

These are some of the concerns that SACID and our members has.

No legislative protections for principle family carers with regard to inclusion in funding arrangements for their family member with disability to assist them in their caring role.

No recognition that a family carer MAY CHOOSE NOT to care for the PWD

NEITHER REFERENCE TO NOR INCLUSION IN THE NDIS LEGISLATION OF CURRENT COMMONWEALTH DISABILITY SERVICES ACT 1986 - C2013C00015



<http://www.comlaw.gov.au/Details/C2013C00015>

or all State's Disability Acts, (inserted is link to South Australian act),



<http://www.legislation.sa.gov.au/LZ/C/A/DISABILITY%20SERVICES%20ACT%201993.aspx>

The objects and principles of these acts are very clear about how people with disability AND where appropriate their family, are to be supported and assisted. These Objects and Principles MUST be included in the new act

To indicate
in this
document
that the
Aged Care

***Residential care service and community care have the same meanings as in the Aged Care Act 1997.
entry, in relation to a person and a residential care service, has the same meaning as in the Aged Care Act 1997.***

Act has the same meaning as entry into disability related accommodation is to inaccurately describe what that REALLY means and is of great concern to SACID and our members.

When people with intellectual disability and their families are talking about accommodation and community assistance, particularly for adults with intellectual disability, this may mean supported accommodation which enables them to go or from work. They may instead choose to attend to community linking activities on a daily basis.

For those who have profound severe and multiple disabilities **WHO CANNOT SPEAK FOR THEMSELVES** this might mean something else altogether. It may mean that they have high medical and/or health needs, but still wish to take part in the activities occurring in their chosen community

What it **MUST NOT** mean for anyone finding themselves in these circumstances, is being stuck in a house with 3 or 4 other people with similar disabilities or going "out and about" in large groups with associated workers in tow, with nothing meaningful to do, AS OCCURS CURRENTLY.

People with intellectual disability and/or profound severe and multiple disabilities are the highest proportion of adults WHO ARE NOT AGED who are most likely to find themselves in supported living/employment/day options and breaks away from home, arrangements.

THEY MIGHT LIVE IN THESE ARRANGEMENTS FOR ANYTHING FROM 20 TO 60 YEARS!!

Comparing aged residential and community care with the sorts of assistance that people with intellectual disability and/or profound severe and multiple disabilities might need is inaccurate and inappropriate.

Residential and community care services for the aged is for those at the “end of their life”. They are in these places because they are going to die probably within the next 6 years.

The consistent and offensive use of the word “support” when “assist” should be used is of concern to some. See Objects and Principles of the various disability acts.

Part 5—Nominees

Division 1—Functions and responsibilities of nominees

How will the CEO be able to approve every nominee?

How will the CEO know everything about every nominee?

DIVISION 2—APPOINTMENT AND CANCELLATION OR SUSPENSION OF APPOINTMENT

An appointment may be made:

- (a) at the request of the participant; or*
- (b) on the initiative of the CEO.*

In, **88 Provisions relating to appointments..** Where it states that:

- (2) The CEO must not appoint a person as a nominee of a participant under section 86 or 87 except:*
 - (a) with the written consent of the person to be appointed; and*
 - (b) after taking into consideration the wishes (if any) of the participant regarding the making of the appointment.*
- (4) In appointing a nominee of a participant under section 86 or 87, the CEO must have regard to whether a person has guardianship of the participant under a law of the Commonwealth, a State, or a Territory.*

In South Australia, The principle of informal arrangements is defined in section 5(c) of the Guardianship and Administration Act 1993:

WHAT ARE THE LEGISLATIVE PRINCIPLES?

The Guardianship and Administration Act 1993 contains four legislative principles, which act as a guide when making decisions for a person with a mental incapacity. These legislative principles are contained in section 5 of the Act:

- what the wishes of the person would have been if he or she had not become mentally incapacitated (where this can be determined);*
- the present wishes of the person, if these can be expressed;*
- whether or not existing informal arrangements for the treatment and care of the person are adequate, and should not be disturbed;*
- which decision or order would be the least restrictive of the person's rights and personal autonomy, whilst still ensuring his or her proper care and protection?*

Chapter 3—Participants and their plans

DIVISION 2—PREPARING PARTICIPANTS' PLANS

33 Matters that must be included in a participant's plan

- (1) A participant's plan must include a statement (the **participant's statement of goals and aspirations**) prepared by the participant that specifies*

How will the CEO be able to approve what might be literally many thousands of plan changes a PWD or their nominee might require throughout any given year

What supports will be put in place to assist a person with intellectual disability to prepare their plan.

How is this to be achieved for a person who cannot speak for him/herself?

How will the CEO know what the wishes of people with intellectual disability and/or profound, severe and multiple disabilities, who cannot speak for themselves, might be?

Why is there nothing in here about an individual who is the principle unpaid family carer being able to self-refer to become a nominee for the person they are supporting is unable to make that decision for themselves?

33. (5), (f) have regard to the operation and effectiveness of any previous plans of the participant.

The very real concern that people will lose their long term and hard fought for current agreements with their state disability agency, their allocations having been derived at using current and accepted assessment tools.

They DO NOT want to have to go through yet another process, given that they are satisfied with their arrangements.

Some agreements have placed the whole responsibility in the hands of the PWD or that person's family, this includes those individuals having full control over who they have working for them and in what form that might be, paying the bills and wages. There is no requirement for the individual or where appropriate their family to purchase services from a registered disability agency.

Workers can be self-employed contractors who the PWD or their family have selected, trained, and supervise.

Persons with these arrangements have a written agreement as to how the funding will be spent and that includes family carer assistance. They are able to have annual allocations paid into individual bank accounts and pay all agreed services on receipt of a tax invoice carrying the worker or company's ABN.

They also have an assurance that they can go back to the funding agency if and when their situation changes for a review of their arrangement.

Just recently in Victoria, a new programme has been established so that people with disability and where appropriate, their families, are able to become Direct Employers.

35 National Disability Insurance Scheme rules for statement of participant supports

- What are the rules?
- Who will be making the rules?
- How will NDIS participants and where appropriate their families be consulted?

DIVISION 4—REVIEWING AND CHANGING PARTICIPANTS' PLANS

SACID is very concerned about what appears to be the high level of control in the hands of one person, the CEO particularly where the CEO is to be "notified and approve" any changes to a person's plan

Individuals MUST be treated as such; allocations of funding MUST be for that person.

Meaningful inclusion and participation, if that is what they wish, must be a part of any persons “plan”. Should that person want or need to change what they do on any given day, they must be able to do so spontaneously and not have to “ASK THE CEO’s permission” for that change of plan. To be required to so, for every change of mind, will result in a massive cost to the agency in CEO’s time or for the time for anyone to whom the CEO delegates that responsibility

Most of us as we go through life have a rough idea of what we want to do with our lives but circumstances change for no apparent reason and with little warning. Why would it be any different for people with disability?

What those of us WHO DO NOT HAVE TO CONSULT ANYONE, would more than likely do, because we have full control over the way in which we spend our money, is move and swap things around within our budget to accommodate any such unexpected changes. We most certainly don’t have to run to our employers or Centrelink to ASK permission as to how we make those changes to our expenditure!!

This requirement is so insulting and serves only to convey to participants that they/ or their families who care for them, are incompetent and untrustworthy and can’t be relied upon to make sensible judgements about how they spend their allocation in order to accommodate their disability or how their families provide assistance to them.

Once an allocation has been made based on what individuals need, there should be NO NEED to go backwards and forwards asking “permission” from anyone!

Another concern we at SACID have, is that there will be a loss of local knowledge and long term relationships with case managers and state agencies if one person, (the CEO), makes **“Decisions about and for us without us”**.

We worry particularly for those people with intellectual disability and/or those with profound severe and multiple disability, who cannot speak for themselves, who do not have family or people around them with long term knowledge or understanding of them, who will be assisted by registered agency’s to develop, and monitor their “plans”.

There is very little in this legislation that protects them from possible exploitation by those agencies.

There is no reference to the National Disability Standards and the requirements and responsibilities which those standards place upon service provider agencies.

While there is reference that in the Rules of the Scheme there will be a requirement for independent oversight and monitoring of reporting and investigation of possible unlawful actions of some of these agencies, how will this be managed and by whom?

There is **nothing in this legislation about safeguarding those persons who need such protections, for a mandatory requirement for workers in the homes of these people to report sexual and physical assault or acts of theft or exploitation.**

Part 2—Board of the Agency

PROPOSED MEMBERSHIP OF THE BOARD

Appointment by the Minister: There seems to be no requirement for transparency and accountability regarding the selection of the membership.

Will there be public advertisement of the positions.

We are concerned that there is no **SPECIFIC** requirement for a person with a disability and a principle family carer on the board.

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Division 2—Members of the Advisory Council

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PROPOSED MEMBERSHIP OF THE ADVISORY COUNCIL:

We are concerned that there at the failure of a requirement for a person with an intellectual disability and the family carer of an adult with profound, severe and multiple disability who CANNOT speak for themselves to be on the proposed Advisory Council

Part 5—Legislative instruments

209 The National Disability Insurance Scheme rules

4) The Minister must not make Category A/B/C/D, National Disability Insurance Scheme rules unless the Commonwealth and each host jurisdiction have agreed to the making of the rules.

- Who beside the Commonwealth and each host jurisdiction will be consulted about the development of the Rules and will the Rules be enshrined within the legislation?

Links included are: South Aust OPA-Informal arrangements; FACT SHEET No 23

http://www.opa.sa.gov.au/cgi-bin/wf.pl?pid=&mode=cd&file=../html/documents//10_Fact_Sheets

C/W Carers Recognition Act; <http://www.comlaw.gov.au/Details/C2010A00123>

SA Carers Recognition Act; <http://www.legislation.sa.gov.au/LZ/C/A/CARERS%20RECOGNITION%20ACT%202005.aspx>

Attached is: "It does". One perspective of how choice flexibility and control can work.

This document was written for and on behalf of the South Australian Council on Intellectual Disability Inc. by,

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SA Council on Intellectual Disability Inc. Apologies for any cross posting

SACID is this state's representative on the National Council on Intellectual Disability

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Working towards achieving a South Australian community in which people with intellectual disability are involved and accepted as equal participating members