may have a lot of training in manual handling and dementia care, but not much training in accommodating people with intellectual disabilities. They are treated as if they have dementia. Yet they can still think and remember and want to be treated with respect.

We cannot make many comments on the interface.

d) an examination of alternative funding, jurisdiction and administrative arrangements, including relevant examples from overseas.

Family Care Packages
Self Determination and Pitfalls
Private Public Partnerships
Charity
For profit business

Information
People Power
http://www.peoplepower.org.au/POLICY%20PAPERS/DisabilityPolicyPaper.htm

People Power stands for

- ✓ **Person-centred arrangements** (services and institutions should be tailored to meet the personalized needs of people with disabilities and their families/carers - disability dollars should follow the consumer and be managed by the consumer's representative or agent.)
- ✓ **Empowerment of people with disabilities and their families** (resources and power should be transferred to people with disabilities and their families or agents, enabling them to grow in community, rather than isolation and powerlessness)
- ✓ **Choice** (individualised funding arrangements should become the norm as a funding method so people can choose the lives they want to build)
- ✓ **Inclusion of people across ability boundaries** (adequate supports and resources are needed to make social inclusion a meaningful reality)
- ✓ **Inclusion of families/carers** (where people with disabilities are not capable of unassisted self-management, families/carers or agents form the core unit of care and are integral to the support system)

People Power will

- Consolidate all existing commonwealth and state disability funding programs (with the exception of respite care) in a person-based funding entitlement (the **Disability Funding Entitlement**) allocated to the nominated agent or family of the person with a disability. The **Disability Agent** may be a community organization, a health fund, a consumer co-operative, a for-profit financial agent, a GP or lawyer, a parent, friend or family or any other entity which has a capacity to manage the financial entitlement, enter contractual arrangements on behalf of the person with a disability, and manage their support and care relationships to the satisfaction of the person they act for. Disability Agents would be permitted to contract with providers and practitioners in developing price and service quality arrangements and would be free to develop packages of care, innovations in care planning and information management, home-care supports, accommodation options and arrangements, and employment services for their people. People with a disability would be free to select their preferred agent, and to transfer from one to another annually.

- Ensure that the **Disability Funding Entitlement** (DFE) is adjusted by factors of age, sex, disability and health status, and life-cycle-stage in such a way that agents will compete to attract the support of people with all kinds and severities of disability.

- Ensure that every child or adult who is diagnosed with a disability is eligible for the Disability Funding Entitlement (DFE) from the time of diagnosis until death or until the disability has ceased to disable.

- Ensure that eligibility for the DFE includes disabilities which are currently not acknowledged or inadequately acknowledged including autism, ADD/ADHD, language disorders, learning deficits, and various neurological conditions.
- Introduce a **Respite Entitlement** assigned directly to family carers or their agents as a respite service voucher, adjusted with a severity-of-disability and difficulty-in-caring rating. The Respite Entitlement may be used to purchase in-home respite or center-based respite according to the preference of the carer.
- Support the establishment of an independent **Disability Support Information Service** to provide comparative online price and service quality data on Disability Agents, disability services, respite services, accommodation services, health services and practitioners.
- Establish waiting time benchmarks for core services, monitored by the independent Disability Support Information Service, and introduce legislation in Commonwealth and State jurisdictions assigning legal liability to the Commonwealth and States for breaches of the waiting time benchmarks. The benchmarks would include three weeks for early childhood assessments, six weeks for early childhood intervention programs, and three months for supported accommodation. Significant penalties would be attached to breaches of these benchmarks.
- Establish a **Supported Accommodation Authority** to research, design, purchase, and build innovative supported accommodation options covering a range of living and support preferences for people with disabilities (as well as people with mental and chronic illness, and the frail aged). Commonwealth and State funds would be directed to this billion dollar national Authority.
- Cut the company tax rate from 30% to 20% for businesses which employ people with disabilities and other disadvantages as 20% or more of their workforce.
- Require state governments to transfer management of accommodation facilities to non-government entities (foundations, community organizations, consumer entities) so as to remove services from direct government control.
- Intervene to alleviate the immediate unmet demand for crisis and supported out-of-home accommodation options for the 600,000 families caring for people with severe and profound disabilities aged less than 65 years. These options should reflect a variety of preferences in living and support arrangements including group homes, hostels, village living, cluster apartments and other such arrangements as suit the individuals concerned.
- Introduce assistance for families of children with a severe physical disability to purchase or lease a modified vehicle.