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PUBLIC INQUIRY INTO A LONG-TERM DISABILITY CARE AND SUPPORT SCHEME.
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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.

Any scheme should be funded as suggested in a similar way to **MEDICARE**.

MINIMAL ADMINISTRATION COSTS DUE TO SELF DIRECTED PAYMENTS MODEL.

SELF DETERMINATION AND SOVEREIGNTY over their lives is essential for people with disability using the Principles of Self Determination.pdf and 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, 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.

CLAIM ON THE SCHEME WOULD BE INITIATED, once a diagnosis had been made, by a self assessment process, using something similar to the Resource Allocation System, (RAS) RAS with amounts SAQ v3-02.pdf which is needs based, as in the inControl model in the UK. This must be followed by transparency over individual allocated funding using a points system 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, baring our souls, mentality.

THIS ALLOCATION TO BE DELIVERED TO INDIVIDUALS 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.

RECIPIENTS MUST BE SUPPORTED AND ENABLED TO BECOME EMPLOYERS 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 DOING SO

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

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 Other supports and services to assist families in a way "which makes most sense to them", must also be available through this scheme.

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 carer, cannot maintain employment and is then forced to become reliant on the inadequate Centrelink payments.

HOW AND WHERE PEOPLE USE FUNDING TO LIVE.

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

Most funded accommodation for people with disability is for those with intellectual disability. People with physical disability and brain injury will not live in congregate arrangements and can speak against such notions.

Unfortunately people with intellectual disability are often not asked and the decision about where they live is 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 intention by many, notion that this is acceptable and appropriate. In other words “good enough”. These decisions might result in living in an institution—yes they are still operating in this country in the 21st century much to our shame. Other arrangements are in larger group homes—up to 20 persons on the one site.

Why is this good enough? Why is 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 support staff. Tom Nerney (CSD) writes about Lost Lives—*can we ever have quality in a system that does not support freedom?* Lost Lives Paucity of Quality in Human Services April 2010.pdf Living in a “Rack’em, pack ‘em, stack’em model of accommodation can never support freedom for those who are unfortunate enough to be placed in such arrangements.

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.

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?

This then leads to the matter of **MONITORING AND AUDITING OF ANY FUNDED DISABILITY SERVICE**.

There must be legislation (similar to that of the **VICTORIAN DISABILITY SERVICES ACT 2006**) Vic Disability Act 2006.pdf which provides for a **COMMUNITY VISITORS/INSPECTORATE PROGRAMME**. Comm Visit program.pdf—whatever it might be called— this must be completely independent and have the capacity for mandatory reporting. This should be publicly reportable in the interest of transparency and accountability. Our adult daughters and sons with intellectual disability with profound severe and multiple disability who cannot speak for themselves are NOT protected by a legislated mandatory reporting mechanism similar to that which protects children and the aged.

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. Results of investigation of reports must be made available to the complainant.

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.