

Introduction

Who am I?

I am...

As a (very wandering) follower along the way of Jesus I am inspired to be a passionate advocate for the inclusion of people with disabilities into any part of our society where we wish to be. I am supported on my faith journey by being a member of Edmund rice Associates (part of the Network which includes Christian Brothers and many other ministries). I am connected with all this through my marriage to Cathy.

I am concerned that some people with disability and parents of children with disability have low expectations of their potential.

I am amazed at the assertiveness and determination of many more who somehow strive successfully against the limited expectations promoted subliminally by our dominant culture.

The unconditional love I have experienced given by many friends and most by my wife Cathy and our now grown up children Lucilla and Joel has made me even more determined to do what I can to remove the barriers of low expectations that can restrict people with an impairment from having the opportunity for a good life.

I do...

Statistics show for example that in employment people with disability fare much worse than others especially if they are women or are from an already marginalised population group.

I have made some inroads into the wider society in voluntary and in paid work helped by things I have no control over such as my sex and culture. My most challenging and rewarding work has been at home as an apprentice to my wife nurturing two young people.

I have been appointed to the South Australian Ministerial Disability Advisory council since 2008.

I have been appointed a workplace representative for the Australian Services Union at the City of Salisbury since 1998.

I was employed by this Council in 1997 so it was the first in South Australia to employ a person with disability to develop a corporate action plan in response to the Disability Discrimination Act (DDA).

One by-product of this work was receiving the National Disability Award (local government category) in 2009.

Structure of this submission

Below I provide some general comments in section A “Overview” then develop these broad ideas and add some specific suggestions in section B “Response to some key questions of the Inquiry”.

A. Overview

I am dissatisfied with the Terms of Reference for this Inquiry and even its title. Using the “social model of disability” I believe that my impairment (total blindness since aged 34, preceded by legal blindness from birth) doesn’t become a disability until I am prevented from living my life with dignity and normative independence due to deficits in adjustment services:

environmental adjustment deficits

lack of accessible streetscapes, road crossings, public transport, screen reader friendly information technology applications at work;

Individual adjustment deficits

Scarcity of quality specialist training in screen reader use with generic I.T. applications.

Instead of terms like “disability care and support” and others in the Issues Paper and the Disability Investment Group’s “the Way Forward” (2009) I suggest that the following are more than simply changing a name.

Instead of “disability care and support ” I suggest “individual adjustment” and “environmental adjustment”;

Instead of “National disability Insurance Scheme” I suggest “AdjustFund”;

Instead of “National disability commission I suggest “National inclusion Adjustment commission”;

And instead of National disability research Institute I suggest “national Inclusion research Institute”.

My reason is that we need to make both individual and environmental adjustments if our impairments are not to become disabilities. Without adjustments both by us and our environment we will continue to be wholly or partly excluded from the wider community.

It is more than a series of word swaps. The “disability care and support” language guides our thoughts to individual adjustment and the resources this requires. As both the Australian Human rights Commission - submission 72(1) and People with Disability Australia – submission 171(1) – assert, this Inquiry must proceed in alignment with Australia’s commitment to implement the United nations Convention on the rights of Persons with Disabilities. This

requires the application of the social model of disability which addresses matters dealing with our impairments but particularly with our environment.

I believe that “a long term scheme for disability care and support” (from now on I will call this the “scheme”) must have both individual and environmental adjustment funding streams. The scheme doesn’t have to fund all of the environmental adjustment which will be part of the National Disability Strategy (released during the 2010 Federal Election campaign by Prime Minister Julia Gillard on 29 July). Other government and non-government sectors are responsible for much of this investment. But high level strategic environmental adjustment is a must for the scheme to give it capacity to reduce its liability for funding individual adjustment.

A national research and development body, recommended in “The Way forward” can accelerate environmental adjustment by promoting the results of research through demonstration projects, evaluation of its own and other demonstration projects and the creation of a national inclusion and adjustment clearing house for innovation.

Example of the scheme’s scope in funding individual adjustment and some environmental adjustment

This example draws from my personal experience of the range of adjustments which the scheme needs to cover. I also include some examples of environmental adjustments outside the scheme.

As a person who is totally blind my impairment can be prevented from becoming a disability with the following classes of adjustment:

Individual adjustment: the scheme can fund

- Training
 - white cane and related mobility skills
 - to orient myself in our house and in the street and public

transport system

- in Braille literacy
- in computer screen reader skills
- purchase of
 - mobility aids (white cane
 - screen reader software for work/home computer use

Environmental adjustments:

Scheme responsibilities:

- Fund Development of information technology application standards and government procurement model policy which expand the range of employment and business applications which are accessible for a screen reader
- Fund local and national strategies to build community awareness of the environmental adjustments required for full social and economic participation by citizens with impairments e.g. funding development of resources to enable Registered Training Organisations to provide I. T. applications training for screen reader users within their usual classes.

Not Scheme responsibilities

Other Government sectors will have responsibility under the national Disability Strategy for funding less strategic but still very large access and inclusion programs , drawing on the research, development and training funded by the

Scheme: these responsibilities would include among many others:

- compliance with the Disability Standards for Accessible Public Transport for example providing bus stops which include a tactile indicator in the footpath surface to alert me to the bus stop boarding point
- promote and assist local government Footpath Trading Policy which maintains a minimum 1800mm clear path from the shopfront line

If the scheme only provides personal adjustment then it will have ongoing high demand for individualised funding used to cope with avoidable environmental access barriers. If I cannot find where to board public transport then I will need funding to pay for taxis.

B. Response to some key questions of the Inquiry

Who should be eligible?

Who should be in the new scheme and how could they be practically and reliably identified?

Eligibility for support under this scheme should reflect the definition of “disability” in the DDA⁽¹⁾. The current barrier between mental illness (impairment) and other impairments must cease. While treatment of illness and impairment is appropriate in a medical / health system it is the task of a national and universal disability care and support scheme to fund the personal and some of the environmental adjustment required to meet the intent of the CRPD.

For this reason I propose the name “AdjustFund” for the revenue raising strategy for this support scheme. “AdjustFund” takes away the focus on disability as something to be insured against and emphasises the purpose of the fund for personal and environmental adjustment designed to eliminate disability as understood in the CRPD.

I support the proposal by People with Disability Australia [Submission 0171(1)] that the World health Organisation’s International Classification of Disability Functioning and Health (ICF-10) is the best developed and potentially most universal basis for assessing eligibility for the scheme.

Who gets the power?

How could people with disabilities or their carers have more power to make their own decisions (and how could they appeal against decisions by others that they think are wrong)?

How should the amount of financial support and service entitlements of people be decided (and by whom)?

In this submission’s “overview” section I expressed my dissatisfaction with the phrase “disability care and support”. “Disability adjustment” or “inclusion adjustment” are better as they cover all adjustments, personal and environmental, which aim to prevent an impairment from becoming a disability.

In brief five elements are required (at least) for people with disability, families and carers to have effective power as provided for in the CRPD:

- Management of the scheme by a national authority governed by a majority of people with disabilities, parents of children with disabilities and carers which is responsible at national and at regional levels for:

- Individualised funding for eligible citizens
- Funding of far reaching social and physical environmental barrier removal;
- Advocacy. (separately funded);
- An ombudsman type agency funded through the scheme charged with quality assurance based on the CRPD and financial accountability measures which would have monitoring, audit and complaint handling functions;
- Short – to medium - term capacity building to enable competent governance and advocacy.
- Review of key legislation (Disability Discrimination Act (1992) and (C'wlth) Disability Services Act (1986).

Below I describe these in more detail.

National Inclusion Adjustment commission

-
- **giving power to eligible citizens while funding strategic macro-environmental adjustments**

The scheme should manage two streams of funding:

Individualised funding

- The scheme should fund the adjustment requirements which enable the eligible citizen and their family to participate in the wider community in pursuit of their life goals. This may include, but range far beyond, purchase of
 - personal services
 - personal equipment and adaptive technologies for use at home, in work of all kinds and community participation
 - training in daily living and employment skills and associated use of equipment and adaptive technology
- This funding should not overlap with income support (as for example the current Disability Support Pension). These funds are to pay for the adjustments required by an eligible citizen to enable their daily living and community participation (examples: employment, recreation) whatever their income.
- The assessment of the level of funding required should not assume continuation of the unpaid assistance which the person may have relied on until now.
- There should be a choice about the level of funding management by the eligible citizen, ranging from self-managed through to agency managed.
- There must be a supported decision-making arrangement, where required, similar to the British Columbia model.
- The funding and management option should be supported by independent professionals capable of assisting the person or family with disability to set up, trouble shoot and manage the support funds and probably be funded by another government source (under a revised C'wlth Disability Services Act.
- funding level to take account of remote location and other factors which make support more expensive for people in specific locations
- funding levels should recognise the double and triple disadvantage experienced by women and girls, Aboriginal and Torres Strait Islander peoples and citizens from culturally and linguistically diverse populations.

- There would be no funding for services and programs which breach the CRPD and legislation should provide a separate funding stream for transition towards CRPD compliant services.

Strategic environmental adjustment which would include:

- National Inclusion research institute
- Intervention programs which may include allocation of funds or negotiation with the various levels of government to deliver environmental adjustments which reduce to a significant extent the requirement for individuals to purchase services in order to overcome such barriers: for example:
 - Changing negative community attitudes
 - Driving inter-governmental initiatives which make public places and public transport more inclusive although funding for infrastructure accessibility could be outside the scheme say through other Government programs under the national disability Strategy.
 - For example the scheme could fund demonstration projects aimed to assist other government sectors to learn about CRPD compliant inclusive physical infrastructure such as playspaces which can provide vital early childhood inclusion experiences ; further roll out of this infrastructure would then be funded from other government sources under the National disability Strategy priorities.

National level

The scheme should be managed by a statutory authority under an act of the Commonwealth Parliament, possibly named the “National Inclusion Adjustment Commission”. It should be governed by a two – thirds majority made up equally of people with disability and parents of children with disability and carers with a representative balance across sex, locality, cultures and impairment type.

This body would be accountable to the Parliament and the Articles of the CRPD would be a core part of its required outcomes and its processes.

Regional level

It would delegate authority to regional resource centres with a population catchment of up to 400,000 people in metropolitan areas located in some of the “transport oriented developments” (from “Adelaide – a 30 year plan”) and in regional zones elsewhere as recommended by a community engagement process with people with disabilities, their families and carers.

These regional resource centres would

- Assess funding levels to eligible citizens
- Negotiate development of individual adjustment plans
- Fund strategic environmental adjustment in the local area
- Recommend environmental adjustments for action by the national Inclusion Adjustment Commission or other bodies implementing the

national Disability strategy

- Would be advised by local “Inclusion forums” made up of people with disability, parents of children with disability and carers.

Advocacy

Independent and effective advocacy should not be funded from the scheme but should be mandated through the Disability Services Act and easily available to eligible citizens at individual, systemic and legal levels.

Without well funded advocacy, in remote, rural and metropolitan areas the scheme’s capacity to learn from practice will be severely restricted.

Quality and complaints

This body would be funded separately from the scheme and have an ombudsman function and may provide outcome monitoring and quality assurance for the scheme.

Ombudsman

This function would manage complaints by individuals about individualised

funding decisions, service quality and scheme decisions about funding of strategic environmental adjustment.

Monitoring

Monitoring of outcomes specified in the scheme and the broader National disability strategy contributing to Australia's reporting against its responsibilities under the CRPD.

Quality assurance

This agency could also provide quality assurance services for the scheme especially evaluating the scheme's operation in light of the CRPD and financial management.

Capacity building – governance and advocacy

A universal scheme will require large numbers of competent citizens

- with disability

- with children with disability
- who are carers.

If employment and business opportunities also expand as the scheme begins to function, there will be a high demand for and constrained supply of competent participants in national and regional governance, the employed workforce and in advocacy.

It is essential in the short – term that funding is provided for training design and delivery in both governance at a variety of levels and in advocacy.

It is important to develop a means of rewarding participants in the governance structure especially those experiencing disadvantage due to disability to ensure effective and healthy sustained participation in the early years of the scheme.

Legislative review

Both the DDA and DSA will need to be reviewed in light of the CRPD and the decisions taken about the scheme. The DSA (and its State and Territory counterparts) should widen the range of impairments it covers (including mental illness) and strengthen the independence and separate streams of advocacy in both funding and accountability.

State disability Acts must also include resourcing and accountability of local

government authorities which are provided for in state legislation.

What services are needed and how should they be delivered?

The first and essential service is that which would be provided by a National Inclusion Research Institute similar to the research body proposed in the Disability Investment Group's report "The Way Forward" (2009). An immediate research effort is required to support the implementation of the National disability Strategy which includes both personal and environmental adjustment priorities.

Using my own experience as an example, it is not possible to say what services I would need because the answer will depend on whether and what environmental adjustments occur. A fundamental service for someone who is employed and blind is a centrally based on line information technology rapid response task force which could:

- Analyse remotely PC difficulties which it is beyond the capacity of generic I.T. support to provide to a screen reader user either in working roles or other settings;
- A "Text access service" which could quickly transform say a table in a PDF document into a form which a screen reader could interpret.

At present these would be valuable services. But if info tech application access standards were developed and promoted by government (and major private enterprise) procurement policies the second of these vital services would not be needed to anywhere near the same extent.

What kinds of services particularly need to be increased or created?

I have three suggestions, the first of which applies across all experiences of disability. The second and third are specific to employees or volunteers who use computer screen readers.

1. Community Inclusion facilitators

(see the comments under the next question “How could a new scheme encourage the full participation by...”)

2. Survey of working age South Australians with vision impairment or who are blind

There is an urgent need to conduct a survey in South Australia which is independent of service providers, of high professional standard and which is CRPD aware. This survey of working age South Australians who have vision impairment or who are blind should be conducted by the national Inclusion research Institute and report on:

- The proportion of this population which feels that its work aspirations are being achieved (owning a business, being employed, being a parent or being a volunteer)
- The factors assisting this achievement or barriers against it
- The level of knowledge of adaptive equipment, funding, training and support available
- Views about gaps in funding, adaptive technology, training and support.

3. Being blind and needing info tech trouble shooting and application training

I could, with more specialist training and support, do much better in my employment and career development and in other roles I have in the wider community including voluntary work.

In South Australia at present there is a screen reader user info tech resource available for free but which is time rationed.

An improvement would be the national on line service referred to above.

As well as trouble shooting, this task force could also provide

on line and on site training in screen reader skills

training for generic Registered training Organisations to include screen reader users in normal I.T. training.

This is an example of strategic environmental adjustment which will reduce ongoing demand for individual funding by

- building capacity in the generic training sector
- providing a national clearing house for adaptive I.T. innovations.

How could a new scheme encourage the full participation by

people with disability and their carers in the community and work?

Community Inclusion facilitators

An urgent need exists for the development of local community inclusion facilitators. These professionals

- will need skills to understand the interplay between a person's impairment, their abilities and aspirations and the social, communication and physical environment barriers they face;
- will need community development competencies to facilitate attitude change and reasonable adjustment to develop an inclusive community
- would be employees of the regional office of the national Inclusion Adjustment Commission
- (mainly) have a direct experience of disability;
- Will have responsibilities based on the CRPD.

It is unrealistic to expect that social inclusion will grow naturally in a society characterised by an individualist ideology and for a significant minority of people characterised by the fear of those who are perceived to be different (for example the current negative attitude to refugees and to Aboriginal people in a small but influential segment of the Australian population).

Local government is the natural host for such professionals employed by the national Inclusion Adjustment Commission. Council programs and services in libraries, community, recreation, seniors' and youth centres provide a physical, organisational and social infrastructure supportive of inclusion in a diverse community.

For example, the facilitator could develop a program with a community library where people with developmental disabilities or mental illness now visit but where they are seen as a challenge rather than another library customer. An inclusion professional could work with the person with disability who has probably had no support in learning how to manage in a library and also support the library staff over time to develop inclusive attitudes, skills and knowledge which they would take into other parts of Council and into their away from work lives.

How could a new system get rid of wasteful paper burdens, overlapping assessments (the 'run around') and duplication in the system?

I suggest an electronic passport which

- Is a record of a comprehensive single assessment
- Can be updated as required
- Is used in any transactions within the scheme across all jurisdictions (Commonwealth, State, Territory and Local Government as well as any non-government organisations providing services under the scheme).

Funding

How should a new scheme be financed?

How can it be ensured that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future?

This is well outside my expertise but I suggest the following:

A scheme called “AdjustFund” be set up drawn from either:

- An extra levy on top of Medicare

OR

- a fixed percentage of all tax revenues accrued by the Commonwealth (personal and corporate taxpayers and if the states agreed, GST).

Organising and implementing a new disability policy

It is vital that an “adjustment workforce development roundtable” be set up including

- National disability Services
- Australian Council of Trade Unions
- National People with Disability and Carer Council
- Fair Work Australia
- Representatives from all three levels of government.

And tasked with developing options and recommendations based on international best practice which provide for:

- Flexible and responsive personal care services consistent with the CRPD

- Workforce development which will meet projected demand and be sustainable over time
- Remuneration and other conditions which will attract a highly skilled and motivated workforce able to provide quality and continuity of care
- With government commitment to fund the outcome of the Australian Services Unions Equal Remuneration Case for the community services industry employees currently before Fair Work Australia.

Footnote

(1) There is some uncertainty about this word now that the United Nations Convention on the Rights of Persons with Disabilities (I use the acronym “CRPD” mostly in the following text) has adopted a social model of disability. In this model it takes both an impairment and an environmental barrier to create a disability. The DDA definition of disability is more a description of impairment while its definition of disability discrimination is closer to the meaning of disability in the social model adopted by the UN Convention.