Productivity Commission Inquiry Into A National Disability Long-Term Care And Support Scheme

SA Council on Intellectual Disability Submission

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The SA Council on Intellectual Disability is an incorporated organisation with an elected board of directors and office bearers. Since the early 1950's when children with intellectual disability in South Australia, were still excluded or marginalised by not being able to attend school. Following the formation and persistence of the parent led Mentally Retarded Children's Society the long awaited special school was opened in 1954.

Over time this organisation was replaced by SACID with the mission statement being **Working towards achieving a South Australian community in which people with intellectual disability are involved and accepted as equal participating members.** SACID's first constitution of SACID was registered with the Office of Business and Consumer Affairs in 1992 and updated in 2007 SACID Const April 2007 final.pdf

Currently there are 11 elected Directors on the SACID board which is made up of self advocates, (persons with intellectual disability), parents and family members, representatives of disability organisations, academia, professionals and the general community.

SACID is the South Australian agency with membership on the National Council on Intellectual Disability and as such has significant input at that national level in to the development of the practises, policy, and position statements of NCID.

SACID at all times invites comment from our 250-300 members and via our extensive email correspondence list which number around 1,200 addresses.

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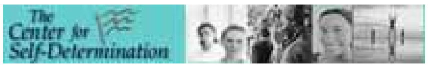
A **NATIONAL DISABILITY INSURANCE SCHEME should** not be just for people with severe and profound disabilities. Some people with intellectual disability may not need intensive support all the time but due to sometimes unpredictable or episodic inability to maintain full functioning there will be an ongoing need for monitoring, assistance and support during these times.

Examine a range of options and approaches, including international examples, for the provision of long-term care and support for people with severe or profound disability.

SELF DETERMINATION AND SOVEREIGNTY Principles of Self Determination.pdf over their lives is essential for people with disability using the where appropriate, their families. Control choice and flexibility over and responsibility for their individual funding allocation.

See Centre for Self Determination, (CSD)



http://www.centerforself-determination.com/index.html

ANY PROCESS MUST BE PROTECTED BY LEGISLATION at a federal level similar to the UK model, **Community Care (Direct Payments) Act 1996** UK Direct Payments Act 1996.pdf using the UN Convention on the Rights for Persons with Disability (UNCPD) as the overarching document**.** There is other relevant documentation available, which can be supplied if required.

Who should be eligible?

Persons born with or having acquired a non compensable disability aged before 65. Claim on the scheme would be initiated once a diagnosis had been made by qualified medical practitioners.

How should a person's needs be assessed?

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Using a self assessment process, similar to the Resource Allocation System, (RAS) RAS with Indicative Amounts.pdf which is needs based, as in the in Control® model in the UK. http://www.in-control.org.uk

TRANSPARENCY over individually allocated funding is assured by using a points system (as can be seen in the RAS document above), which matches the level of need to an amount of dollars. This must be is a rights, not welfare based model of support. No more begging bowl, cap in hand, bare our souls, mentality.

Who makes the decisions?

INDIVIDUALS AND/OR THEIR FAMILY where appropriate, in the form of an entitlement which then goes into that individual's/family's specific bank account as a Direct Payment, (see UK Direct Payments Act 1996), to be used by the individual or their family on their behalf, if they are unable to do this themselves, **to purchase supports and services which "make most sense to them"** in support of their disability. Acquittal should be uncomplicated in the form of receipts or brief explanation to be collected on a regular basis by the NDIS agency.

SUCCESS STORIES -

UK in Control: http://www.incontrol.org.uk/site/INCO/Templates/GeneralChild.aspx?pageid=429&cc=GB

Danielle and Amy's Story Butterfly Story-Bk Grnd.pdf

US Cash and Counselling participants are able to do this can be seen in
Myra Turners story at: http://www.cashandcounseling.org/success/myra_turner
and Grace Wall's story at: http://www.cashandcounseling.org/success/grace_wall

More Stories at: http://www.cashandcounseling.org/success/index_html

EXAMPLES OF SELF DETERMINATION/SELF MANAGEMENT

7 steps to being in control - inControl
http://www.in-control.org.uk/site/INCO/Templates/General.aspx?pageid=38&cc=GB

5. Organising my support

I can choose how I get my support.

6. Living life

My life's changed – I'm in control.

7. Seeing how it worked

It's gone well. Let's talk about what's next.

1. My money – finding out how much

So it looks like I can get £15,000.

2. Making my plan

Who else can we get to help us do this plan?

3. Getting my plan agreed

Yes – it looks like a good plan.

4. Organising my money

I'm opening a bank account for my support money.

IN THE UNITED STATES the Cash And Counselling Programme Is another model of self determination/self management which has had successful outcomes for people with disability and the aged, http://www.cashandcounseling.org/

This programme has developed a handbook for participants
http://www.cashandcounseling.org/resources/handbook
For an overview of Self Direction Ctrl+Click **http://www.cashandcounseling.org/about/index_html**

National Resource Center for Participant-Directed Services - Boston College
http://www.bc.edu/schools/gssw/nrcpds/

Research and Evaluation Reports
inControl UK

- Your Support Your way – Richmond upon Thames report
- Finding our way Barnsley report
- Self-Directed Support in Hartlepool 2006-2009
- Way Ahead – North Lanarkshire
- Steering my own course Cambridgeshire report
- Doing it your way Worcesteshire report
- This time it's personal Northamptonshire report
- It's Your Life - take control Hertfordshire report
- My Budget My Choice City of London report

Cash & Counseling

Implementing Self-Direction Programs with Flexible Individual Budgets: Lessons Learned from the Cash & Counseling Replication States

Cash and Counselling ReplicationReport_fin

What Impact Does The Ability To Purchase Goods And Services Have On Participants In Cash & Counseling Programs? Click the link below to access the page.
http://www.cashandcounseling.org/resources/20090325-145632/index_html

More evaluations from website www.cashandcounseling.org,.

RECIPIENTS MUST BE SUPPORTED AND ENABLED TO BECOME EMPLOYERS OR HIRE WORKERS AS CONTRACTORS, IF THAT IS THEIR CHOICE.

RECIPIENTS CAN CHOOSE TO FULLY MANAGE THEIR DIRECT PAYMENTS OR TO HAVE AS LITTLE OR AS MUCH FACILITATION ASSISTANCE AS THEY REQUIRE TO DO SO

RECIPIENTS MUST HAVE CHOICE OVER WHERE AND FROM WHOM THEY CAN SEEK FACILITATION ASSISTANCE.

This should not be seen as the next “Golden Goose” for the operators of agencies. This should NOT be seen as further opportunity for these agencies to **“make a fine living from our misfortunes”.**

People with disability and where appropriate their families have, often because of the poverty many of them experience, had to manage their lives in the most economical and efficient way in order to “get the best bang for their disability income support dollar”. There is no reason why they wouldn’t equally be able to self manage their supports and services allocation in a similar fashion.

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PRINCIPAL FAMILY CARERS OF FAMILY MEMBERS WITH PROFOUND SEVERE AND MULTIPLE DISABILITIES, in particular sole family carers who currently have as their ONLY income the Carer Payment must be able to access from the allocation a decent income for the work which they perform in the care of their family member, thus removing the poverty of this group in particular. (See Carers Aust 2006 research on Sole parent Carers). Sole Parent Carers.pdf and the stories from inControl and Cash and Counselling

The current shortage of competent and committed support workers often adds to the pressure and stress of all parties and in particular families who rely on paid assistance. When this is not forthcoming, the result is often that the family carer, particularly the sole parent carer who is usually a mother, is unable to maintain employment a consequence of which is that they are forced to become reliant on the inadequate Centrelink payments.

Access to payment from the allocation of funding should be a “choice” available to them. Why should others who are strangers be able to “make a fine living out of our misfortunes” when family are better able and willing to provide the support themselves? See again stories from UK and US

Consider costs and financing of any proposed scheme,

ANY SCHEME SHOULD BE FUNDED IN A SIMILAR WAY TO MEDICARE. Will leave it to the number crunchers to work this out.

POSSIBILITY OF MINIMAL ADMINISTRATION COSTS DUE TO SELF MANAGEMENT OF DIRECT PAYMENTS

HOW AND WHERE PEOPLE USE FUNDING TO LIVE.

Article 19: Living independently and being included in the community. The UN Convention on the Rights of Persons with Disabilities.

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

(a) *Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;*

(b) *Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to **prevent isolation or segregation from the community;***

(c) *Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.*

Malevolent criticism is often directed at those of us, who through long term and personal experience of awful institutionalised arrangements, continue to advocate for the closure of institutions and village/ congregate living arrangements for adults with intellectual disability.

If those of us who have been cited by some as crusty academics, ideologues, “misguided and behind the times” parents or family members (with a right based focus on what make a “good life” for their daughters or sons), had sat on our hands and allowed the status quo to remain, people would still be in the back wards of “institutes for mentally defectives”. They would still be living in those terrible circumstances. Some examples of which can be seen at…
Parallels in Time: A History of Developmental Disabilities: http://www.mnddc.org/parallels/
Parallels in Time II: 1950-2005 http://www.mnddc.org/parallels2/index.htm

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Money should not ever again be used for large institutional/congregate living arrangements. It should be used to enhance an individual's capacity to participate and be included in everyday life the same as most other citizens of Australia.

Dignity, safety, security, quality of life, using quality assured support must always be intrinsic within the considerations of those who provide such services.

PEOPLE WITH INTELLECTUAL DISABILITY

Most funded accommodation for people with disability is for those with intellectual disability. People with physical disability and brain injury will not usually choose to live in congregate arrangements and often speak out LOUDLY against such notions. Unfortunately people with intellectual disability are not usually asked and the decision about where they live is often made without them.

"Someone" makes that decision for them. These "someone's" might be family or government often in the mistaken and with all good intentions by many, notion that this is acceptable and appropriate. In other words "good enough".

These decisions might result in them living in an institution—yes they are still operating in this country in the 21st century much to our shame or in other arrangements such as larger group homes—up to 20 persons on the one site. Most of us who DO NOT have intellectual disability would never dream of living for almost the "whole of our life" in such circumstances. The exception being as a student/young adult in their "time of life"/early years or as an aged person in their "time of life"/end years.

Why is this good enough? Why it that our daughters and sons are not deemed important enough to be supported to live in an ordinary house in an ordinary street in an ordinary suburb with really well paid and educated workers to support them?

Having such an arrangement has the capacity to support the making and maintaining of their connection with their neighbours and to take their place in the community of their street and suburb. At the same time enables that community can get to know them as individuals in their own right and not as one of, "those people who live there!!"

Tom Nerney (Director-Centre for Self Determination) writes about Lost Lives Lost Lives Paucity of Quality in Human Serv—he talks about the *"unspoken "bargain" made with many individuals who need support is to require all or most of their everyday freedoms to be surrendered in return for support"* and also says *"can we ever have quality in a system that does not support freedom?"*

Tom's assertions that quality assurance systems in US have guidelines which are more directed at system requirements and not personal quality of life apply equally in Australia. Guidelines which are developed to ensure compliance of funded organisations often do little to support a life the way in which an individual might want to live

Professor Jim Mansell is Professor of Learning Disability in the Tizard Centre at the University of Kent, England and Adjunct Professor in the School of Social Work and Social Policy at La Trobe University, Melbourne. He is a Fellow of the British Psychological Society, a Chartered Psychologist and an Academician of the Social Sciences.

In his report (Updated October 2007), "Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs (1993)", 0505_Mansell_Report.pdf Jim talks about how "Direct Payments and individual budgets should always be considered in planning for individuals and should be made more widely available" he also says that governments should discontinue using support services which are too large and too far away from their person networks and which fail to give people a "good quality life" at home and in their local community.

In the position statement by the Comparative Policy and Practice Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disability Comparative and concise evidence to identify the main implications when comparing institutional and community-based services is written about by also by Prof Maxwell

In Prof Mansell's "Outline For SIRG Position Statement On Deinstitutionalisation And Community Living he reports that, "Over and over again, studies have shown that community-based services are superior to institutions.

SIRG position statement DECL 020C

it is identified that *"More recently, dissatisfaction with group homes has led to the development of what is generally called 'supported living', in which people live with individuals they choose, in housing they own or rent, receiving staff support from agencies which do not control the accommodation (Allard, 1996; Kinsella, 1993; Stevens, 2004). This development has often been linked with arrangements to give control of funding to the disabled person or their representatives to purchase the services they need directly (e.g. as 'individual budgets' or 'direct payments'), rather than services being defined and allocated by public bodies (Glendinning et al., 2008; Moseley, 2005)"*

Jim concludes by saying, "Community-based systems of independent and supported living, when properly set up and managed, deliver better outcomes than institutions".

Living in a "Rack'em, pack 'em, stack'em model of accommodation, currently employed by some state governments in this country is entirely inappropriate for younger adults. In one particular state these accommodation arrangements are called "6-12 or 20 packs". Such attitudes can never support "ordinary lives" for those who are unfortunate enough to be placed in them.

In his review of literature around the "**Deinstitutionalization of People with Developmental Disabilities"** Raymond A. Lemay (*Services to Children and Adults Plantagenet, Ontario),* identifies some interesting facts and figures in that clearly show that people disability have improved lives when living in the community rather than in institutionalised arrangements.

Lemay2009-Deinstitutionalization.pdf

He does however also identify that inadequate training of those working in services which support community living has resulted in their "serious under performance".

For successful community integration and participation for the persons concerned this documents also identifies that it is essential for an education process around attitudes and skills for workers, families and the community to be made available for successful outcomes.

Lemay concludes his report with*, "Very simply, the institution cannot replace the community in providing individuals—including those with developmental and serious psychiatric disabilities—with the opportunities for the good life. There are no compelling client-related arguments left for keeping people with cognitive limitations, and possibly people with psychiatric disabilities, away from their families and communities".*

There are many examples of alternative and more individualised accommodation arrangements which are being modelled around the world. Most literature indicates that large congregate living arrangements are detrimental to the persons who live in them and that they are more in danger of neglect and abuse either by fellow residents or paid staff than if they are well supported to live in more "natural" and "ordinary" arrangements.

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What would happen if we said to our adult daughters and sons who DO NOT have a disability, when they are ready to leave home, that we had decided where they were going to live, who they would live with and who would come into their home to provide and services that they require? AND that they would live there for the rest of their lives?

WORKFORCE

Well trained and experienced workers are hard to find. The low income for many workers does little to encourage longevity of employment in the field of disability support.

Those of us who wish to take on the responsibility of training workers should be able to sign off on taking that responsibility.

Many people with intellectual disability who are not supported by family and close friends are particularly vulnerable **when in institutionalised models of accommodation/work/ respite/recreation.**

Currently there is no federal (and some states), legislation which requires independent inspectorate, auditing and quality monitoring of such services, to legally protect our daughters/sons and they continue to be at risk of neglect, abuse, and exploitation. **The ongoing failure of respective governments to do this makes this sort of work a magnate to paedophiles and those with violent and abusive tendencies**.

There must be independent inspection, auditing and monitoring of these environments. Failure to do this laces such people in positions of considerable power over those who are less able to stand up for themselves.

Commonwealth
dsa1986213.pdf

The Commonwealth Disability Services Act 1986 would need to be re written to support whatever an NDIS becomes. It must be rewritten using the UNCRPD as the overarching regulation as a guide. Any new act must include in the legislation a mandatory reporting component to protect our vulnerable adult family members when living/working/recreating and using respite

MONITORING AND AUDITING OF ANY FUNDED DISABILITY SERVICE.

The UN Convention on the Rights of Persons with Disability. Article 16 Freedom from exploitation, violence and abuse requires that;

"*States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects."* And that *"In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities."*

Article16 also states "States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted."

SACID would argue that ADULTS WITH INTELLECTUAL DISABILITY who cannot speak for themselves must also be protected separately within any such legislation.

Vic Disability Act
2006.pdf

The **VICTORIAN DISABILITY SERVICES ACT 2006**) is a very good example of this and within it is a part specific to people with intellectual disability in acknowledgement of the often quite different requirements of such persons.

Also within any legislation there must be provision for a **COMMUNITY VISITORS/INSPECTORATE PROGRAMME** cvp_community_visitors_protocol_pdf_17 —whatever it might be called— an example of which can also be found in the Victorian Disability Services Act 2006 this must be completely independent and have the capacity for mandatory reporting.

MANDATORY REPORTING. Our adult daughters and sons with intellectual disability and who may also have profound severe and multiple disabilities, who cannot speak for themselves are NOT protected by a legislated mandatory reporting mechanism. It is essential that all instances of neglect and abuse to and of such vulnerable adults are subject to a mandatory reporting requirement. Any such incidents should be publicly reportable in the interest of transparency and accountability.

A complaints process which is appropriately designed for people with intellectual disability and for those who cannot speak for themselves is essential. Protections must be built in so that there is no retribution for complainant, be they resident/employees or staff. Outcomes of investigations of reports must be made available to the complainant. The Hon Kelly Vincent has presented the **South Australia Disability (Mandatory Reporting) Bill 2010** to the Parliament of South Australia. Other states have similar issues with abuse and neglect of vulnerable adults see…. http://www.smh.com.au/national/carer-abuse-of-disabled-on-the-rise-20090919-fw4f.html

As written previously in this document all monitoring, auditing MUST be independent of the respective departments. To date we have witnessed departments of the departments monitoring themselves, with no public reporting facility to ensure openness, transparency and accountability to the individuals they are charged with to protect.

Similarly (once again using the Victorian Disability Services Act 2006 as an example) there is also an urgent requirement for an **OFFICE OF SENIOR PRACTIONER** for the protection of our daughters/sons who may need it. http://www.dhs.vic.gov.au/disability/about_the_division/office_of_the_senior_practitioner

The Senior Practitioner is generally responsible for ensuring that the rights of people who are subject to restrictive interventions and compulsory treatment are protected, and that appropriate standards are complied with in relation to restrictive interventions and compulsory treatment.

Currently people with intellectual disability in particular still suffer the actions of staff with regard to restrictive practises which are not only demeaning and terrifying for them they are also against the law. This practise must be stopped as a matter of urgency.

Consider governance and administrative arrangements for any proposed scheme including:

To ensure equality of support, uniformity of regulations and portability of an individual's allocation of support funding, SACID believes that it is essential that such a scheme be administered from a Federal level with all of the legislation developed at that level.

A Commission for Disability with an associated membership made up of the people who such a scheme is established to support, at a federal level, is essential to ensure that all Australians with disability are equally protected, leaving no room for conjecture around who is responsible for what. No passing the buck from states to federal.

OUR DAUGHTERS AND SONS and THEIR FAMILIES DESERVE TO HAVE LIVES WHICH ARE

HONOURED, RESPECTED AND VALUED