SOUTH AUSTRALIAN COUNCIL
ON
INTELLECTUAL DISABILITY

SUBMISSION
TO THE
SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE

INQUIRY INTO THE FUNDING AND OPERATION OF THE COMMONWEALTH STATE/TERRITORY DISABILITY AGREEMENT

August 2006

The SOUTH AUSTRALIAN COUNCIL ON INTELLECTUAL DISABILITY'S mission is to work towards achieving a South Australian community in which people with an intellectual disability are involved and accepted as equal participating members.

SACID is the South Australian representative on the National Council on Intellectual Disability.

The Council works at both the State and/or National level and has a single focus on the issues of key importance to people with an intellectual disability, their families and advocates.

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1. Introduction

The current and former CSTDA’s are agreement’s between THE COMMONWEALTH OF AUSTRALIA and THE STATES AND TERRITORIES OF AUSTRALIA in relation to Disability Services which encompass the Principles and Objectives outlined in the

- Disability Services Act 1986 (Commonwealth),Commonwealth dsa1986213.pdf
- Disability Discrimination Act 1992 (Commonwealth) Disability Descrimination Act 1992.pdf
- State and Territory legislation. SA Disability Services Act 1993.pdf
- The rights of people with disabilities under the United Nations Declaration of Rights of Disabled Persons Declaration on the Rights of Disabled Persons Proclaimed by General Assembly resolution 3447 (XXX) of 9 December 1975.pdf

2. The intent of a CSTDA

Intrinsic in each of the documents cited on the previous page are the requirements that providers of disability services must apply the principles and meet the objectives set out in the schedules of those acts

The CSTDA's were established as a formal process of a co-ordinated and national framework for the provisions of disability services.

The agreement states that:

"The Commonwealth and the States/Territories agree on the following objective to underpin the national framework for services for people with disabilities –

- **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.**"

The Agreement also states that "it seeks to respond to **individual needs** as they vary across stages and areas of life", and is made even more clear in **PART 4 – NATIONAL FRAMEWORK.**

3. SCOPE OF SACID'S SUBMISSION

- 3.1. UNMET NEED
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3.1. UNMET NEED

None of that which is written about in the following pages can be achieved unless the extraordinarily high levels of unmet need are not addressed.

Unless this CSTDA demands that the states aggressively attack the matter of unmet need, the notion of satisfactory outcomes for consumers and their family carers will never be addressed.

In the preamble of the current CSDTA it is stated:
Commonwealth, State and Territory Governments have agreed on the incremental implementation of five strategic policy priorities.

The 4th policy priority is:
4. **improve long-term strategies to respond to and manage demand for specialist disability services;**

Given the parlous circumstance which surrounds many people who have disabilities who have not had their needs met, identification of the current positions of all governments with regard to "incremental implementation" of this particular policy priority would be very useful.

With regard to "unmet need for accommodation services and support" it must be remembered that in PART 3 of the agreement – INTERPRETATION it is stated:

"accommodation support services" means services which provide
accommodation to people with disabilities, and services which provide
the support needed to **enable a person with a disability to remain in their
existing accommodation;**

"community support services" means services which provide the support
needed for a person with a disability to **live in a non institutional setting;**

This does NOT mean recreating institutional type accommodation in the form of many group homes or congregate living. This means an "ordinary life in an ordinary home in and ordinary street in an ordinary local community"

Over the past few years it has been noted that there has been an "incremental" move **BACK** to "all in together" residential arrangements. Once again going against the principles of all of this country's various disability acts and those of the Self Determination movement.

PEOPLE WHO HAVE DISABILITIES HAVE THE SAME RIGHT AS EVERY OTHER AUSTRALIAN CITIZEN TO HAVE SOVEREIGNTY OVER HOW THEY LIVE THEIR LIVES.

3.2 FAILURE OF PREVIOUS CSDTA'S TO DELIVER SATISFACTORY OUTCOMES TO CONSUMERS AND THEIR FAMILY CARERS.

Currently there is little opportunity for people who have disability to have their support funding in the form of:

3.2.1 INDIVIDUAL FUNDING PACKAGES

In addition to the high levels of unmet need the CSDTA's have also **failed to deliver satisfactory outcome**s to consumers who have managed to secure CSTDA funding for their supports and services.

The unavailability of suitable levels of individual funding has negated the ability of many consumers to have their supports and services delivered based on the principles of self determination as alluded to in the principles and objects all of this country's Disability Services Acts and the CSTDA.

In the second instance there is little evidence that consumers have been offered the opportunity for **individually funded supports and services** - see AIHW report below.
Individual Budgets are intended to:

- *allocate resources transparently, giving individuals a clear cash or notional sum for them to use on their*
- *care or support package*
- *streamline the assessment process across agencies, meaning less time spent giving information*
- *bring together a variety of streams of support and/or funding, from more than one agency.*
- *give individuals the ability to use the budget in a way that best suits their own particular requirements*
- *allow support from a broker or advocate, family or friends, as the individual desires*
- *be delivered within local authorities' existing resource envelope.*

Individuals and their family carers frequently report that they have NEVER been offered such a choice and lay the blame firmly with their particular service providers. More now than ever there appears to be a mentality of power and control over consumers by many service providers (who are entrusted with assisting people who have a disability), as they seem hell bent on NOT providing those services that "make s most sense" to the consumer/family carers.

Currently there is little opportunity for people who have disability to have their support funding attached specifically to them to enable:

3.2.2 PORTABILITY OF FUNDING

That CSTDA funding is not allowed to be used across borders is also another obstruction that consumers/family carers have to deal with.

On the National Disability Administrators website http://www.nda.gov.au/ it states: "*States and Territories have agreed to facilitate access into their service system based on relative priority of need."* What exactly does this mean???? http://www.nda.gov.au/1/2088/64/portability_of_.pm

As cross border transfer due to employment, education, family support etc., becomes more and more a reality for individuals and families, the fact that a person, who is already in receipt of disability supports and services funding, cannot take that funding with them creates a situation that in effect makes them **prisoner of the state in which their funding emanates.**

If a person who has a disability or their family carers need/wish to move to another state or in some cases even a local jurisdiction they must forgo their (usually hard fought for), current funding and go to the bottom of any “list” wherever they choose/need to live. Or wait until they have everything “arranged” before they move. Sort of defeats the purpose, I think. There is no room for “serendipity” about how/where/when and with whom a consumer/family carer may wish to live or work.

3.2.3 DIFFERENTIATION FROM STATE TO STATE

In the recitals of the current CSTDA it states:
(f) provide for a nationally consistent approach to quality across specialist disability services (clause 9)

There seems to be no common ground from state to state with regard to the sorts of supports and services that people who have a disability and their family carers are able to access. There is no conformity of the way in which the states provide supports and services.

Given the ease of communication and travel in the 21st century it would seem sensible to have **ONE** federally operated system so that all Australian citizens who have a disability have their supports and service delivered in a way that is transparent and reduces the confusion that is current to date.

3.3 A NEW WAY OF RECEIVING SUPPORTS AND SERVICES.

"This Agreement promotes the development of innovative solutions to address the broad scope and range of supports and services needed in order to create conditions where people with disabilities and their families and carers thrive, and their opportunities are enhanced. This includes recognising and supporting leadership at the community level "

One of the CSTDA Policy Priorities is that it will:

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.***

To date this policy priority has not been met. To satisfactorily achieve this particular policy priority it is essential that all consumers are offered the opportunity to have their assessed and allocated amount of funding as an **Individual Budget** in the form of a **Direct Payment** as their **FIRST** choice of how they wish to purchase supports and services.

The Australian Institute of Health and Welfare at http://www.aihw.gov.au/publications/dis/dss03-04/dss03-04.pdf **Disability support services 2003–04 National data on services provided under the Commonwealth State/Territory Disability Agreement - August 2005** ***Part 3.7 Individualised funding:*** it is reported that only 31,193 CSTDA funded service users **(17%)** reported that they received **individualised** funding. **Hardly an overwhelming figure.**

Self Determination, using Direct Payments of an Individualised Budget for people who have disability **should be the major focus** of any future disability supports and services agreement. Whether this be administered and funded through a CSTDA or some different model of support needs to be canvassed by **wide consultation with people who have disability and their family carers**

In a report of the **Human Rights of Disability for the Office of the High Commissioner for Human Rights** http://www.unhchr.ch/disability/index.htm it is identified that there are:

"Four core values of human rights law are of particular importance in the context of disability:

- the ***dignity* of each individual**, who is deemed to be of inestimable value because of his/her inherent self-worth, and not because s/he is economically or otherwise "useful";
- **the concept of *autonomy* or self-determination, which is based on the presumption of a capacity for self-directed action and behaviour, and requires that the person be placed at the centre of all decisions affecting him/her;**
- **the inherent *equality* of all** regardless of difference;
- **and the ethic of *solidarity***, which requires society to sustain the **freedom of the person with appropriate social supports.**

In the US the Center for Self Determination http://www.self-determination.com stated in The Declaration of Freedom, Center for Self-Determination July 4, 2000,

"that all individuals with disabilities, including those with cognitive and other significant disabilities, should receive necessary supports to live meaningful lives in our communities through the Principles of Self-Determination"

The Principles of Self Determination for people who have a disability are:

- **Freedom to choose** where and with whom they will live as well as what important things they will do with their lives;
- **Authority** over a targeted amount of dollars **sufficient to provide necessary supports**;
- **Support that is individually designed** to meet the unique needs of the individual with a disability and **support** from **freely chosen family and friends** in obtaining and monitoring this support;
- **Responsibility** for the wise use of public dollars and for exercising the benefits of citizenship

Despite this, in Australia many consumers and their family carers are still struggling to receive even the most basic of supports and service and have no certainty that they will ever have the opportunity to have,

- an appropriate needs assessment or the opportunity to have
- an individually funded and adequate allocation by way of a direct payments to meet those needs as their first choice

Currently in most states the only support or service that an individual is offered **usually due the high level of unmet need is what a service provider thinks a particular individual can have**…which are usually far removed from the principles of Self Determination which is the essence the principles and objects of all of the above mentioned acts

3.4 EXAMPLES FROM OTHER COUNTRIES WHICH PROVIDE INDIVIDUAL SUPPORTS AND SERVICES.

3.4.1 IN THE UNITED KINGDOM

Community Care (Direct Payments) Act 1996
http://www.opsi.gov.uk/acts/acts1996/1996030.htm made it **mandatory** to **offer** individuals who have a disability and their family carers as their “first choice”, the opportunity to have their assessed and allocated support funding paid directly to their designated bank account in the form of **Direct Payments**. If they choose to do this they can also be supported to learn how to become self managers of their allocated funding.

All policies and Guidance with regard to this act can be found at
http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/FinanceAndPlanning/DirectPayments/fs/en

Direct Payments has been in operation since 1996 with the main take up being by people who have physical disabilities. Because of the low take up rate from those who have an intellectual disability it was thought that a separate document needed to be written because of the different kind of assistance and support that they need in order to become equal citizens

Because my particular interest is for people who have an intellectual disability and their family carers I have chosen to use **Valuing People**, the UK Government’s White Paper and **vision for the lives of people with learning disabilities** which came out in March 2001. It was the first white paper written for UK individuals with learning (intellectual) disabilities, for 30 years.

Valuing People is the UK governments plan for making the lives of people with learning disabilities and their families better. It is based on people having:

- their rights as citizens
- inclusion in local communities
- choice in daily life
- real chances to be independent

It was written following wide consultation with people with learning disabilities, family carers, and people who work in services or other organisations for people with learning disabilities. An “easy read” version is also available.

Valuing People and all relevant reports can be found at this site:
http://valuingpeople.gov.uk/index.jsp

Review of the Valuing People programme

In 2004 the UK government requested that a report be written to evaluate how the Valuing People programme was going. The person who wrote the report was is Rob Greig from the Valuing People support team. **The report can be found on the above VP website under Valuing People Review.**

The minister who requested the review sates in his foreword to the report that:
“Experience so far suggests that this strategy, with its emphasis on independence, choice, inclusion and civil rights is standing the test of time”.

He goes on to say that the framework should continue to deliver improvements for people who have learning disabilities and their families for many years. He further continues: “Valuing People has been **groundbreaking in its insistence on putting people with learning disabilities and their family carers at the centre** of the picture. As this report shows, up and down the country people with learning disabilities increasingly have a say in the shape of their lives. More and more they are getting the chances to have the same everyday choices as everybody else.”

Rob Greig the author of the report also identifies that **not everyone** in the UK getting the benefit of the changes and states that there is still a long way to go before everyone who has a learning disability has the opportunity of choosing the new way of getting supports and services.

He also say’s **“Put bluntly, <u>too many people in public services</u> see Valuing People as being ‘optional’ – something they can get away with <u>not</u> doing”**. He goes on to say that what must occur over the next 5 years is that: ”everyone takes the lives of people who have a learning disability **more seriously** “ even though government policy and the law says that this must occur NOW.

It should be obvious by now that this is not an easily achievable objective and that it takes time, effort willingness and acceptance that this is a pathway to equal opportunity that is every person’s right.

IT IS THE SAME FOR PEOPLE WHO LIVE IN AUSTRALIA!!

3.4.2 inControl

http://www.in-control.org.uk

inControl is an individual budget pilot programme and is an important part of the government's agenda to give people who use public services more choice and control. It has been developed to assist people who have a disability to learn how to use their Direct Payments as per above. It enables people be in control over their support - and their live. This particular programme offers a whole system – with policies and procedures for resource allocation, support planning, supported decision making etc. I would urge you to read the “stories” section to get a good idea of just what “incontrol” means for people who have a disability.

http://individualbudgets.csip.org.uk/index.jsp
http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/SocialCare/SocialCareArticle/fs/en?CONTENT_ID=4125774&chk=/Ubh1q

A REPORT ON THE INCONTROL PILOT will be published in the English Summer of 2006. Below is the link to summary of the quantitative data gathered in ‘before and after’ questionnaires.
http://www.in-control.org.uk/downloads/0101_Evaluation_data.ppt

IN THE US

3.4.2.1 CASH AND COUNSELING

In the United States there are many states now practicing Cash and Counseling.
www.cashandcounseling.org

Cash and Counseling is an expanded model of consumer-directed supportive services. It provides a flexible monthly allowance (based on the consumer's care plan or on claims history) that consumers can use to hire their choice of workers, including family members, and to purchase other goods and services to meet community support needs.

It is a flexible individualized budget that the participant may spend on services that assist the individual to meet his/her community support needs and enhance his/her ability to live in the community.

Cash and Counseling requires that consumers develop participant-centred-planning to ensure that the participant is making personal choices for the spending of the budget based on his or her own goals and to meet their needs for supportive services.

It also provides counseling and fiscal assistance and a system of support to assist the participant in developing and managing his/her spending plan; fulfill the responsibilities of an employer, including managing payroll for workers he/she hires directly; and obtain and pay for other services and goods.

Consumers who are unable or unwilling to manage their allowance and responsibilities themselves can designate a representative, such as a family member, to help them or do it for them.

Cash & Counseling obtains feedback from participants, representatives, and family members (when appropriate) as well as data from support service providers to continuously improve the program.

These features make Cash and Counseling adaptable to consumers of all ages and with all types of impairments.

> Following a "demonstration" program, and extensive review it has been decided that due to the success of the Original Demonstration, http://www.independentchoices.com funders have granted an expansion of the Cash & Counseling program. Following the success of the original States:

Arkansas
Florida
New Jersey
the following states are now using the programme.
Alabama
Illinois
Iowa
Kentucky
Michigan
Minnesota
New Mexico
Pennsylvania
Rhode Island
Vermont
Washington
West Virginia

The vision guiding this expansion is the promise of **"a nation where every state will allow and even promote a participant-directed individualized budget option for Medicaid-funded personal assistance services**

I draw your attention to the IndependantChoices "Stories" and Manuals for further information about this model

2003 review of Cash And Counselling- Arkansas. N.J. Florida; http://aspe.hhs.gov/daltcp/reports/cclesson.pdf
On pg 43 it is identified that:

The experience of the three programs shows that Cash and Counseling can be successfully implemented with elderly adults, non elderly adults with physical disabilities, and children and adults with developmental disabilities.

With help from representatives, counselors, and fiscal agents, almost all consumers who were interested in receiving the allowance and able to hire workers learned to manage their own supportive services.

Abuse of the allowance was almost nonexistent. While a very few cases of possible exploitation of the consumer were identified, these were resolved without incident, often before the consumer received the first allowance.

Nearly all consumers appear to have been well satisfied with the Cash and Counseling program. At this writing, more than three-quarters of those who received the allowance in Arkansas (the only state for which complete data are available on consumer satisfaction) said that it had improved the quality of their lives (Schore and Phillips 2002).

The percentage was roughly the same or higher for early cohorts of consumers in Florida and New Jersey.18 Moreover, in Arkansas, disability-related health outcomes (such as the incidence of decubiti) for treatment group members were at least as good as those for control group members, and treatment group members were less likely to report unmet need and more likely to report satisfaction with their supportive services (Foster et al. 2003).

People who have disabilities are now being supported by the US government to have greater control over the way in which they receive their funding. The use of the Medicaid waiver has had a beneficial effect for people who qualify for government funding for their supports and services.

The Center for Self Determination (p.11) is working across the whole of the United States, with people who have a disability to use the Medicaid waiver to support them in their bid for control over their lives by using the Principles of Self Determination as they self direct their support dollars.

3.5. ACCOUNTABILITY OF STATES TO CONSUMERS AND FAMILY CARERS IN THE DELIVERY OF INDIVIDUALLY FUNDED SUPPORTS AND SERVICES

There is currently **no system** that **monitors**, **reports** and **requires accountability** *of the states* to people who have a disability with regard to how they provides supports and services using the principles in any of the Disability Acts, there is no system available to consumers that ensures that every person who has a disability can have input into how they perceive the **outcomes** of their funded supports and services.

It is essential that a system be developed that enables consumers to report to government about the positive and negatives of how they receives the supports that they require to have an "ordinary life" in whatever way **makes the most sense to them** and their family carers

3.5.1 LACK OF CONSULTATION WITH CONSUMERS AND THEIR FAMILY CARERS

Also written in the preamble of the current agreement is that "continuing collaboration and partnership with individuals, families, carers, community agencies, service providers, advisory and advocacy bodies and local government is **essential** to the achievement of these outcomes.

While acknowledging that this is **essential** to the achievements of satisfactory outcomes for all, it must also be said that this requirement is not met by most governments in a satisfactory way for those for whom the agreement was designed.

There has been little effort made by the states over the past few years with regard to consultation and participation of and with consumers. Only when matters have been bought to a head by families using public meetings and rallies has any form of consultation occurred with regard to any of the above. In fact this senate enquiry has been brought about by the actions of some very unhappy family carers

It is clearly stated in all Disability Services acts and the Disability Discrimination act that **BEFORE** any major changes to the way in which disability services are to be delivered in this state **consultation with consumers and their family carers must take place**. This must be made a MANDATORY requirement of any state or federal government should there be a desire to make such changes.

As things stand to date and for the past few years **this has not occurred.**

3.5.2 QUALITY STANDARDS

The Agreement states that the Commonwealth and the States/Territories agree that:

*(a) the **core quality standards** applicable to all services receiving funding under this Agreement **shall be the National Standards;***

*(b) **nothing in this section shall limit their capacity** to require services for which they are responsible for administering under this Agreement **to adhere to quality standards and requirements over and above the National Standards**;*

*(c) **they will work towards continuous improvement** in services provided under this Agreement and **in quality assurance processes and systems including service review processes;***

While there are processes in place for monitoring and reviewing the Commonwealth's responsibilities i.e., The Auditor-General Audit Report No.14 2005–06 Performance Audit of the Administration of the Commonwealth StateTerritory Disability Agreement, there is nothing in place which requires the States to be monitored and reviewed in the same way.

In particular there is NO mandated requirement of state or federal governments with regard to reporting of abuse, neglect or failure to comply with regard to how services and standards are delivered people who have a disability.

This particularly refers to people who have profound, severe and multiple disabilities or who have an intellectual disability. In many instances these people are unable to make use of the various abuse hot lines or complaints processes that are currently available. Unlike individuals who have sufficient language and discernment skills many of the above mentioned group cannot avail themselves of this course of action.

There needs to be an independent agency which has the authority to receive reports, be reported to with regard to how reportable offences are dealt with and the outcomes of the investigation.

It is essential that something similar to the **Commission for Social Care Inspection (CSCI),** http://www.csci.org.uk/ which registers, inspects and reports on social care services in England.

The Commission was launched in April 2004, and is the single, independent inspectorate for all social care services in England.

The Commission was created by the Health and Social Care (Community Health and Standards) Act 2003. it's creation was a significant milestone in social care in the UK and it has a much

The Commission has much greater powers than its predecessor organisations.

The inspection, regulation and review of all social care services is now in one central point with total overview of the whole social care industry, which has the advantage of greater effectiveness and seamless system.

CSSI has four key aims **that they use to guide them in all their work:**

- **Put the people who use social care first**
- **Improve services and stamp out bad practice**
- **Be an expert voice on social care**
- **Practice what we preach in our own organisation**

5. RECOMMENDATION

THAT A COMPLETE REVIEW OF THE CSTDA IS UNDERTAKEN, WITH FULL CONSULTATON AND PARTICIPATION OF PEOPLE WHO HAVE DISAB ILITIES AND THEIR FAMILY CARERS.

Many people who have a disability and their family carers are of the opinion that the Commonwealth should take over all of the disability funding for support and services and develop a totally new and consistent way in which supports ands services are delivered throughout Australia