Australian Federation of Disability Organisations

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Bring It On

Submission

to the Productivity Commission Inquiry into a

National Disability Support Scheme

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Introduction

The Australian Federation of Disability Organisations is the national voice of people with disability formed in 2003 and represents the interests of all people with disability across Australia. The mission of AFDO is to champion the rights of people with disability in Australia and assist them to participate fully in Australian life.

AFDO is a cross-disability human rights organisation and comprises key national and state disabled people's organisations.

- Blind Citizens Australia
- Brain Injury Australia
- Deaf Australia
- Deafness Forum
- National Association of People living with HIV/Aids
- National Council on Intellectual Disability
- National Ethnic Disability Alliance
- Physical Disability Australia
- Women with Disabilities Australia
- Disability Resources Centre
- People with Disabilities (Western Australia)
- Australia for All

Framework of a Disability Care and Support Scheme

AFDO supports the following Framework as developed by advocacy and disabled persons organisations.

- People with disabilities and Disabled People's Organisations (DPOs) to be involved in all levels of governance in a new funding model.
- UN Convention is the framework for the design of a new system requiring a significant cultural paradigm shift based on a human rights and social model of disability.
- Proposed scheme is a national scheme which is:
    - Based on entitlement for all who are eligible.
    - Properly funded to address additional costs related to disability so that a person is able to have full enjoyment of their human rights.
    - Based on equity for all who are eligible.
    - Takes into account the impact of gender, indigenous background, cultural diversity and specific needs of children.
    - Based on self determination.
    - Committed to the empowerment of people with disabilities.
    - Portable (a national scheme).
    - Responsive to changing circumstances of an individual over their lifespan.
- That all existing obligations and commitments to non-discrimination and inclusion of people with disabilities are maintained outside this scheme – i.e. – costs not to be shifted to individuals and preventative mechanisms put in place to prevent this happening.
- This scheme will form a major initiative under the National Disability Strategy.
- A strong independent advocacy support program is separately funded under the scheme to support and protect the rights and interest of people with disabilities eligible for funding.

- That there is transparency in funding arrangements and appropriate consumer rights protection mechanisms.

Definitions of Disability and their Impact on Modeling and Assessment

It is important that any new system does not fall into the trap of using meaningless labels to decide who needs support. This is a human rights issue: the United Nations Convention on the Rights of Persons with Disability (UN CRPD) sets out a broad definition of disability under Article 1:

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

As the Australian Human Rights Commission points out in its submission to this inquiry, this definition, along with the general spirit of the UN CRPD should lead to an approach which takes into account both the presence of disability and the presence of social and attitudinal barriers. For any disability scheme to effectively meet the human rights of people with disability, it has to be inclusive of everyone who needs support, no matter how they are labelled.

There are also serious practical problems with labeling people with disability. Modeling should take into account that, even when people are labeled as having a certain type of disability, the statistics may not be accurate or complete. Often, disability statistics use different definitions of ‘disabled’ with different cut off points based on medical criteria or an understanding of how someone functions. Many also rely on self identification of disability, which can be problematic. In spite of common estimates that 20% of the Australian population has a disability, only 4% chose to identify as disabled as part of the 2006 census. People who need support because of disability are not always identified as ‘disabled’, either in a medical sense or in their own words. This may be true of:

a) People who cross the divide between medical conditions and disability, such as those with psychosocial disability or chronic health conditions such as HIV/AIDS which, under the UN CRPD and the DDA are defined as disabilities but which may not be treated as such by individuals or society at large;

“There’s an older generation of people with HIV who got it pre 1997 when the drugs weren’t very good. They were at a very real risk of dying and became heavily involved in lobbying and raising public awareness. Nowadays if you become HIV positive the medications can mean you lead a longer life, with some side effects. The side effects

can be really different between two people on the same drugs; some people lead relatively normal lives. Those people know the stigma associated with being positive and they often don't make it widely known."

Often supports for this group are provided through Federal and State/Territory Departments of Health, further reinforcing a divide which is not made in disability law and which may or may not hold true for people with certain disabilities themselves.

b) People coming to terms with newly diagnosed or progressive disability, such as multiple sclerosis or degenerative vision loss;

c) People from Aboriginal and Torres Strait Islander (ATSI) backgrounds or Non-English Speaking Backgrounds (NESB), for whom concepts of disability may be non-existent or vastly different[1].

People with multiple disabilities may not have issues with recognizing that they are disabled, but are often asked to pick a 'primary' disability or to simply disclose that they are disabled without providing additional information.

"My son has Down's Syndrome but his primary disability is actually dysphasia, that affects him much more. When I'm asked I usually say his primary disability is Down's because that's what will get him the support."

This information is equally important for planning disability supports; we know that the higher the number of disabilities, the more likely a person is to have coexisting health conditions[2]. We also know that people labeled as having certain types of disability are more likely to have multiple disabilities, such as people with acquired brain injury or intellectual disability[3].

The interaction of definitions and support

In many existing service and support systems, disability often needs to be diagnosed or labeled before supports are offered. For example, a child experiencing difficulty with

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[1] Disability Services Commission WA, 2008, *Aboriginal People with Disabilities: Getting Services Right*, viewed online at: http://www.disability.wa.gov.au/publication/aboriginal.html

[2] Australian Institute of Health and Welfare, 2009, *Disabilities in Australia: multiple disabilities and need for assistance*, viewed online at: http://www.aihw.gov.au/publications/index.cfm/title/10788

[3] Australian Institute of Health and Welfare, 2009, *Disability Support Services 2007-08: national data on services provided under the Commonwealth State/Territory Disability Agreement,* viewed online at: http://www.aihw.gov.au/publications/index.cfm/title/10751

concentration and social skills may get little or no support in the education system without a label, or the label of ‘autism’ may provide greater support options than the label of ‘attention deficit disorder’ or ‘psychosocial disability’. Depending on where the child lives, it may be the other way around entirely. Sometimes there may be multiple, complex, unidentified causes of disability. Continuing to work on a model which labels disability types or even the severity of a disability has many restrictions.

Even within one label type, overly bureaucratic decisions can be made about whether someone requires support or not. To use the above example, a child with autism in the Victorian school system may only be considered as needing assistance if she has language development issues rather than difficulty responding to social interaction and emotions. In reality, both issues can cause social isolation and poorer outcomes in key measures of social success and wellbeing: how long you stay at school, whether you get a job and how much you feel like you can have a say in your community.

Whether someone is considered severely or profoundly disabled may depend on the kinds of assistance and equipment they have access to. For example, a person with a severe hearing impairment who prefers to use English as their first language might be considered severely or profoundly disabled if they do not have access to a captioned telephone service, if they lack computer literacy and computer equipment and they have not been taught to lip read. Such a person would need regular assistance to communicate. With the right equipment and skills, this person may be able to communicate independently most of the time, making them less likely to fall into the category of ‘severely’ or ‘profoundly’ disabled.

The impact of disability may not depend only on the disability type itself. NESB people with disability, people with disability from Aboriginal and Torres Strait Islander heritage, women and children will all experience additional discrimination because of the combined effect of disability and their gender, race, age or identity. For example, women with disability are more likely to experience domestic violence, are less likely to get a job and often have no support as primary caregivers to their children. As the National Ethnic Disability Alliance points out[4], additional discrimination and disadvantage extends to accessing disability specific services and supports.

Solutions and Recommendations

Recommendation: That the scheme enables people with disability to access it because they perceive themselves as having a need for support.

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[4] National Ethnic Disability Alliance, 2010, *NEDA Fact Sheet 2: Access to Disability Services for People from Non English Speaking Backgrounds with Disability*, viewed online at: http://www.neda.org.au/page/fact_sheets.html

Self-definition is the only way of ensuring a human rights based approach to disability, without meaningless cut off points. People with disability and their supporters live daily with the experience of disability and its impact. Allowing people with disability and their supporters to articulate what they need and how serious they feel the impact of disability is on their lives is critical to maintaining a rights-based disability support system.

As stated above, the opportunity to self-define does not always automatically make a system inclusive. Thought will need to be given to how, and whether, the system can be labeled in a way which ensures people who are having some issues identifying themselves as disabled are still able to get the support they need. It is critical that this work is done in close consultation with people with disability and their organizations.

Eligibility

General Principles

The perils of an overly bureaucratic eligibility and assessment system should never be forgotten. Falling through the gaps can mean that people with genuine need are left in isolating and vulnerable positions:

"I'd love to be able to use the Attendant Care Scheme here in NSW. It would mean I could get 35 – 40 hours of support and I could do the hiring and firing myself, which is all I really want. I can't access it because you have to go through all the hours offered by Home and Community Care. They offer you fourteen hours a week, but they're so inflexible it's hard to get through that much. I prefer to do my toileting at night. You can't get them to come out after hours.

Even if I just gave in and used all the hours in a way I wouldn't like I don't know how long I'd have to do it for before I'd get onto the Attendant Care Scheme. There's not a waiting list as such, it depends on how critical you are, so some people are moved up before others. I got myself on their list ten years ago and I haven't seen anything.

I have to rely on my housemates for support. It can get a bit weird sometimes. My physio has said that all I need to do is break my leg or something so I can get into the hospital. Once you're in hospital they want you out of the bed as quickly as possible so you're listed as critical for Attendant Care."

Unfortunately, this is not an isolated example. People with disability fall through the cracks consistently because they do not meet eligibility criteria based on their medical background or their functioning ability. For this reason, and the issues outlined above about perception of disability, AFDO strongly recommends that the following principles be used as part of eligibility for a care and support scheme:

1. All people with disability should be eligible for the scheme, regardless of their perceived severity of disability. This is:

a) rights based and compliant with the UN CRPD;

b) aimed at lowering the impact of disability on our economy by ensuring greater participation and preventing costs associated with lower wellbeing, isolation and poor health.

For many people with disability, the costs of lost taxes, decreased wellbeing and lost productivity can be significant. For people who are Deaf or hearing impaired, the cost to society was $3,314 per person in 2005, while government spending was $62 per person per year[5]. Among people who are blind or vision impaired, the costs are also high: the cost of lost productivity, aids and equipment and lost carer opportunity were $7,373 per person in 2009, while the cost of lower wellbeing (higher risk of falls, depression, admission to nursing homes and use of the health care system) was $16,360 per person[6]. Similar costs combined for Australians with spinal cord injury and traumatic brain injury came to $1.79 billion in 2008[7].

c) a more efficient to administer system, much like the argument against means-testing some benefits (Medicare) and retirement payments (superannuation contributions by government);

d) focused on making people accountable where it matters, i.e. not at the point of proving their level of need but by proving that they access appropriate supports.

2. All people with disability should be eligible, regardless of their income level. This is for a number of reasons. Firstly, people with disability are by and large in lower income households. They are less likely to own their own homes. Many are unemployed or underemployed. Those with work are in lower paid jobs, and the costs of disability are especially difficult to manage on a low income.

Secondly, the costs of disability are often associated with fundamental rights many people take for granted. Most of society, for instance, takes it for granted that they will be able to have regular toilet breaks at work. A person with a physical disability who needs the assistance of a personal support worker to go to the toilet may not have this "luxury" if their workplace refuses to pay for personal support workers. The person with disability is then left with three choices: pay themselves, fight their employer in a stressful process to get funding, or simply go without a toilet break and risk kidney infection and other health problems. Choices like these are fundamentally undignified, regardless of how much money you have.

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[5] Deafness Forum Australia, 2010, *Submission to the Productivity Commission Inquiry*

[6] Access Economics, 2010, *Clear Focus: The Economic Impact of Vision Loss in Australia in 2009,* viewed online at: http://www.accesseconomics.com.au/publicationsreports/showreport.php?id=234&searchfor=2010&searchby=year

[7] Access Economics, 2009, *The Economic Cost of Spinal Cord Injury and Traumatic Brain Injury in Australia*, viewed online at: http://www.accesseconomics.com.au/publicationsreports/showreport.php?id=209&searchfor=2009&searchby=year

3. People with disability should be eligible for support regardless of their citizenship or residency status. The UN CRPD stipulates that people with disability should have the freedom to move between countries as all others do. This freedom is seriously restricted when those who are not Australian citizens are forced to wait ten years in order to access the Disability Support Pension (DSP). In turn, services and supports which are offered only to people on DSP cannot be used by people who really need them.

4. **People with disability should be granted access to support when they are in vulnerable situations.** The new scheme will have to give consideration to making sure that people with disability in prisons, domestic violence shelters and those people with disability experiencing homelessness are given appropriate supports. For these people in particular, it is critical that the system is founded on the idea that there is no wrong door to access disability support, and that all people with disability are entitled to choice and dignity. In addition all people with disability living in congregate care situations should be able to access community based housing and supports in line with Article 19 of the UNCRPD.

5. **Eligibility to access the system should not be based on access to any other form of disability support.** For example, basing eligibility on whether or not someone receives DSP would exclude people with disability who have been assessed (sometimes inaccurately) as being able to work more than fifteen hours a week, people who are working, people with disability whose medical diagnosis leaves them a small number of points short of eligibility via the impairment tables and migrants with disability who have not been in the country for ten years or more. None of these criteria have anything to do with a person's genuine need for support.

Ageing and Disability

Australia's concept of who is an 'older person' is changing as our demographics change. Increases in retirement age and Old Age Pension eligibility reflect these shifts and point to the fact that 65 may no longer be the age at which people have the lifestyle and issues associated with an 'older person'. Any proposed cut off age for access to disability supports would have to be open to regular review and scrutiny, especially if people over the cut-off age who are still working are taxed for a system they cannot access.

At present, there are a number of artificial divides in the disability support system. These include artificial divides set up by medical or functional definitions of 'severity', but also divides created by age. The aged care system has, as the issues paper notes, responded to ageing-related disabilities, such as dementia and Parkinson's disease. While the vast number of people with these conditions will be older, some are not, and in some very specific cases, people with disability are more vulnerable to acquiring ageing related conditions. People with Down’s Syndrome, for example, are more likely to acquire dementia in their thirties.

People under 65 who acquire natural ageing-related disabilities still need age appropriate supports. Some disability types which are most common in people over the age of 65 begin occurring before that magical age is reached: acquired brain injuries associated with strokes and falls, arthritis, declining vision and hearing are all key examples. If the system were to shift this group of people from a disability support system to an ageing support system, they and their families would be left dealing with a new administrative regime, and in some cases, a loss or increase in access to appropriate supports just because of their age. For example, a person who is vision impaired may find that before 65 they are unable to access local Home and Community Care (HACC) services to help them with household cleaning and other tasks because they are not old enough, leaving them more vulnerable to moving out of their stable home to live with family or in an aged care facility. Once they have turned 65, the support is more likely to be available.

Other disability types – such as psychosocial disability (which exists among most age groups in similar proportions) or cultural Deafness – are not associated with ageing. These people may find that they enter an aged care system which does not have staff trained to respond to their needs, such as communicating in Auslan or responding effectively to psychosocial disabilities. Where-ever supports are allocated for these people as they age, it is important that they remain disability appropriate, with staff trained to understand their specific needs and to respect their human rights.

Furthermore, some disability types, such as HIV/AIDS, appear in large numbers among particular age brackets and require coordinated planning across ageing and disability systems. 30% of the positive population in Australia is over the age of fifty, thanks to medications which allow people with HIV/AIDS to live longer and an increasing trend of infection among older people. Despite the looming need for a coordinated, well thought through approach to HIV/AIDS and ageing, service providers in the ageing and disability sectors have not decided who is responsible for planning to meet the needs of this group as they age.

While it seems simple to break the system into people with non-ageing related disability and those with ageing related disability, the above issues show that it is clearly not the best option. Instead, consideration should be given to appropriate outcomes, which include:

a) Seamless funding transfers between disability and ageing systems, so that people with disability have some certainty. This should include portability of aids and equipment between ageing and disability systems, as well as portability in supports between community based housing and aged care accommodation;

b) Workforce and resource development to make sure that people with disability can get the help they need in an age-appropriate and disability appropriate way. This should include staff training and development, and the development of new programs to meet specialized needs;

c) Empowerment through advocacy and community support across both systems. People with disability do not stop needing advocacy services as they age.

Solutions and Recommendations

Recommendation: That the disability system should cover people of all ages to ensure that their human rights are respected regardless of age, and to ensure certainty of service.

Key principles of age appropriate care, portability and appropriate workforce development need to be enshrined in the support of older people with disability. Ideally, people with disability should not have to ask "Where will my support come from?" They should expect, regardless of age or circumstances, that what they need will be delivered.

Temporary Disability and Eligibility

While there is little information available about how and where people access supports for temporary disabilities, one rural local government provider offering community transport services notes that:

"We offer community transport for people with temporary disability. It might be that they've had a broken leg or they've got to get home from an operation. Some people have ongoing chronic illnesses where the boundaries between what's a disability and what isn't aren't clear. About 7% of our clients would fall into that temporary disability category.

I've been in this job thirteen years and I know that people don't use the service unless they need it. People who have family and friends around will use them because it's easier."

As with ageing, from a human rights standpoint the system should be able to respond to the needs of people with temporary disabilities. If a cut-off point is to be made based on the temporary nature of disability, it should:

a) Take into account the severity of impact of a temporary disability (as opposed to the severity of the disability itself). For example, someone with a back injury meaning they are unable to lift heavy objects for six months will not be able to engage in child care for small children. This will have a serious impact on a single mother of two children under the age of five, especially if she has no reliable support networks nearby.

b) Should not exclude people with ongoing episodic disability from receiving appropriate support. For example, an episode of psychosocial disability might only occur once every few years, but each episode could threaten a person’s employment, health and wellbeing.

Both of these criteria make a strong argument for a system which is flexible enough to support people in crisis situations who may not need regular support. This would require the system to be able to:

1. Refer people with temporary disability to mainstream services which may help;

2. Provide a swift assessment of need and fast access to supports; and

3. Offer emergency funds in addition to the main funding of the program, to prevent the creation of another ad hoc system which places priority on people only because of a state of crisis.

Assessment

Assessment of People with Disability

“Every time I get reassessed by Centrelink or a government service I have to prove to them all over again that I can’t walk. It’s degrading and it wastes my time. Why can’t they all work off one set of information?”

People with disability are the experts about their needs, and any assessment process should be based on accessing their expertise and the expertise of their supporters.

For people with disability, the assessment for the scheme should be:

- Based on an assumption of entitlement to have needs met;
- Simple to complete, and quickly administered;
- Used as far across disability supports, equipment and income support systems as possible to prevent duplication and increase efficiency for both people with disability and government.

While assessing someone’s ability to function is part of knowing what they need and how urgent their needs are, it is only one useful piece of information among many. As noted elsewhere, understanding an individual’s life circumstances and other types of disadvantage can be just as important. For example, a person with a moderate intellectual disability with a large family network willing to offer informal support will have very different needs to a person with the same disability who has few social connections. This also means the assessment process should take account of other forms of discrimination, such as Non-English Speaking Background (NESB), Aboriginal and Torres Strait Islander heritage and gender.

Medical assessments hold the danger of arbitrary eligibility for a certain level of support, even if every person with disability is eligible for some kind of assistance. A good example of this are the requirements listed under the impairment tables used to assess Disability Support Pension (DSP) eligibility. Potentially, a few IQ points could mean the difference between getting DSP or not.

Frequency of Assessment

The system should have a set reassessment timeframe which is used as a standard, but should be flexible enough to respond to the needs of individuals. Someone going through a period of crisis may have much higher support needs than usual, but if the crisis passes fairly quickly a new assessment will need to be done sooner than is mandatory. Substantiated cases of abuse of a person with disability should automatically trigger more frequent assessments, along with appropriate measures to end the abuse.

The scheme should also make a division between monitoring ("how are you going?") and reassessment of needs ("have your needs changed?"). Suspected abuse of a person with disability and their funds, as opposed to substantiated abuse, should mean greater monitoring rather than a reassessment of needs. More monitoring may also be appropriate for people who are new to using individualized funding, while formally reassessing their needs more often would not necessarily be appropriate.

As time goes on, people with stable support needs who have shown no evidence of abuse should be subject to more efficient reassessments and/or monitoring.

Reassessments should include not just whether or not the needs of a person have changed, but also whether the supports they are accessing meet their needs in the best way possible. Are people with disability happy with their supports? Do they find them easy to use? Has the available equipment and technology changed in the last while?

It is important that people with disability themselves are able to request support or reassessment. As noted elsewhere, people with disability are the experts in their own lives. For example, a person with a disability who moves from the country to the city will know better than anyone else if they need more or less support because of that move. Some people with disability will be happy to continue with their previous level of support, and should not be subjected to an automatic review. Others will want to sit down and plan new or different supports.

Administration of Assessment

Assessments should be administered as consistently as possible across Australia. This means:

- One national agency disseminating assessment material and assisting with assessments as necessary

- No State or Territory based differences in laws (such as privacy laws) should affect the way a national assessment process is undertaken

- One nationally consistent option – or range of options – is available to review self assessments and make complaints about the administration of the service.

- Portability across the country, so that moving from one location to another does not mean an automatic reassessment or bureaucratic snafus in funding.

The main goal of assessment should be letting the person with disability provide information. If the person needs assistance to do this, they should be given the choice to nominate a support person, who should be as independent as possible from the outcome, such as a friend or family member, and not a care worker or service manager. Formal assistance should also be available for those who request it.

While people formally assisting with assessments should have a nationally standardized level of training and the ability to carry out nationally standardized types of assistance, they should be based as locally as possible. This will enable those providing assistance to have locally required skills, such as a language other than English in a suburb with a high migrant population, or a background in responding to a particular disability type.

Assistance with assessment for those who need it should not be undertaken by service provider organizations or their staff to avoid conflict of interest issues. Under some of the current State and Territory regimes, a service provider is free to act on its prior knowledge of a person with disability – as a member of a family which provides significant donations, as a person who has behaved ‘badly’ in the past, or as someone who is ‘not as badly off’ as others on the books – when deciding on eligibility for services and priority level, instead of simply responding to the needs of each individual.

Here, ‘service provider’ also includes government agencies offering direct and indirect services. For example, it would be inappropriate for the Disability Services Commission in Western Australia to assist people with their assessments if they would potentially be using services which are contracted out by the Disability Services Commission unless there were safeguards in place.

Assistance should be provided by staff who specialize in disability from a social model perspective. This deliberately excludes medical professionals from providing primary assistance as a means of making sure that all of the circumstances of a person’s life are taken into account, not just the level of medical disability.

Concepts of Support and Information about Support

Information about the use of supports is hard to get because there are many definitions of what ‘support’ is, and because the system is so complicated. For instance, aids and equipment schemes do not fall under the National Disability Agreement and are funded by government and non-government organizations, with a variety of models (loans, purchase and part-purchase). As a result, a true understanding of the aids and equipment systems across the country is difficult to come by.

Some things which a person with disability might consider to be ‘disability supports’ may not even be considered as support: to use aids and equipment as an example, a person who is vision impaired may use their iPhone map application to navigate a new area independently. Yet the iPhone is not considered a disability related ‘aid’. Even when we measure supports, there are gaps. As the Australian Institute of Health and Welfare (2009) notes, data on disability supports is focused on outcomes, not the way that support is delivered (individualized funding, block funding or self directed). It is important that outcomes remain central to the provision of support, because otherwise flexible responses – like an iPhone – may not be allowed. For the widest possible range of outcomes to be possible, we need to use a delivery system of funding which offers meaningful choice. The way funding is delivered also needs to be collated and monitored because it is critical to allowing independent choice of supports.

Flaws like the ones outlined above exist in nearly all disability related data, and should be a priority area of reform for both the National Disability Strategy and any governing body for a future Long Term Care and Support Scheme.

The number of people using CSTDA level formal supports might seem large, but in 2008 it amounted to only 1.5% of Australians under the age of 65. Likewise, Disability Support Pension (DSP) payments went to approximately 5% of the entire working age population in 2008. These figures are in spite of the fact that 20% of the population has a disability. DSP comprised 19.3% of the total working age welfare expenditure in 2008[8], while the number of people on DSP was 30.8% of the working age income

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[8] Department of Families, Housing, Community Services and Indigenous Affairs, 2008, *Pension Review Background Paper – Appendix D: Payment Costs and Recipients 2006 – 07,* viewed online at: http://www.facs.gov.au/sa/seniors/progserv/PensionReview/Documents/pension_review/appb.htm

And *Pension Review Background Paper – Trends and Characteristics* viewed online at: http://www.facs.gov.au/sa/seniors/progserv/PensionReview/Documents/pension_review/sec3.htm support population. It is important to note that these figures are problematic because people with disability may receive other forms of income support included in the total budget without receiving DSP, and because significant increases have been made to all pension payments since 2008. However, they do highlight that need for financial support from one portion of the community is not always matched with an equal portion of funds.

Unmet need is as difficult to measure and understand as support itself: some people with disability and their families are largely happy with informal supports because they mean less intrusion into their lives by strangers. Many, however, would like a genuine choice between formal and informal supports. For example, a woman with intellectual disability living with her parents may enjoy their day-to-day support, but still wants a life of her own and the formal support necessary to get it:

"I like living with my Mum and Dad. I've gotten used to their company since my husband died a few years ago. I'd like to get out and meet new people on my own though."

The 2003 Survey of Disability, Ageing and Carers says that 25% of people with disability either had their needs partially met (22%) or not met at all (3%). Using data from sources like the Survey of Disability and Carers (SDAC) to work out real levels of need may also be inaccurate because the survey relies on a person knowing – and admitting – what they need. "Need" can become very subjective. People with disability often become used to not getting the supports which best suit them, and will adjust what they ask for to line up with their low expectations of the system. Sometimes people with disability dismiss their own needs as insignificant compared to what someone who seems to have a 'more severe' disability needs.

"Need" is also often linked to what a person can do with or without assistance, but for many people with disability it's not that simple. A person may be able to do a task – such as doing the washing – without any physical problems, but may have trouble simply finding the energy because daily life is very draining.

It may take significantly longer for the person to do the washing because they have problems remembering when or how to do the washing (acquired brain injury or intellectual disability), they are using an inaccessible washing machine and can't be sure their clothes will come out intact (blind or vision impaired), or they are anxious about doing the washing (psychosocial disability).

Even so, a person with disability facing problems associated with energy or time can still make the argument to themselves, and the system, that they *can* do the washing. It "just" means that they may sacrifice another thing they want or need to do because they don't have the energy or the time to fit it in. In the long run, this attitude can mean that people with disability who go without supports have less chance to have a social life, indulge in hobbies or simply to rest and recuperate. They lead stressed and tired lives because they see their disability related need as a choice.

Types of Support

Supports can be broken down into several different types:

a) Ongoing formalized support, such as paid personal care workers or Auslan interpreters

In most parts of Australia, formalized supports are paid for by government and provided by service provider agencies. This is done through block funding or a system of packages attached to individuals, with varying degrees of individual choice. In some cases – New South Wales, Victoria, and the Northern Territory – individuals can have the option of full control, meaning they can get their supports privately. Some private providers offer services and access to housing, but this is still less common.

The system of supports available at the moment is complicated. Even among government services, the range of providers can be diverse, and includes:

Federal	State	Local
1. Department of Human Services (Centrelink, Australian Hearing) 2. Medicare (continence aids, health care) 3. Department of Veterans Affairs 4. Department of Education, Employment and Workplace Relations (DEEWR) (Disability Employment Services, tertiary education) 5. Department of Families, Housing Community Services and Indigenous Affairs (FaHCSIA) (Australian Disability Enterpresises, long term advocacy)	1. Housing 2. Education 3. Transport 4. Disability services 5. Health	1. Home and Community Care 2. Disability services

Without even taking into account most non-government service providers, it is possible for a person with disability to have relationships with a number of government departments on an ongoing basis.

For example, a person with disability might use:

- Centrelink for income support
- Medicare for medical requirements
- Department of Health (state) for medical requirements
- Department of Housing (state) for public housing
- Department of Transport (state) for taxi vouchers
- Department of Disability (state) for attendant care, recreation or transition to work
- Local government Home and Community Care (HACC) program

That's seven government departments, with seven different application, assessment and renewal processes. It may mean at least seven different points of contact. Any change in circumstances – such as moving house or getting a job – means contact with each one separately. This assumes, of course, that some of the supports offered by State governments aren't accessed through one or more service providers, in which case a person may deal with more contacts depending on how divided the services are. Just dealing with one service provider can be confusing and difficult:

"When I go to Centrelink it's hard. I get confused by the forms and the people there don't know how to help."

This means that to successfully navigate the system, knowledge equals power, and to a certain extent, efficiency. That includes both formal knowledge – which programs exist to help you and how you can access them – and informal knowledge – who is the best service provider, or the best team member on staff at a certain agency. Getting access to information can help with planning for the future:

"We used to have access to a case worker who would give us information about what we needed to do as the next step for our daughter – how to get the pension, that sort of thing. The case worker might change, but they always kept really detailed files and knew where we were up to. When the government closed that program it meant more things for us to follow up on as a family."

Having knowledge does not necessarily mean having choice. The type and quality of supports may depend on which state or local government a person uses. The difference between HACC services in local council areas, for example, can be very marked:

“I work for a non-government organization (NGO) which is the lead agency in our area for a few HACC services, including respite support for older parent carers. A lot of those carers don’t want to interact with formal services because they’ve got that old fear that their child will be taken away and put in an institution. Usually their adult children don’t get the skills and support they’re going to need when their parents are gone.

So we try to be as flexible as we can in giving those families support. If they’ve got a rusty leaking fridge we’ll replace it for them because then the family isn’t stressed about having to go to the shops to buy food every day, and that’s respite. It’s also an OH&S issue for anyone else coming into the house to work with them.

We’re able to be this flexible because my manager is the mother of a child with disability. The next council over, their HACC services are run by the Department of Health. I think most of what they offer is much more medically based.”

As this example shows, there is no guarantee of keeping the same level of services if you move between one administration area and another. It also shows the value of having people with a clear understanding of disability running programs. AFDO believes that people with disability themselves should be given a strong presence in the day to day management and running of disability related programs.

Inefficiencies are not just limited to how these programs are structured. They often seem to be more focused on using limited funding to provide stop-gap solutions to crises than meeting genuine ongoing need:

I was in an aged care facility for four years because I needed more care than my husband could give me and there wasn’t anywhere else. While I was there I couldn’t go to the toilet independently because they didn’t have a hoist. They said it was because this was a low care facility; they only put hoists in at high care places.

Eventually I escaped. I met a man who offered to be my support 24 hours a day and we moved in together. Well, that was a huge mistake because he turned out to be an abusive alcoholic. It took another four years of going to the police and to court to get apprehended violence orders and get him done for stalking before he was out of my life. When he left the house we were in it was hard for me to get the support I needed.

In addition, perceived ‘need’ may be cancelled out by the perception that informal support will cover a person’s requirements:

“My husband lifts my chair into the back of our car. His back is getting worse because of it. If I had a chairlift or a ramp and it was broken they’d help me get a new one. Because it’s my husband I can’t get anything.”

Support availability is an ongoing issue across disability types, especially in rural and regional areas:

“I’m one of two part-time qualified Auslan interpreters covering a 500km area. That means that if you need an interpreter and we have to travel long distances, you pretty much have to book one or both of us for the day.

I work fifteen hours a week. The organization I work for had to do some cost cutting recently, so of course rural and regional was the first to go. I have a client who lives four hours away. I’m happy to take the time to meet him and work with him, but I can’t get the company to pay the petrol money to do it.”

Once a person is considered eligible for a support, inflexibility means that many people either put up with something sub-standard or lose their support altogether.

“I was in public housing for a while. My neighbour started saying horrible things to me and harassing me. I told that to the housing people and they said I should either put up with it or move out. I didn’t feel safe, so I lived in a caravan park for a while after that.”

This is not just a matter of bureaucratic inefficiency or lack of education. Some supports, in bringing together people with a range of needs, can create abusive environments.

“I get annoyed when people come up and hit me on the arm. Some of those people are here today, so I probably shouldn’t say who. I’ve tried talking to [supervisors at the Australian Disability Enterprise where the participant works], *and it keeps on happening.”*

Providers themselves can deliberately abuse or neglect people with disability:

“I heard about a friend who’s living in [a private accommodation provider for people with disability]*. They put people with disability up the back of the houses in rooms with boards over the windows. They don’t get to see no light. Nothing but darkness.”*

Power imbalances in the relationship between support workers providing ongoing support and people with disability can be especially subtle:

“I like to pick out my own clothes. It makes me feel independent and I like my own independence. If someone says I shouldn’t wear something or it looks bad I just put something else on. I don’t feel so independent then.”

These issues all go beyond being unpleasant for individuals. Each one leads to a serious consequence: alienation of friends, homelessness, abuse and depression. In turn, these problems have their own real monetary costs. Putting more money into the system or changing the way funding is delivered will not get rid of these problems. It is critical that any disability care and support system is run by people who have appropriate attitudes, that it offers information to empower people with disability and gives them true flexibility and choice through self directed funding.

b) Infrequent or one-off formalized support, such as travel training or aids and equipment;

As noted earlier, there is limited information about when and how people with disability access supports they need temporarily. According to the 2003 Survey of Disability, Ageing and Carers, one in ten people in Australia access aids and equipment to help with daily living. The PriceWaterhouseCoopers survey estimates a yearly cost of $1,039 per person on aids and equipment, but does not address other areas of infrequent support beyond home modification and taxi subsidies.

Infrequent support includes support to travel for medical appointments, support to access aids and equipment, and support to learn new skills, such as how to travel independently or what needs to happen in a new workplace.

These supports are often inadequate because they fail to recognize real levels of need. This can be about failure to recognize all the steps in a process, or failure to compensate for real costs:

“If I want to get new hand controls for my car I might be able to get some money for the controls themselves, but I have to pay five hundred dollars for an engineer to look at what I need and how it can be fitted to my car before I can even think of doing anything else.”

“Anything to do with seeing a specialist has to be done through Sydney, eight hours away. I’m supposed to see the doctors four times a year but I go maybe once every six months unless it’s really necessary because we just can’t afford it. The government pays 15 cents per kilometer for petrol, and $45 a night per couple for accommodation. Where are we going to find a place to stay in Sydney for that kind of money, let alone an accessible one?”

This is a real risk with any economic modeling of need for intermittent supports. Any assumptions about level of need should be discussed with people with disability themselves before being used for modeling or planning purposes.

Like other systems, temporary supports are often hopelessly fractured and difficult to access. Barriers across different States and Territories can cause a great deal of stress:

"I've got an electric wheelchair on permanent loan from the Victorian State government. Thing is, I'm supposed to stay in Victoria to keep it. I've lived in South Australia and New South Wales with this chair now, and I feel like I'm a fugitive from the State. You might think that's funny, but I can't go back to Victoria or I'll get caught out."

Sometimes a need for support is cut off at what seems to be a meaningless point. This is true of the Australian Hearing program, which offers cochlea implants and hearing aids to people up until the age of 21, and then after the age of 65 unless they are an Aboriginal and Torres Strait Islander or a person on a pension. The fact that the system offers least support during the time when people should be encouraged to be most productive in society has been recognized by the Senate Inquiry into Hearing Health. The Inquiry recommended that all people with hearing impairment should have access to services and equipment offered by Australian Hearing.

c) Informal support from family and friends, which may be ongoing or one-off

In 2003, 65% of people with disability under the age of 65 received only informal care and support. This support can range from minimal – reading out mail once a week for a person who is blind, helping with gardening and odd jobs for someone with arthritis – to more full time informal support that replaces the majority of twenty four hour professional support.

Informal support is often a complex area: people with disability want to be valued members of their families and friendship circles, and placing an onus of extra support on those closest can be difficult to navigate because it changes the dynamic to being a 'burden' or 'obligation'. However, in some instances, informal support is the best option. A family member may know the needs of a person with intellectual disability best when it comes to personal preferences, for example. For some, informal support is the only option: one of the reasons for the Northern Territory's introduction of Individual Support Packages (ISPs) has been the lack of service provider presence and the need to offer options to people in rural and remote areas[9]. Informal support can also mean fewer strangers coming into your life and a more adaptable, flexible approach to support:

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[9] Department of Families, Housing, Community Services and Indigenous Affairs, 2009, *Occasional Paper 29: Effectiveness of Individual Funding Approaches for Disability Support,* viewed online at: http://www.fahcsia.gov.au/about/publicationsarticles/research/occasional/Documents/op29/default.htm

My husband does most of my care. We live 30 kilometers out of town, so it's hard to get carers to come in for a few hours here or there because then they lose time travelling to the next job. Most of the time it works alright for us, but when he wanted to go away for a week we had to get our son and his partner to come down to help. We'd really like to be in a position where we don't have to ask them to do it.

On the other hand, some people with disability are disadvantaged by receiving informal support alone, or by not having an appropriate mix of formal and informal supports. Just as with formal supports, informal supporters can be worn out, ill informed, under-resourced or abusive. Sometimes informal supporters are in fundamental positions of conflict of interest, such as a husband acting as an Auslan interpreter for his wife at a counseling appointment. Conflicts of interest in this area can also be much more subtle and fraught: a parent's major concern for their child is to make them as independent as possible, while their role as a supporter is one which can, even with the best of intentions, make their child with disability more dependent upon them.

Whatever the pros and cons, informal support will be increasingly hard to come by as Australia's population ages. It is important that any new system of support is built to interpret both the pros and cons of informal support for each individual. Informal supporters, such as family members, friends and neighbours, should receive information, emotional support and opportunities to have their own space, just like people with disability themselves.

d) Access to information and advocacy

Information and advocacy are not traditionally considered 'supports', but can often mean a person with disability is able to access mainstream supports and services which might otherwise be inaccessible.

Some things we could define as supports are actually about social change or compliance with legal obligations such as the UN CRPD or the DDA:

"I wanted to see a local GP and the one guy who had space in a short time frame had a few steps up to his surgery door. When I told him I had an electric wheelchair he offered to examine me in the shed. I said no, of course. It [lack of accessibility] affects lots of things. Because the doctors around here don't have height adjustable examination tables I have to go to a specialist office just for a check up. I also miss out on pap smears. If I get cancer it's going to get picked up much later than it should."

Likewise, any care and support system should recognize that current obligations for governments and the public to provide access do not disappear because a new system has been put in place. For example, the provision of individualised funding to support students with disabilities at university level does not mean universities shouldn't build accessible campuses or provide tutors, accessible materials, support workers and interpreters where needed. It is still the law under the DDA that they should do these things.

This includes ensuring that mainstream organizations and governments work on their own accessibility and the accessibility of the community proactively. For example, accommodation for people who are homeless should be accessible so that those who have specific support needs (such as women with disability experiencing domestic violence) can get appropriate assistance. The lack of a wheelchair accessible room or a policy allowing support staff for women with intellectual disability may mean the difference between a safe house with counseling and no safety or emotional support. In the absence of appropriate support, many women with disability experiencing domestic violence will have no choice but to stay put in high risk situations.

Without proactive community work on disability access, people with disability need to resort to formal and informal dispute resolution processes. For a community which is made up of people who have less access to information and lower education levels, this is a daunting task, even without taking into account the time and energy that making a complaint or resolving an issue takes. Many people with disability choose to simply carry on as best as they can because they come across so many instances of discrimination and poor access that addressing them all would consume them. In spite of all this, 43% of discrimination complaints received by the Australian Human Rights Commission – the largest single group – relate to breaches of the Disability Discrimination Act in 2008-09[10]. The majority of these focus on employment and education. These are areas of life especially critical to full, productive participation in society.

For these reasons, individual and systemic advocacy need to be an important part of the infrastructure of a new system of support. They should be provided to people with disability as a freely available service which works to make their supports and their communities better. Under no circumstances should people with disability have to pay for advocacy from a support package.

At present, advocacy is poorly funded across Australia. **According to the 2007-08 National Minimum Data Set, as of 2008, advocacy made up 1.2% of spending**

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[10] Australian Human Rights Commission, 2009, *Annual Report, 2008-09, p62,* viewed online at: http://www.humanrights.gov.au/pdf/about/publications/annual_reports/2008_2009/ar09_complete.pdf

within the then CSTDA. **By contrast, CSTDA administration made up 8.1% of total spending.** Although there have been increases in advocacy funding over the past few years, it is unlikely that the spending on advocacy has come to match or outstrip the spending on administration. We know that their role can be vital: research into current Australian individualized funding schemes shows that the primary sources of information about supports are government and advocacy agencies[11].

While formal advocacy is crucial, it is important to remember that many people with disability gain information and emotional support through peer support networks, self help groups and simply having the opportunity to meet other people with their own disability. Peer support can come in many different forms: through volunteer-run groups, funded advocacy groups and formally run sport and recreation activities. It is through these channels that people with disability come to gather informal information not necessarily printed on brochures about disability: how it feels to acquire a disability, what to do to get through bureaucracy.

e) Access to mainstream services and activities: housing, education and employment

Although some of the barriers to generic services and supports have been outlined elsewhere, this section aims to highlight the pervasive discrimination and disadvantage facing people with disability in terms of access to everyday life.

Housing

A place to live is the most basic of requirements for all of us. For many people with disability, this becomes an ongoing struggle. According to the 2007-08 National Minimum Data Set, over 3,000 people with disability still live in institutions across the country. While the problems for this group are fairly obvious - seclusion from society, vulnerability to abuse – they also exist for some people with disability in other types of housing. Group homes can be an enjoyable connection to others, but residents rarely get a choice of who they live with or where they live. In addition, the service provider offering group home services may also be providing other supports, like access to employment or recreation. This creates an inherent conflict of interest making it difficult for people with disability to complain about their circumstances.

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[11] Department of Families, Housing , Community Services and Indigenous Affairs, 2009, *Occasional Paper No. 29: Effectiveness of Individual Funding Approaches for Disability Support,* viewed online at: http://www.fahcsia.gov.au/about/publicationsarticles/research/occasional/Documents/op29/part5_3.htm

For others, physical access to housing is a barrier to a choice in where and how they live. Some research and policy work[12] has been done to encourage universal design; most recently the Australian government and industry have committed to a voluntary code of practice for universal design by 2020. The lack of an accessible home can lead to increased costs because of injury, the need to relocate to an aged care facility or even higher rates of morbidity, yet there is little data or solid action in this area[13]. Substantial changes need to be made to the law regarding housing construction.

According to the Characteristics of Disability Support Pensioners data (2008), disability support pensioners are less likely than the general population to own their own homes. This, combined with high rates of unemployment, means that people with disability are often ghettoized in the poorer suburbs of capital cities[14]. Many face ongoing challenges to pay for private housing which is both affordable and close to reliable public transport.

Education

Students with disability can spend a lifetime struggling to access the education system. Others come to education because they have acquired a disability later in life and need to regain skills. While the numbers of people with disability attending both mainstream schools and tertiary institutions has grown over the past few decades[15], this growth has come with its own problems.

For all students with disability, outcomes are lower than for their temporarily able bodied counterparts[16]. In the vocational education sector, research shows that some disability types, such as learning and intellectual disability, are less likely to complete

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[12] Australian Network on Universal Housing Design, 2010, *Initiatives: Australian* viewed online at: http://www.anuhd.org/content/initiatives-australian

[13] Home Modification Information Clearinghouse, 2005, *Accessible Housing in Australia: HMMinfo Consultation Paper Response*, viewed online at: http://www.homemods.info/files/HMinfoAccessibleHousingResponse.pdf

[14] Australian Institute of Health and Welfare, 2009, *The Geography of Disability and Economic Disadvantage in Australian Capital Cities,* viewed online at: http://www.aihw.gov.au/publications/index.cfm/title/10703

[15] Australian Institute of Health and Welfare, 2008, *Disability in Australia: Trends in Prevalence, education, employment and community living*, viewed online at: http://www.aihw.gov.au/publications/aus/bulletin61/bulletin61.pdf

[16] Australian Bureau of Statistics, 2006, *Disability, Ageing and Carers Survey – Summary of Findings,* viewed online at: http://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0

qualifications than other types, such as vision and hearing disability. There are many barriers to ongoing participation for all groups[17].

Many still report difficulties with bullying and understanding information provided by their teachers. They are exposed to a lack of physical access, accessible information (books transcribed into Braille, or qualified Auslan interpreters), chemical and other restraints used inappropriately and a lack of choice between public and private school systems. Young adults may be attempting to complete their education at the time when a psychosocial disability first appears; many do not get the appropriate support to continue their education and rely upon ad-hoc non-government programs to assist them to pick up where they left off at a later age.

While early intervention is critical for children with disability, the levels vary drastically:

I’ve got two girls with disabilities. When my oldest girl went through early intervention it was great, we got what she needed. Six years later all the services have really dropped off and we’ve had to struggle through the second time.

Again, attitudes can be everything: people with disability and their families talk about extremely positive experiences in the school system, starkly contrasted by those only a few suburbs away.

Employment

Participation in employment is consistently lower for people with disability across disability types[18]. In particular, people with psychosocial disability and intellectual disability have difficulty finding and keeping work.

Among people with intellectual disability especially, Australian Disability Enterprises are seen as an alternative to ‘open’ employment. Employees working in these ‘closed employment’ environments have a range of responses. Some are happy to do the work they do, but others would like to be in open employment.

At the moment I do one day a week work. That’s mostly stuffing envelopes. I’d like to do something that uses my brain a bit more, like working in an office doing reception, answering the phones. I’ve been in the same job for twenty five years. It would be a bit hard to change now, but I’d like to try.

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[17] National Centre for Vocation Education Research, 2010, *Disability and vocational education and training,* viewed online at: http://www.disabilityandvet.edu.au/Barriers-to-participation

[18] Australian Bureau of Statistics, 2006, *Disability, Ageing and Carers Survey – Summary of Findings,* viewed online at: http://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0

Others also complain that work is monotonous or is not always available. Because of the low rates of pay, some employees pay more to attend work than they make doing their job.

Employers are also able to subsidise the wages of their employees because of disability depending on their productivity;

I have a Bachelor's degree. I'm working at Coles stacking shelves and making less than most people – all because I'm Deaf! This isn't fair!

AFDO contends that both of these options are isolating and insulting to people with disability who should be allowed to work within the community at the same rate of pay.

The welfare system currently removes people from Disability Support Pension eligibility if they can work more than fifteen hours a week. As a result, many are placed on lower rates of income support with requirements to look for work. Not only does this mean that people with disability are less able to meet the costs of their disability and their entrenched poverty from longer term unemployment, but they can also face an unrealistic job target: being able to work over fifteen hours a week does not make a person with disability able to do a wide range of jobs. For example, many young people would apply for jobs working as waiters, delivery drivers or in child care work. These jobs are not necessarily appropriate for a person who is blind.

Once in the disability employment 'system', employment services remain obliged to find people with disability work or training places within very limited timeframes (six to twelve months), which may be difficult for those who do not know what their capabilities are or who have very low education and training qualifications. Staff in employment agencies do not always have specialist knowledge of particular disabilities, though there is some evidence to suggest that this can help achieve successful employment.

As the Australian Human Rights Commission has found[19], there are many ongoing systemic issues with regards to the employment of people with disability, including (often misconstrued) occupational health and safety concerns, costs of participation and attitudes. While the National Mental Health and Disability Employment Strategy makes some attempts to deal with some of these issues, there are still many left open.

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[19] Australian Human Rights Commission, 2006, *National Inquiry into Employment and Disability – Inquiry Report,* viewed online at: http://www.humanrights.gov.au/disability_rights/employment_inquiry/index.htm

RECOMMENDATIONS: IMPLEMENTING SUPPORT

PRINCIPLE 1: NATIONAL CONSISTENCY

a) For the scheme to resolve some of the issues outlined above, it needs to be national and nationally consistent. This is true of benefits as well as other supports. National programs have been developed for parking permits and companion cards with minimum standards and consistent documentation (similar looking cards and permits). This still leaves State and Territory governments with control over applications and the generosity of benefits; AFDO believes that all aspects of support should be nationally consistent.

b) People with disability should be able to access supports in a way which is readily available to them and should have access to independent advice about the supports available to purchase. Where possible, this should include ongoing relationships with case workers or organizations providing case management. Such organizations should be separate from those providing services to avoid information arms 'independently guiding' people with disability to the services arm of the same organisation

PRINCIPLE 2: PLANNING FOR SUPPORTS

c) A good governance structure is critical to make sure that the disability care and support scheme is rolled out appropriately, based on strong evidence and careful planning. AFDO strongly recommends that the governing body should be overseen by a majority of people with disability at a board level, and people with disability should be employed where-ever possible within the organisation. This will make sure that the governing body sets the best example by complying with the UN CRPD (participation of people with disability and their representative bodies, the right to employment) and will hopefully help to eliminate some of the problems within current systems which are based on attitudinal issues.

d) Data collection is critical to both a disability care and support scheme and the National Disability Strategy. Work to implement the care and support scheme should be undertaken on the best evidence base possible. The governing body, people with disability and their organizations and the overseers of the National Disability Strategy should work together to ensure data collection priorities best meet the needs of people with disability.

e) Planning for formal supports in certain geographical locations should be a part of any data collection process. 2006 Census data found that people with disability tend to live in regional areas, while 2008 Australian Institute of Health and Welfare data shows that people with disability tend to live in the poorest parts of our capital cities.

f) Exploring new solutions offered by other government initiatives should be encouraged as part of planning. For example, while some services can be delivered to rural and remote locations by means of fast speed internet – such as real time captioning, Auslan interpreting and TeleSchool programs such as the one offered by the Royal Institute for Deaf and Blind Children – it is important to remember that technological solutions are only as good as the technology itself. The National Broadband Network implementation provides a strong opportunity for positive change, but must ensure that services are accessible (the system should interact with adaptive technology, for instance), available (a concern for rural and remote people with disability who will be receiving satellite access) and affordable for people on low incomes.

Ensuring the best outcome for people with disability in a situation like this should be the shared responsibility of the Department/s concerned, systemic advocates and staff within a governing body for the scheme.

g) Innovation in the provision of supports has to be factored into modeling. This means having money to trial new projects which could benefit a large group of people with disability, or a smaller group with very specific needs, should be an ongoing part of the scheme.

PRINCIPLE 3: INDIVIDUAL FUNDING, INDIVIDUAL CHOICE

h) Power needs to be given to individuals to decide their support needs. This should be achieved through genuinely self directed and, where appropriate, self managed funding. AFDO calls this concept a Disability Inclusion Allowance (DIA), and maintains that it should be based on self-assessment, flexibility and an open eligibility which does not promote one kind of disability as ‘more needy’ than others (see Appendix A).

Research shows that some people are more likely to access self directed funding like a Disability Inclusion Allowance, including men, younger people with disability and those who have one disability. People with physical disability are more likely than others to take up the opportunity, and those with psychosocial, cognitive and intellectual disability are less likely to feel as though they can navigate well through the system. As part of planning and ongoing review the governing body should seek to make sure that all people with disability have equal access to information about the scheme and the support to use it properly.

For example, the decision about who accesses what level of autonomy should be up to the person with a disability and their supporters, not the government or an assessor:

"I've got a self managed package [with documentation and hiring undertaken by an agency] *at the moment. I'd love to be able to fully manage it; I was a manager at a community services organization for some time so I'm quite capable of working out pay issues and taxes and things. I've approached the State government about it, but they tell me "it would be very difficult". For who? I've asked for the forms to get the fully managed package application underway and they just don't send them out."*

This is also a lesson learned in the UK, where the law had to be changed to make it compulsory for local councils to tell people with disability about the option of direct payments (individualized funding).

h) As the Disability Inclusion Allowance paper notes, flexibility about access to different kinds of support is critical. Lump sum payments and small one-off grants may work better for some than others, and referral to other appropriate, accessible mainstream services may be all that is needed in some cases.

Another consistent lesson from self directed funding is the need for good structures to assist with decision making. As FaHCSIA (2009), notes:

Good approaches to individual funding offer administrative support to people with disabilities if they need it to manage the technical, financial and accountability requirements of individual funding, in particular when the funding is provided directly to the person. Mechanisms can include facilitators, brokers, network builders, financial intermediaries, advocacy and consumer organisations, microboards, independent living centres, or networks of family members, guardians or friends.

A risk of poorly managed individual funding is that the administrative support mechanism might replace the decision making and control of the person with a disability (Williams & Holman 2006). This risk is more likely if the administrative and accountability requirements of individual funding are too onerous.[20]

These can, and should, include:

- Supports for people with disabilities which make it difficult to express their wishes, such as microboards or circles of support;

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[20] Department of Families, Housing , Community Services and Indigenous Affairs, 2009, *Occasional Paper No. 29: Effectiveness of Individual Funding Approaches for Disability Support,* viewed online at: http://www.fahcsia.gov.au/about/publicationsarticles/research/occasional/Documents/op29/part5_3.htm

- Formal, independent intermediaries to help with planning and accountability, including financial managers, case managers and/or handing over provision to a service provider completely;
- Information offered to people who are able to access their supports independently, including teaching financial management skills and offering resources to decide which resources to use.

PRINCIPLE 4: TRUST

i) Trust in people with disability and their families is critical to reducing bureaucracy and increasing supported choices. While the things which create a ‘culture of trust’ are hard to quantify beyond a system which trusts people to make their own decisions, they include qualified, well trained staff who stay within the system with reasonably low rates of turnover. Trust is built through ongoing relationships.

j) Preventing problems from arising in the first place is also a way to build trust. This means that staff involved in the system need to be able to take whatever amount of time is necessary to support planning for a person with disability and their networks. In some cases, this will be very limited, while others will require ongoing support. Staff engaged in case management should not be driven by the number of people they assist alone, but rather the outcomes for the people concerned.

k) When potential problems are identified before they come to exist, there should be clear processes in place for responding to them. For example, there should be a clear way to resolve issues when a life change becomes apparent partway through a funding period; if an informal supporter has become sick, or a person with disability needs to move house, funding systems should be flexible enough to respond.

l) Trust is also built by engaging in dialogue when things go wrong unexpectedly. For people with disability, this means a system which supports advocacy and which operates simple to use complaints and mediation processes. An effective complaints system should:

- Be developed and run with strong input from people with disability and their organizations;
- Be well known to people with disability using the system;
- Offer a range of options for resolving complaints, including safe and cost-free ways to notify abuse of a person (such as the currently available National Abuse and Neglect Hotline);

- Actively work to include and support advocates;
- Have an option which operates separately from the agency providing funding and/or case management for when complaints escalate beyond a certain level. This might be through an ombudsman or another government agency

m) For people with disability to trust the system it must be well regulated and transparent. Anecdotally, some service providers currently buy up the personal attendant care available through private agencies in order to be able to dominate the market and to control the price of support. It is also possible for service providers to collude to set prices, and to promote themselves as “independent” information providers and case managers under different branding.

PRINCIPLE 5: GENERIC SUPPORTS

While a strong disability advocacy sector will go a long way to supporting change in the broader community, there are significant ongoing issues within certain areas of support for people with disability. These should be addressed as part of the Productivity Commission findings and should be considered crucial to making sure that long term care and support really works for people with disability.

n) Encourage and legislate for universal design where possible. People with disability face access barriers to housing and technology because there is little, if any, forethought put into design. While technology presents some difficulties because much of what is bought in Australia comes from larger overseas markets, universal housing design should be legislated and prioritized within Australia.

o) Close all large scale institutional housing for people with disability across Australia.

p) Work to separate accommodation from home support so that people living in group homes and other residential settings have a genuine range of choice about where, and with whom, they live.

q) Develop a clear national plan to address the barriers to education for people with disability, including how supports will interact with legal obligations under the Disability Discrimination Act.

r) Further act upon the findings of the Australian Human Rights Commission research into employment and people with disability as soon as possible.

Funding for a Disability Care and Support Scheme

AFDO firmly believes that the scheme should provide support to all Australian residents and citizens who get a disability, regardless of when and how. Based on this principle, Australian society should pay directly for disability support through a specific tax like the Medicare levy. Set at between 1% and 1.5% of income (excluding the Medicare surcharge), the Medicare levy brought in $8.2 billion in 2009 - 10[21], a figure projected to rise to $8.47 billion in 2010-11 and $10.5 billion by the 2013 – 14 financial year.

In contrast, disability expenditure by all Australian governments in 2007-08 totaled $4.85 billion with the Commonwealth government spending $602.6 million[22]. While detailed figures for 2009-10 total expenditure by all governments are still not publicly available, the Commonwealth government has increased its payments to $1.05 billion in 2010-11 as part of the five-year National Disability Agreement, which includes a growth factor calculated from the "rolling five-year average of year-on-year growth in nominal gross domestic product" rather than more traditional indexation[23].

Home and Community Care (HACC) expenditure in 2008 – 09 was expected to total $1.788 billion, with 60% of funding coming from the Commonwealth[24].

The PriceWaterhouseCoopers report (2009) costs a National Disability Insurance Scheme at $19.8 billion, including people with disability over the age of 65. For people under 65, costs are estimated at $10.8 billion. This is probably a conservative costing: for example, average costs for people with sensory disability ($5,000 per year, not including aids and equipment, home modification and transport) are set very low for those using regular supports such as Auslan interpreters, transcription of materials into accessible formats, home cleaning services and one-off training in new technology or communication skills.

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[21] Department of Treasury, 2010, *Budget Paper No.1, Statement 5: Revenue, Appendix A: Revenue and Receipts Forward Estimates* viewed online at: http://www.budget.gov.au/2010-11/content/bp1/html/bp1_bst5-07.htm

[22] Australian Institute of Health and Welfare, 2009, *Disability Support Services 2007-08: National Data Provided on the Commonwealth/State/Territory Disability Agreement* viewed online at: http://www.aihw.gov.au/publications/index.cfm/title/10751

[23] Department of Treasury, 2010, *Budget Paper No. 3, Part 2: Payments for Specific Purposes: Community Services* viewed online at: http://www.budget.gov.au/2010-11/content/bp3/html/bp3_spp-4.htm

[24] Department of Health and Ageing, 2010, *Home and Community Care Program Overview,* viewed online at: http://www.health.gov.au/internet/main/publishing.nsf/Content/hacc-index.htm

The costs of the system may vary dependent not just on the level of support required, but the complexity of need. For some people with very high needs, there is a concern that the system being proposed may not allow for constant or near-constant support. People who require very specialized supports – such as people with communication disabilities and people who are deafblind, who need one-to-one support from someone trained in specialist communication techniques – appropriate supports will be rare. Additional support to train and maintain staff and offer other specialist supports will be necessary.

Whatever the actual costs, AFDO believes they should be weighed against the costs of not doing anything differently. This submission has already outlined the deadweight costs for several disability types. Providing support for people with disability to participate in society is critical for society to function well, especially as our population ages.

RECOMMENDATIONS: FUNDING THE SYSTEM

1. That the system be based on a specific levy of Australian taxpayers, with scope for growth and change as necessary, and protection from financial downturns to ensure stability of support as much as possible;

2. That the scheme be funded to cover all people with disability.

3. That the scheme be a no-fault, National Disability Insurance Scheme based on principles of equity and efficiency;

4. That the scheme be costed in a way which takes into account the savings made through increased participation and wellbeing.

Appendix 1

Rural Issues

- Funds need to be used in a creative and flexible way to provide support to people with disabilities in remote areas.
- Many people who are frail aged or have an acquired brain injury need to come to a major town for respite.
- There can be significant issues for people who obtain equipment funded from one state if they move to another. One person who was funded for a wheelchair lived in NT. The person subsequently moved to SA. A support organisation had to charter a plane to bring the chair from SA to NT for repair. This was at significant cost and time delay for the person with a disability.
- A person who accessed the Continence Assistance Scheme in NT moved to WA. When the person contacted WA to request the same service they were advised that they had to go to the scheme provider in person to be able to receive the service. This would have meant the person would have had to travel 2,000km.
- SA have an “Assist Team” which has an Allied Health Service which includes Physiotherapy and Occupational Therapy. This service visits communities approximately every 6 weeks and is felt to be a good service
- There can be issues with getting and maintaining staff to provide services in remote areas.
- It can take a significantly long time to get equipment to rural areas.
- For children with disability there are limited or no support services or schools that can meet their needs.
- If a person with disability gets sick and requires the Royal Flying Doctor Service to transport them to hospital – the service will not take them back home again.
- Services are crisis driven.
- A lot of services run strictly to guidelines – supports could be better delivered if they were given flexibility on how they could deliver the service.
- It’s very difficult to get services for people who display behaviours of concern.
- One mother lived in a remote area and her child with a disability was sent to a city to live. She wasn’t able to visit her child or be involved in any decision making.
- Bring it on!
- Support service asked why did you choose to have kids?
- PWD needed support to stay at work.
- The Productivity Commission doesn’t see what happens at a grass roots level in rural areas.
- I don’t know what would happen to me if my wife is unable to provide support to me.
- I don’t know what would happen to my 46yo son if I am unable to care for him at home.

- The organisation had no idea of what to ask when assessing me for support.
- Whilst my wife was pregnant the support service expected my wife to still provide all my personal care.
- Seems the assessors are not well trained.
- Assessor meets with people with disabilities then presents info to panel. The person with a disability can't make presentation to panel directly.
- The amount of time it takes fluids to go through naso-gastric tube. Parents stay up to 1am to get fluids into 4yo child. Response from service provider was to increase the flow of fluids. This can cause other problems for child.
- My son has had his disability for 45 years. Every 2 years parents get a form from Centrelink asking for an assessment – has your disability changed. Need to go to doctor to get this form completed.
- RE NDIS - We need to run with this. We need to push it. We need it today.
- When we moved from one state to another – my son needed to be re-assessed.
- Supports – people with disabilities are pitted against one another.
- Current funds are not being used efficiently.
- I've been in a chair for 10 years and didn't know that there was funding for continence aids. This cost me $500 out of my own pocket.
- ALL people with disability should be eligible for NDIS.
- Currently assessment based around eligibility for a pension.
- There are additional costs for water and electricity which are not met in any way.
- Not eligible for schemes such as solar panels when in public housing.
- At times funding is provided and it can be only used at a particular service. This can mean having to fly to get to the service. This doesn't make sense.

Billy's story

Billy is 10 years old. Last year he moved to live in supported Accommodation in NT. Billy's family live in a remote area in WA. They are keen to keep contact with him and to include him as much as possible in their family activities.

It can be difficult for the family to have and maintain even the most basic household items. One of the difficulties faced in Billy's trips home is the ability to keep his food refrigerated. There is also difficulty in having access to water suitable to be able to adequately clean his equipment.

When Billy lived with his family he would attend school with his siblings and many of his cousins. Since moving to NT he has been enrolled in a special school. When talking about schooling there was a sense that at home it was socially and emotionally better for Billy. However in NT teachers could provide a specialist education program.

Billy lives with 2 other males with disabilities – one aged 14 and the other 17. Billy has 4 visits with his family a year for a week at a time. Currently twice a year his family will travel to NT to visit him and the other two times he will visit them. On a practical level this can be hard for the family as they can lose their confidence in caring for Billy. These visits are organised by an agency in NT and can take in excess of 35 hours to organise and are planned many months in advance.

Currently transport for Billy to visit his family is by 4 wheel drive or chartered plane. He is not able to use the "Bush Bus" as he is prone to car sickness. Billy can only travel short distances each day therefore it takes 2 days for him to travel home.

At the moment Billy is light enough to be lifted into the back of a 4 wheel drive vehicle which is fitted with a suitable car seat to support his head. His weight also means that his family and the carer who travel with him can also manage transfers at home without the need for a hoist. As he grows, visits home will be more difficult to organise. When Billy is no longer able to be manually transferred he will not be able to travel in a conventional car and will require additional equipment for his daily needs. These would need to be transported in a trailer. He would most likely also have a larger wheelchair meaning the family's home would need to be altered so he could enter and move about.

Appendix 2

Disability Inclusion Allowance

(1) Introduction

In 2008 the Australian Government ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which sets out a range of rights for people with disability including the right to live in the community, the right to education and the right to employment. Also in 2008, the new Rudd government initiated its Social Inclusion Agenda, which is consistent with the rights based approach of the CRPD.

For these rights to be put into effect, people with disability need access to an accessible environment as well as a range of supports. The present delivery of supports in Australia is crisis driven, ad hoc, piecemeal and confusing. To access a service, people with disability must meet narrowly defined eligibility criteria and present themselves as needy, perpetuating the charity model of disability services. The system is a mess.

In order to implement the CRPD, an overhaul of the support system is urgently needed. The simplest and most effective way to do this is through a Disability Inclusion Allowance. The Australian Federation of Disability Organisation calls upon the Federal Government to introduce a Disability Inclusion Allowance for people with disability by 2010.

(2) Guiding Principles for a Disability Inclusion Allowance

(2.1) Universality

In the new era of social inclusion and disability rights, no person with a disability should be at risk of poverty – or of social exclusion – because of their costs of living with a disability. In particular, the discriminatory costs of exclusion imposed by a society that fails to accommodate people with disabilities should not be borne by people with disabilities themselves. All people who need assistance with their costs of living with a disability should be entitled to an appropriate Disability Inclusion Allowance.

(2.2) Needs Based

Calculating a Disability Inclusion Allowance for any particular individual should be based on their needs, not the ‘severity’ of their disability or any particular type of disability. The underlying principle for identifying – and calculating – the assistance required should be that people with disability are entitled to support that enables them to be truly included in all aspects of Australian life.

(2.3) Individualised

The calculation of any individual’s Disability Inclusion Allowance should be customised according to their particular needs. The wide and often complex variation of needs, with similarly wide and complex associated costs, means that there is no “one size fits all” amount for a Disability Inclusion Allowance.

(2.4) Whole of Life Approach

Calculating an individual’s Disability Inclusion Allowance must adopt a whole of life approach, taking into consideration all of an individual’s costs of living with a disability in all aspects of their life. This also means that it must be sensitive to people’s changing circumstances and needs – and costs – over time.

The cost of living with a disability can fluctuate over time. For some, they will increase, perhaps due to the deterioration of their health or perhaps due to changes in their living circumstances, such as finding themselves living alone after having previously lived with family or friends.

A Disability Inclusion Allowance needs to be flexible enough – individualised enough – to be sensitive to a person’s changing needs and circumstances across all areas of life. A Disability Inclusion Allowance will therefore require regular reviews to adjust the allowance.

(2.5) Single Point of Assessment for Eligibility

A Disability Inclusion Allowance should have a single point of assessment for eligibility, a ‘one stop’ process that calculates an allowance based on the person’s needs. Once this has been established, no further eligibility tests should be required.

(2.6) Portability

A Disability Inclusion Allowance should not tie a person to a particular geographical location. Once established, it should be portable across all jurisdictions.

(2.7) Participation

The people who best know the needs of living with a disability are people with disabilities themselves. Calculating an individualised Disability Inclusion Allowance requires the active participation of the person concerned, to identify their particular needs in order to ensure an acceptable standard of living, according to their particular circumstances at the time.

(2.8) For Recurrent not Lump Sum Expenses

A Disability Inclusion Allowance is primarily for the everyday costs of living with a disability rather than the occasional lump sum expenses that arise, such as aids, equipment or home modifications.

Another, separate mechanism is required to assist with the larger, one off expenses that arise for some people with disabilities. Whatever mechanism is put into place it must be designed in conjunction with a Disability Inclusion Allowance in an integrated way. For instance, the assessment and eligibility requirements can and should be combined.

(2.9) Not Means Tested

Along with the principle that a Disability Inclusion Allowance should be universally available to all people with disability and not just those on pensions, a Disability Inclusion Allowance should also **not** be means tested. Even if a person does have an adequate income, their costs of living with a disability can still compromise their standard of living in substantial ways.

(2.10) Concession Card

A Disability Inclusion Allowance should automatically include a concession card equivalent to the Pensioner Concession Card. Following the principle of universality, such a card should be available to anyone eligible for a Disability Inclusion Allowance. And following the principle that a Disability Inclusion Allowance should not be means tested, the card also should not be means tested.

Concession cards can significantly reduce the costs of living with a disability, sometimes dramatically. Indeed for some people with a disability, a concession card may be the most important component of a Disability Inclusion Allowance for them, perhaps even the only component that they require.

(2.11) Episodic Disability and Emergencies

Eligibility for a Disability Inclusion Allowance should include those who experience ‘episodic’ disability, such as psychiatric/psychosocial disability or chronic illness. Following the principles of a needs based, individualised and whole of life approach, the assessment of eligibility for a Disability Inclusion Allowance needs to be sensitive to disability that is experienced intermittently. It needs to also factor in a provision for emergencies.

(3) Implementation

There are a number of ways that a Disability Inclusion Allowance can be implemented. The simplest one is for a dollar amount to be allocated after assessment and given to the individual in the form of an allowance or to a second party if the individual does not wish to have responsibility for it. The individual or their chosen representative then buys the supports that are needed from relevant service providers.

(4) Funding

The Disability Inclusion Allowance should be funded by way of a levy through the taxation system.

Acronyms used in this paper

CRPD – Convention on the Rights of Persons with Disabilities