physical disability
AUSTRALIA

SUBMISSION

TO THE PRODUCTIVITY COMMISSION INQUIRY

INTO

DISABILITY CARE AND SUPPORT

AUGUST 2010

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APPENDIX

Issues for people with physical disability in Australia

1. PDA and who we represent.

Physical Disability Australia (PDA) is the national disability peak organisation representing the interests and views of people with physical disability across Australia. PDA is funded by the Australian Government through the Department of Families, Housing, Community Services and Indigenous Affairs.

PDA is pleased to be able to make a submission to the Productivity Commission on this most important issue. We consider the subject of the Inquiry and its potential to completely re-orientate the disability sector to focus on the person with the disability and provide surety of funding, to be very exciting.

We hope our suggestions and recommendations will assist the Productivity Commission in its work and look forward to the final report next year.

People with physical disability in Australia:
Of those with a reported disability, 86% (3,387,900) (ABS - 2003) were limited in the core activities of self-care, mobility or communication, or restricted in schooling or employment. Most people with a disability (76%) were limited in one or more of these core activities.

Physical disabilities can be permanent, episodic or temporary and can include:

- congenital factors
- trauma including accidents
- infection
- degeneration
- disease
- Chronic medical conditions.

Physical impairments differ from one person to another. These differences can range from:

- difficulties with balance,
- gait and coordination;
- dizziness and weakness;
- pain or paralysis.
- Communication by way of speech
- Level of independence without support
- Vision or hearing impairments

The most common physical disabilities are partial or total paralysis, amputation, spinal cord injury, various forms of arthritis, cerebral palsy, motor neurone disease, multiple sclerosis, muscular dystrophy, polio and post-polio syndrome, spina bifida, and many respiratory, renal and cardiac diseases as well as cancer or diabetes may affect mobility.

2. Key principles to underpin a new disability support system

PDA joined a large working group of disability advocacy organisations convened by the Australian Federation of Disability Organisations and People with Disabilities Australia, and together we agreed on a set of working principles.

1. People with disabilities and Disabled People's Organisations (DPOs) to be involved in all levels of governance in a new funding model.

2. UN Convention on the Rights of Persons with Disabilities is the framework for the design of a new system requiring a significant cultural paradigm shift based on a human rights and a social model of disability.

3. Proposed scheme is a national scheme which is:
    a. Based on entitlement for all who are eligible.
    b. Properly funded to address additional costs related to disability so that a person is able to have full enjoyment of their human rights.
    c. Based on equity for all who are eligible.
    d. Takes into account the impact of gender, indigenous background, cultural diversity and specific needs of children.
    e. Based on self-determination.
    f. Committed to the empowerment of people with disabilities.
    g. Portable (a national scheme).
    h. Responsive to changing circumstances of an individual over their lifespan.

4. 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.

5. This scheme will form a major initiative under the National Disability Strategy.

6. 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.

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

3. The Model

As PDA is the national organisation representing people with physical disability our first proposal to the Productivity Commission is to suggest an entirely new way of delivering services and support to people with disability in Australia. Accordingly, we present the following model as a recommendation:

Proposed NDIS Model

Person needing support

Regional Resource Centres
Information, support, advocacy and assessment

Managed by people with disability

National Centre of Excellence

Training, research, service development, evaluation, and innovation.

Formal links to university and DPO's and the Disability Sector

Governance Statutory Authority – NDIS

Fund manager & auditor

Accountable to government though

Ministry of Disability

Independent Complaints & Mediation Service

Accountable to Governance Authority

National Ministry of Disability

Responsible for policy development, service co-ordination & development and funding

4. The focus of the proposed model

PDA believes that the new scheme should focus on the individual costs associated with supporting a person with disabilities to lead an 'ordinary life'.

It should however retain a 'systemic watching brief' on the other issues which impact on the lives of people with disabilities such as community education and the encouragement of employers to employ more people with disabilities.

This brief should ensure that the state, territory and federal government focus on the macro issues of infrastructure, building codes, national training standards and access.

- A new scheme must focus on the individual needs of a person who has a disability and has support needs as a direct result of their disability. This should include the associated costs with:
    - Their costs to live at home
    - Their costs to access their local community
    - Their costs to get a job and keep a job (including support, equipment and transport)
    - Their costs to take a holiday or visit friends and family
- The family's needs must also be taken into account if the person is still living at home.
- The scheme should be available to everyone irrespective of age

"The service system should stop telling us what we need and start listening to us, we know what we need. The system has to change and become more responsive" [quote from the PDA consultation forum held in South Australia]

"Whole of life service approach needed, best delivered from the most local level" [quote from PDA consultation forum held in WA]

PDA recommends that:

A new scheme must focus on the individual needs of a person who has a disability and has support needs as a direct result of their disability. This should include all the associated costs.

PDA is keen to ensure that any new system set up as a result of this inquiry should collapse all the different schemes currently administered and run by state, local and federal governments. For example, PDA suggests that the mobility allowance, workplace modifications scheme, taxis subsidy schemes etc should be incorporated into the individual's NDIS allowance – if this is what the person with the disability needs.

A. Assessment process

- People with disability know what they need, it's not rocket science and it's not complicated. People with disability should compile their own list of what they need to become as independent as possible. Specialised 'assessments' or prescriptions are only needed for the ordering of made to measure equipment or specialised services.

- Requests for further services or new equipment should be able to be made at any time by the person with the disability – if this affects their allocation of funds.

B. Deciding who gets what

- PDA suggests that a local panel of people with and without disabilities should be paid by the Governance Authority to take the decisions about how much money a person should get.

- Ideally the funding should be allocated for a three year term with an automatic review at year 2.5 to ensure that the person has enough funding to lead a full and ordinary life.

- The individual and or their nominated advocate must have the right to request a review of any decision that has impacted negatively on the person.

- The review process should be carried out by people who are 'independent ' of the original decision which is up for review , and should occur within a reasonable time once the review has been requested.

- A right of appeal must be enshrined within the framework which also is conducted within a reasonable time after the request has been received. The system must be free, easy to access and have advocates available. The complaints and appeals system should be operated by people who are peripatetic

C. How is the scheme to be funded ?

PDA recommends that:

the National Disability Insurance Scheme be funded by additional amount attached to the existing Medicare levy.

The German long-term care insurance premium, as an example is,

> "uniform and fixed by law at 1.7 percent of salary, which is shared equally by employers and employees. Retirees pay half of the premium, and pension funds pay the other half."[1]

The NDIS should also directly receive the funds currently allocated by the states and the Commonwealth for existing disability supports and services.

It should also receive the premiums collected by private insurance companies, unless 'personal injury' becomes redundant because of the existence of NDIS.

This would deal with the issues highlighted by the DIG Report where the cause and circumstances of an accident can see some people compensated and others not.

PDA would also like to suggest for reasons of simplicity and equity that:

- Individuals should no longer be made to pay co-payments for any services (often services such as HACC , funded by the Federal Government would also ask people on the DSP (Federally funded) to make a co-payment. PDA believes that the HACC services should be properly funded. People accessing aids and equipment likewise, should not be made to subsidise the program because the items they need happen to be expensive.)
- Different funding schemes such as the continence aids programs should be abolished and the appropriate amounts allocated into the individualised funds through NDIS. This will promote equity of access across the country and lessen bureaucracy.
- All GP's and specialists should bulk bill people with disabilities for their services. Again, this promotes equity of access and reduces bureaucracy.
- The costs of all individualised services and equipment should be met through an individualised budget allocated to an individual through the NDIS.

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[1] ***Can Social Insurance For Long-Term Care Work? The Experience Of Germany***
by Alison Evans Cuellar and Joshua M. Wiener HEALTHAFFAIRS ~ *Volume 19, Number 3*
©2000 Project HOPE–The People-to-PeopleHealth Foundation, Inc.

5. How this scheme could work in practice (please see chart attached on page 5)

We recommend that seven (7) new elements be set up to deliver the range of services and supports needed by people living with disability in Australia.

They are:

1. **E Medicare card:** The current plans for a 'smart' health card fit perfectly with a NDIS concept. Once allocated, an individual will have their Medicare Card credited with the financial allocation for their personal supports and equipment for three years. This card will be accessed by the person, and the services. Each service provider will be able to 'swipe the card' and have their company credited for the services delivered. An authorisation or approval system should be incorporated for the person to enter, to approve the payment. Issues of 'confidentiality' have already been discussed by the national working party and as for example, pharmacists can see a patients pharmacy records but not the medical records on the existing Medicare Card – similar 'walls' can be programmed into the card for other service providers.
2. **NDIS Governance Authority**: to be established as a Statutory Authority and responsible for funds management and auditing. Accountable to government though the Ministry of Disability.
3. **Independent Complaints and Mediation Service**: this new service must have legislative authority to provide advocacy and support to anyone who needs it. The service must be free of charge, simple in its procedures and easy to use. It must be mobile and available to people across the country. Ideally the advocates would be based at the Regional Resource Centres. The Service would have powers to interview people, access documents and have access to the people wanting to make the complaints. The Service would have powers of investigation and arbitration. Mechanisms of appeal must also be provided
4. **National Centre of Excellence**: Responsible for training, research, service development, evaluation, and innovation. One of its main purposes is to establish common forms of data collection across national and state boundaries. It should have formal links to university, the Australian Institute of Health and Welfare and DPO's
5. **Regional Resource Centres** across the country:
   In all the consultations conducted by PDA for this Inquiry, everyone was clear that they needed a 'one stop shop' to access the support they needed.

   We envision the centres to:

   - Understand the current systems and services available in the region;

- Assist people (from birth to death) needing support to access the supports in a timely manner
- Organise the links and referrals to specialists (with funding for travel and accommodation if necessary)
- Link people into local networks of support from other people who have disabilities or are carers
- Link people into the training they may need to manage their own supports (and ensure the funding is available to get them there)
- Link people to advocacy, complaints, mediation as needed
- Keep a register of accredited supports and remain up to date with what they offer and the associated costs
- Link people into co-ordination /brokerage / finance services who can assist people to use the NDIS if they don't wish to directly manage their supports (the resource centres may choose provide this direct service and it could provide an income stream for the Centres if there were no conflict of interest)

6. **Ministry of Disability**: Responsible for the development of Australia wide compatible policies and practices; funding of infrastructure, community education and support, service co-ordination & development and funding.

7. **A new profession** of 'assistants / personal managers' to support the individuals to co-ordinate and receive the individualised services and supports

Recommendation

That the government immediately sets up a new Ministry of Disability, a Governance Authority to manage NDIS, an independent Complaints and Mediation Service with powers to arbitrate; a new Centre of Excellence and fund independent Regional Resource Centres across the country.

5. Transition /Development Phases

The new system of 'service delivery' has the person needing the supports to be at the centre, to be the fulcrum of the system.

To set up the new system well, some actions are needed immediately.

They are:

- **The design of a new nationally accredited training module** which is designed for service providers and the individuals to understand how to get the best out of the new scheme. As an example the Stil cooperative in Sweden runs courses and,

> *“Before anyone can become a member of the cooperative he/she has to take a course in which experienced members teach newcomers the necessary skills a supervisor must have. Thus, we train our members so that they, in turn, can train their assistants. Our "boss course" consists of 10 evenings. Passing the course is a prerequisite for becoming a member in the cooperative and for employing one´s own personal assistants. The course covers such topics as assessing one´s needs, negotiating with government agencies for funds, advertizing for assistants, interviewing job applicants, setting up a job contract as well as scheduling , training, supervising and - if necessary - firing assistants. Instructors are members of the cooperative who have long personal experience of employing assistants.”*
> http://www.independentliving.org/docs3/stileng.html

- **Current services must establish a common costing system** The Department of Human Services Victoria recently employed Price Waterhouse to conduct a price review of Out of Home Services which showed that many services are operating over budget and are not ready to offer ‘individualised’ services.

> **“a. Inconsistency and unpredictability of cash flow / income**
>
> • Many Agencies reported to us that they are nervous about an expected unpredictability of cash flow and that this in particular would have an impact on their ability to employ permanent staff which would have a flow on of reducing quality of service. This was highlighted specifically for Day Services and Respite. This was reported more by smaller organisations.
> • This is indicative of a risk averse culture and the need for more detailed analytical capability to fully understand and model the expected scenarios. “
> http://www.dhs.vic.gov.au/__data/assets/pdf_file/0005/367268/PwC_price_review_out_of_home_ds_final_report_pdf_0309.pdf

PDA strongly recommends that NDIS establishes a fixed maximum administration and management fee for all agencies and services to use.

Some service providers take a large percentage of a person’s ‘package’ of care for their own use – or dictate that case-management is a compulsory part of the package even if the person does not need it.

- **Develop the self assessment system for eligibility** People with disability who will be wanting to access the new scheme will be most interested in participating in the design of the self assessment system. The designing process will need to start early as the ‘dollars’ come through this assessment.

PDA suggests that:

  - Pilots are established in cities and rural areas
  - Every part of the design must involve future 'users' of the scheme
  - A public golden rule / guarantee should establish 'no worse off' principles for anyone choosing to move to the new NDIS scheme
  - First, transfer people with disabilities who currently have some dollars of support. These experienced people will assist in the development of a flexible and 'listening' new scheme.
  - If the scheme sets up a minimum level of support, it should provide the funds to allow a person to buy an emergency call up system and access after-hours emergency support

- **Set up the Regional Resource Centres** (RRC's) as NGO's with a management committee made up predominately of people with disabilities and their support persons. The staffing mix should include advocates, assistants / personal managers (to assist in every part of the process) and specialists. It will take the RRC's a considerable period of time to discover what services are available, and make recommendations about what new services are needed, and then get them set up. (e.g. emergency and after hours services) All the workers must be mobile and able to visit people in the location of their choice.

- **Set up the Centre of Excellence** The disability sector has been needing and wanting an expert Disability Centre to use for many years. It will need to be set up very early in the development of any new system to allow it to assist with:
  - Collecting current data about the existing service system to allow proper and valid comparisons and evaluations at a later stage;
  - Facilitating the development of new services where there are existing known gaps;
  - Supporting new Regional Disability Resource Centres to set up (development template?)
  - Developing the new accredited course for 'individualised funding' for both the service providers and the users;
  - Begin the negotiations across government departments (at all levels) and authorities to ensure a commonality of data collection and definition to develop credible and comparative data.

7. Consultation: What our members and stakeholders had to say.

Over the past few months, PDA has consulted widely across Australia using the following methods:

1. Four face to face forums were held in the following places:
    - Alice Springs NT – in conjunction with Office of Disability Alice Springs
    - Adelaide SA – in conjunction with Physical Disability Council of SA
    - Perth WA – in conjunction with People with disabilities WA
    - Hobart TAS – in conjunction with Tasmanians with Disabilities.

2. On line survey distributed through:
    - www.pda.org.au
    - Facebook page – Physical Disability Australia Ltd
    - Emailing to members across Australia – (over 300 on email)
    - Emailing to organisations across Australia (over 200)

3. Telephone survey with 1300 local call cost number

4. Word of mouth.

5. PDA Board members (all board members have a physical disability)

Questions put to members were taken from the Productivity Commission Issues Paper.

1. Who should be eligible?

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

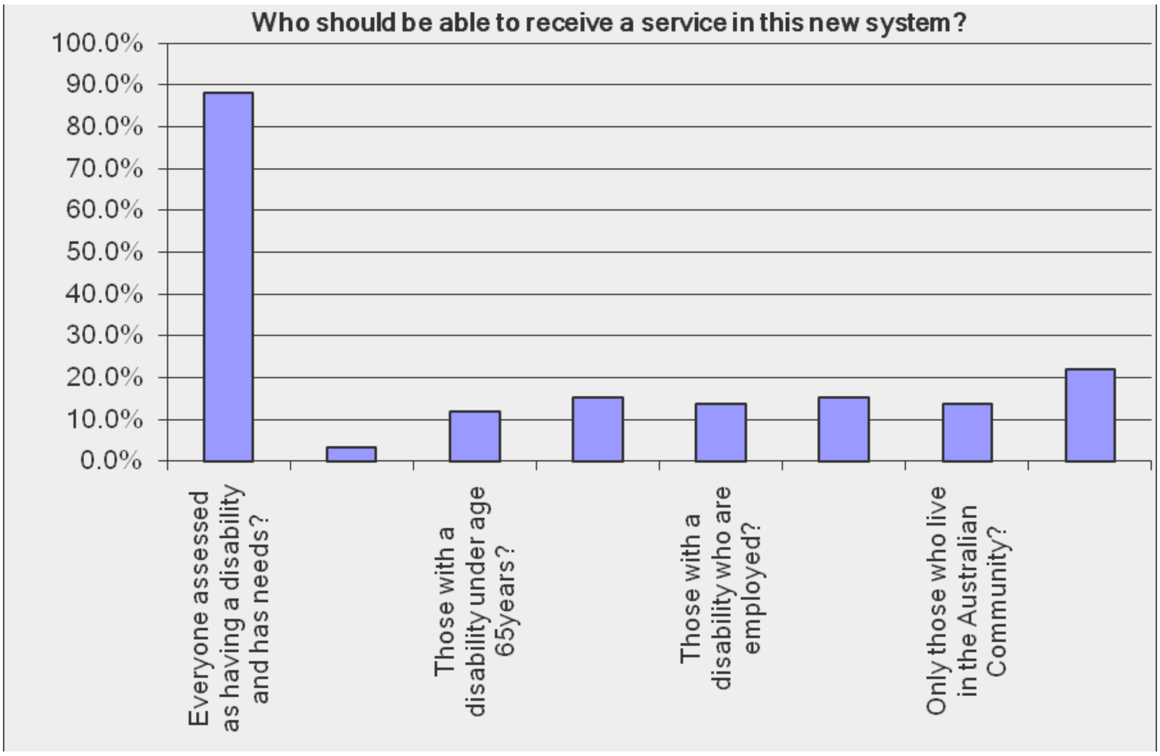
"Any person with a disability, where that disability results in an impairment on independent functioning"

"Age should not be a factor. "

"If you have or acquire a disability at aged 1 year that impairs your ability to function as you grow older your disability and the impairment on your functioning does not disappear. In fact it is known in life stages the older humans get, the less the function they have. So this needs to be lifelong and not end at age 65 as is the current practice."

"All people who have a disability whether it be physical, sensory intellectual, mental health or other disability.

"All people with disability should receive the services they need and this should not depend on how the person acquired their disability."



Which groups are most in need of additional support and help?

PDA did not specifically ask this question as we believe that all people with disability should be assessed individually according to their needs, and not assessed as a group of people, such as Spinal Cord Injury, or Cerebral Palsy, or Muscular Dystrophy etc.

PDA also believes that it is impossible to determine who is most in need of additional support and assistance because each person is an individual with unique needs for support (some minor and some major needs) and should be assessed as such.

What could be done about reducing unfairness, so that people with similar levels of need get similar levels of support?

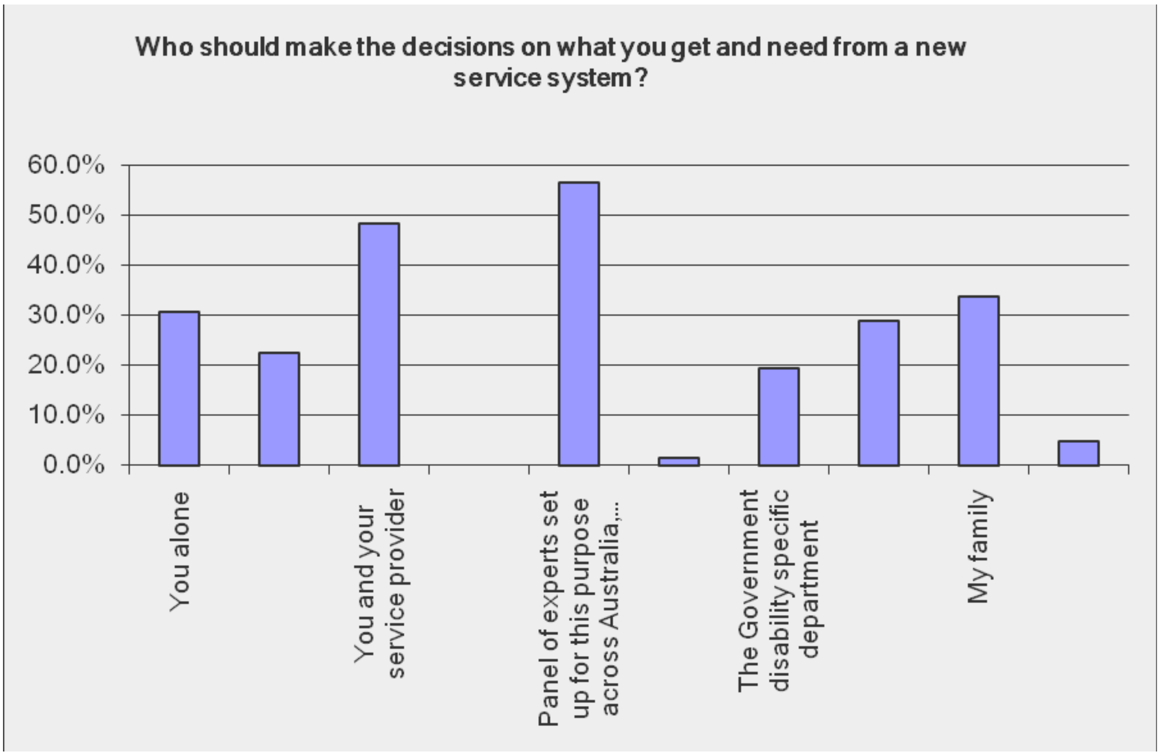
All people with disability with recognised need for support of some type should be assessed in the same way and receive the response to their individual needs. This will reduce unfairness.

- *"… should be for anyone who needs it and not based on the highest needs only".*
- *"All services focussing on individual need"*
- *"Individual gets adequate funding to purchase what is needed."*
- *"Individualised funding for the person to purchase their own services"*
- *"Being able to "get what I need when I need it"*
- *"Able to use my support hours when I want them, or bank them up to use for a holiday "*
- *"Eligibility for services and support not so restrictive i.e. out of hours support when needed"*
- *"I choose who comes to my home and how long they stay and what service they provide"*
- *"Where I am in control"*

- *"Not restricted by a service organisation budget or someone who says they know what I want better than I do."*

2. Who gets the power?

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



PDA is promoting (supported by the responses from those we consulted with), in the use of expert panels across Australia through, a series of regional resource centres to be set up. Each of these centres (including in rural and remote areas) are specifically designed to meet the needs of people with disabilities.

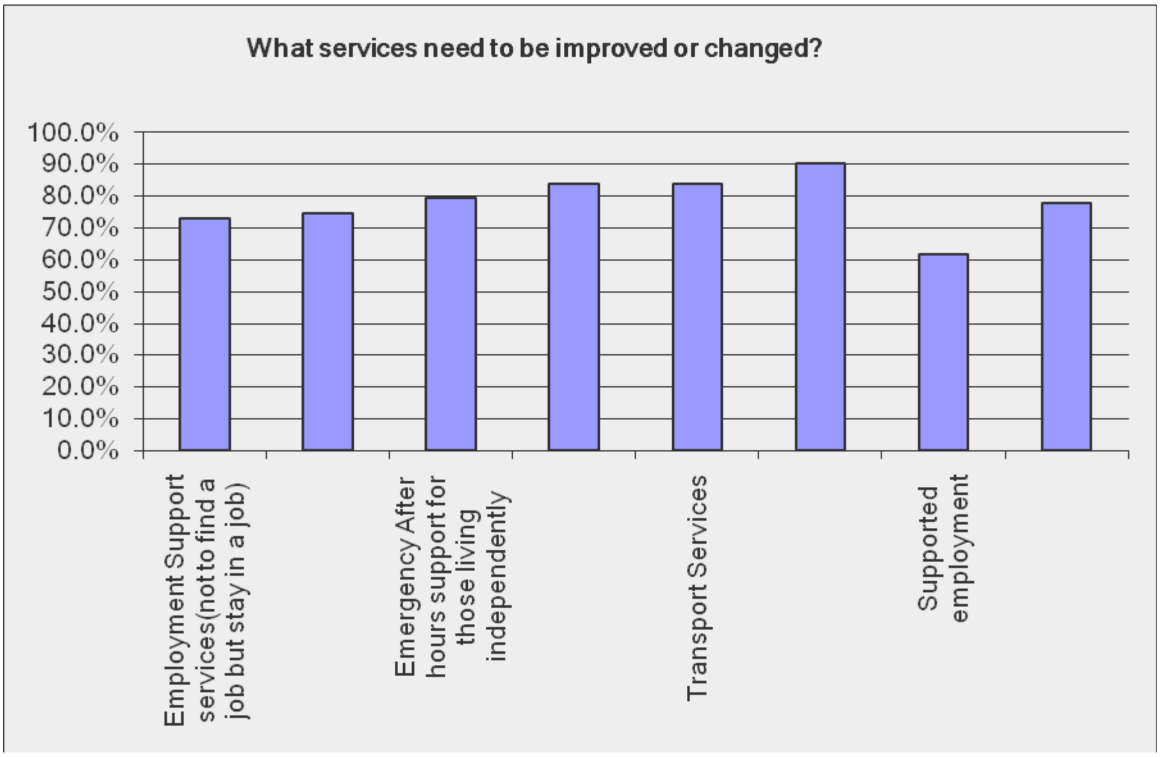
How should the amount of financial support and service entitlements of people be decided (and by whom)?

" A panel of experts with an independent manager/advocate for me sounds like a decent option, but I would have to have discretion to get another manager/advocate if mine didn't get along with me or I didn't think they understood my needs properly. Also transparent options to appeal would be necessary."

"I think it has to be a consultative approach between the client their families and advocate for that client, the service provider and anyone else who has the clients best interest at heart."

3. What services are needed and how should they be delivered

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



"A fair and equitable service would make a difference to quality of life for many. There seem to be many disparities about how many hours of service people can receive in a week."

"To have ONE place to go to for everything and have it dealt with together. Not having to explain things to numerous organisations and having to keep copies of everything."

"For my daughter it would give her a completely different life to the one she has now, she is almost 16 and is at home full time, she does distance education and we receive no respite (by choice). To be able to plan outside activities for her with funding made available to her she could have a much better life outside of her home. The outside activities would be ones that include us, her family, so she has the support of those who know her best so for example is she wanted to do horse riding someone from our family would go with her, if she wanted to swim, again we would be there as her support. It is very important for our daughter that she always have her family to support her and we are more than happy to do so."

"I want independence and security. People with disability shouldn't have to live in crisis. Recently I got sick for 3 months. I was very sick for about six weeks with severe breathing difficulties. If it wasn't for my family I would probably not have survived. Every time I gasped for air which was very frequent I would feel very afraid even with my family providing round the clock care. Without them even if I didn't stop breathing I would probably have had a nervous breakdown due to stress and fear. People that sick need someone to administer their medicine and check their breathing regularly as if your struggling to breathe you can't phone a doctor or ambulance. "

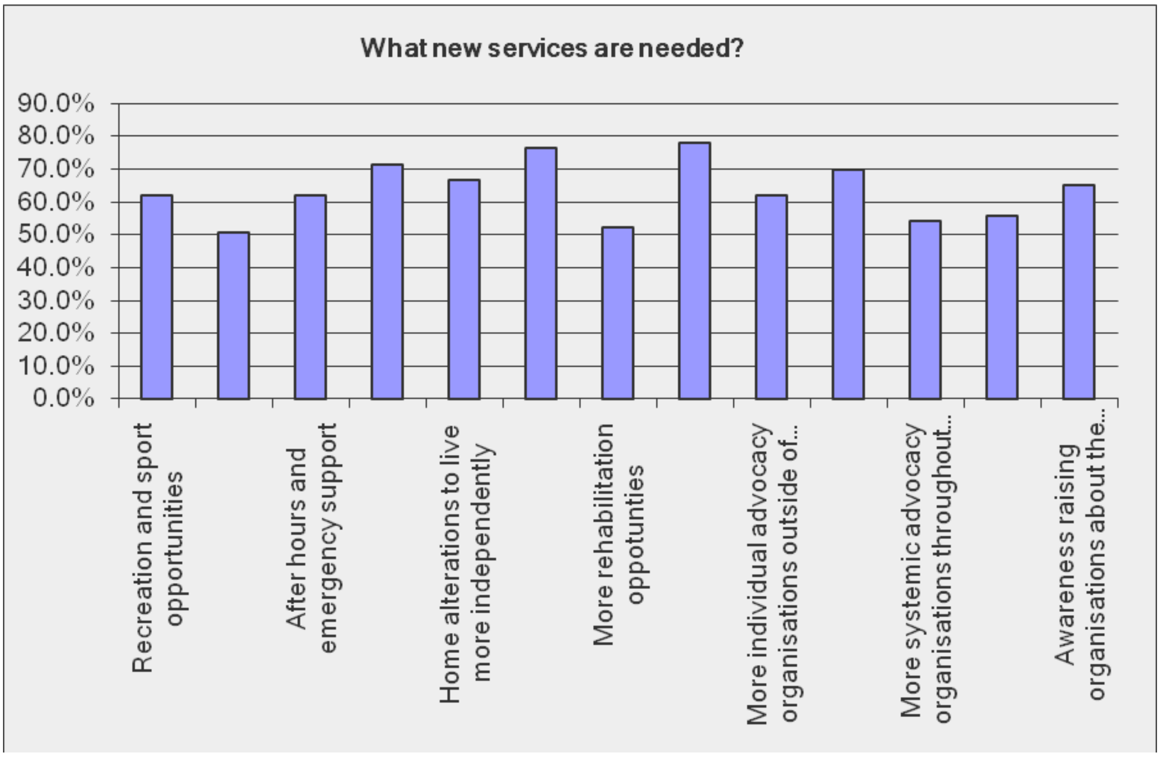
“A few years ago I was so sick I stayed in bed unable to shower or eat for 4 weeks. I didn't have the energy to ask for care and as I wasn't receiving home care at the time few people knew my circumstances. Also I didn't like to ask for care as there are many people who are seriously ill who get grossly inadequate care and even though I couldn't get my meals or order groceries on the internet I was too sick to eat anyway. I certainly needed a bath though.

My friends and family did as much as they could but didn't have time to help me have a Bath except for when I had to go to the DR. They did come to my house 4 times a day to give me my medication as I was too ill to remember. I ended up with respiratory distress. Everyone gets sick however it's hard to manage with a disability at the best of times without being sick. After a month in bed I had quite a bit of muscle atrophy which didn't help the situation. Services can't make people well but with adequate care people with disabilities will be healthier and less likely to get sick and when they do get better quicker. The first time when I was very sick I got worse due to the dust and mould in my house and my sheets hadn't been changed in a month. When I was well enough to eat I had to rely on frozen meals or take away. I also didn't return to physiotherapy as soon as I was well enough as I had no clean clothes to wear and didn't have the mobility to wash them myself. If I had a carer to feed me soup when I was sick then I probably would have got better sooner.”

“I was seriously injured 11 yrs. ago and did not receive rehabilitation for over five years which left me with arthritis and medically disabled. I was told by my GP the only rehab available was private. I was living on a pension and couldn't afford private services. I was already paying for private specialists for many years until I went to another GP who referred me to a public clinic that I didn't know existed.”

“Independence is a critical component of participation in Australian society. Without the services that I require to be independent, I am unable to fully participate.

4. New services needed.



- *"If I had a service which helped me look after my children, or a service that wasn't limited to just house cleaning but could be used for a variety of purposes such as transport etc. At the moment I struggle to look after my two small children and could do with support."*

- *"I might be able to get out and about more and have a social support network. It would be good for my mental as well as my physical health."*

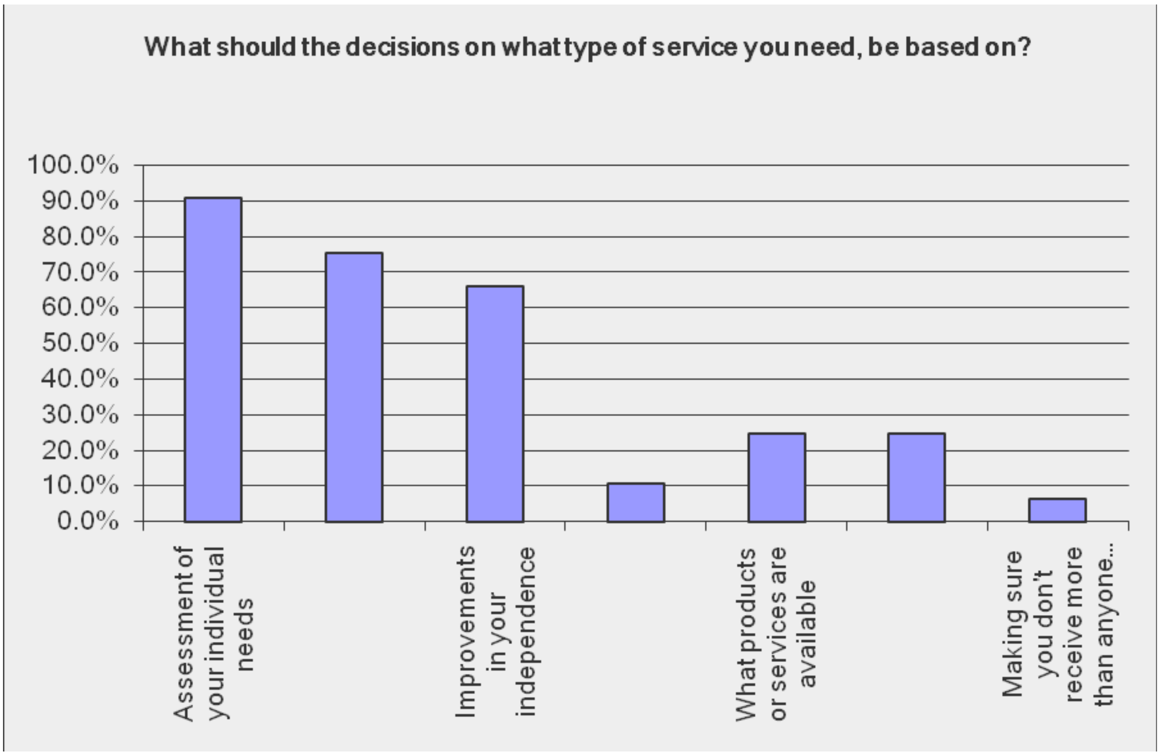
- *Someone needs to investigate the exorbitant costs of equipment for the disabled. Ripping off the government is ripping off everyone.*

- *More services to assist with housekeeping, gardening, maintenance around the home at very low cost.*

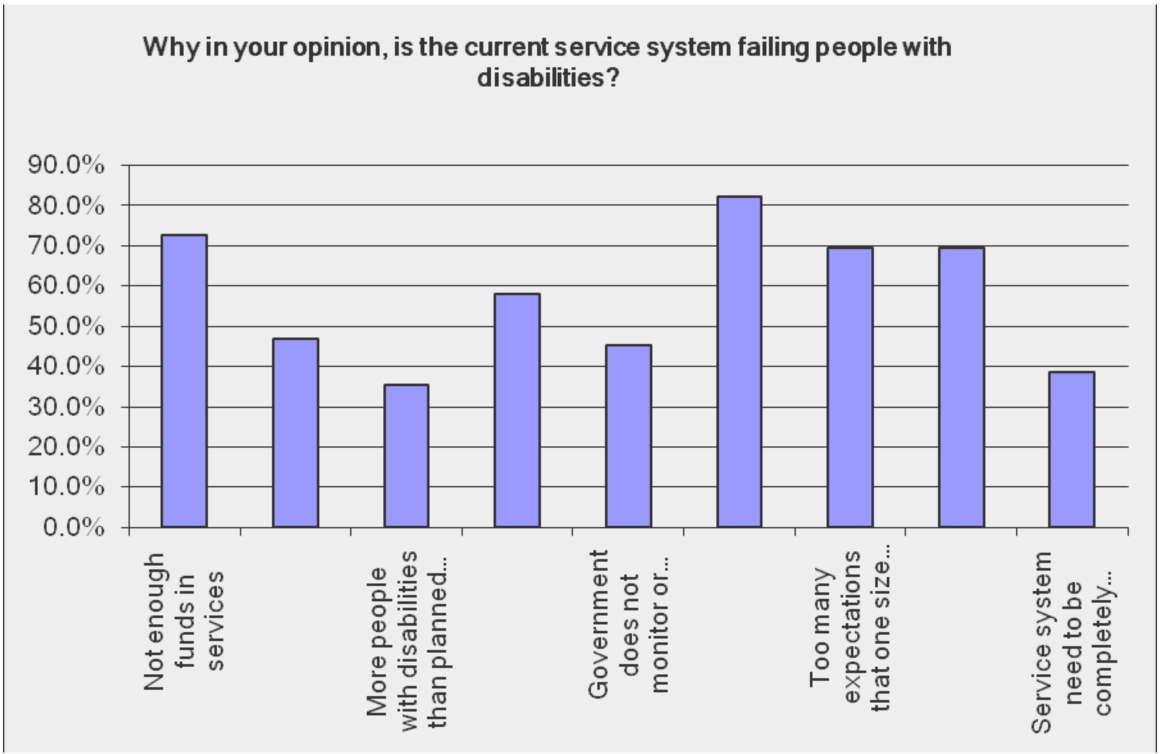
- *People being told of their entitlements by one central department e.g. disability aids and where to get them or what's available*

- *Disability services' ability to link and liaise with other services better. For example, to liaise with the local theatre, gallery or museum so people with a disability can visit there; to insist that they have disability access, to link them up with organisations that can help them do this e.g. Accessible Arts or Arts Access Australia, and to help them understand that people with a disability are people of all ages, all abilities and are interested in community issues and culture.*

How could the ways in which services are delivered — including their coordination, costs, timeliness and innovation — be improved?



PDA believes that individualised funding should be part of any new scheme introduced into Australia, in line with other countries.



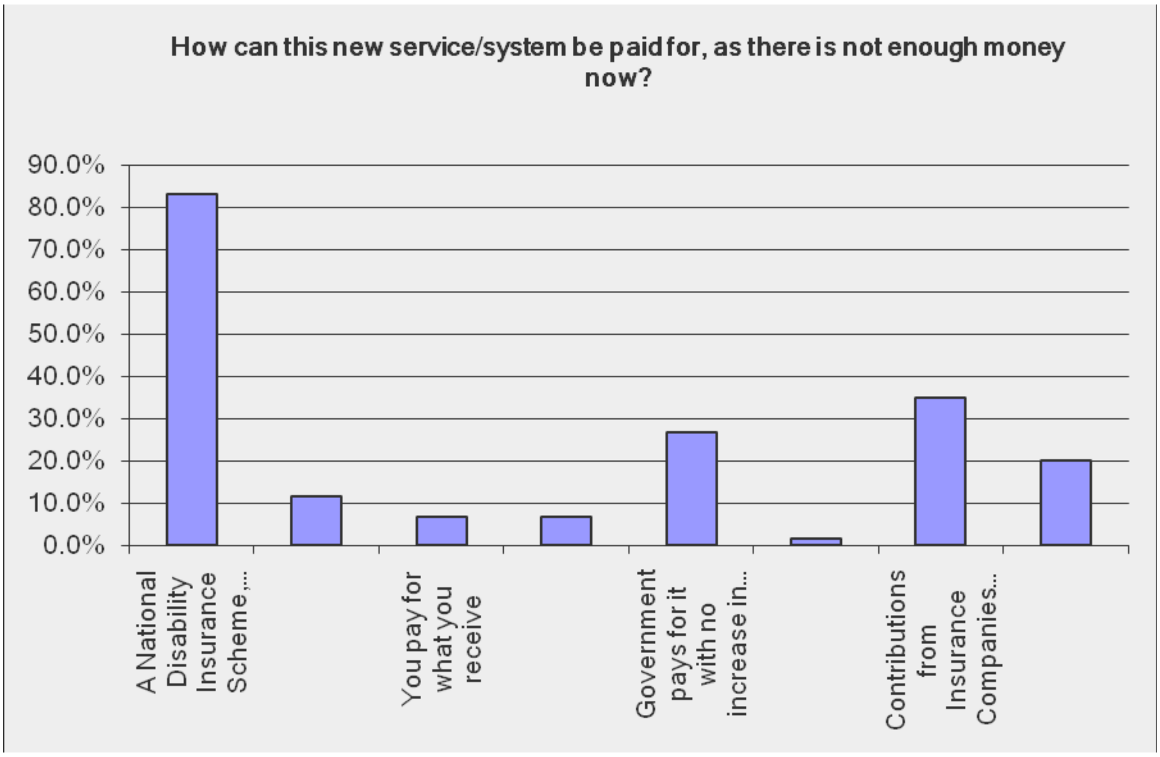
How could a new system get rid of wasteful paper burdens, overlapping assessments (the 'run around') and duplication in the system?

> *"This new system needs to be a complete clean break from the current rationed system"*
>
> *"Too much bureaucracy – just get on and do it "*
>
> *"Not enough information gets to the people who need it about the different services.*
>
> *"Governments fail to accurately assess needs"*
>
> *"Equipment recycling in equipment services is inefficient if done at all."*
>
> *"It is a mess and there is a lack of communication across and within services PLUS people are NOT being listened to. COMMUNICATION FAILURES are often the biggest problem of all. People get things they do not want or need because other people do not listen. They do not get things they need because of a one size fits all and you do not know what you need attitude. If people LISTENED and PWDs DARED to COMMUNICATE it would be a start but most of us are too scared we will lose what little we have."*

PDA believes the system should be a universal system, streamlined across the country, the same in all states and territories and based on Individualised funding

5. Funding

How should a new scheme be financed?



8. Conclusion

Physical Disability Australia in providing this submission encourages the Productivity Commission to ensure that every effort is made to develop a new system or scheme that is person centred and driven, first and foremost, and meets the individual needs of those who have a disability, in order to be equal to those without disability.

Historically people with disabilities have been viewed with 'pity,' and 'inability,' or conversely, as ''heroic and brave,' if they achieve life milestones equal to those without disability. . In effect there is a different set of standards for people with a disability, ranging from lower expectations, to hopeless situations that require (in some peoples eyes) little more than a roof over their head.

In reality every person with a disability, regardless of diagnosis, cognitive or physical abilities, has been assigned this different set of norms. Norms that include being a burden, a welfare cost, receiving handouts, to be pitied or in the worst cases, locked away because they do not fit societies' norms.

However many people with disability are able to achieve and live these same milestones, provided they receive the support needed to do so. Rather than say these same milestones are unable to be reached, we need to look at the barriers that are preventing people with disabilities from doing so, and question our attitudes toward providing appropriate and accessible support that encourages people in general to achieve their own potential.

PDA consultations for the purposes of this submission, believes that any new system/scheme must encourage and support people with disabilities to move forward to take their own place in society. This can be done by meeting people's needs in a way that ensures equality and equity, and will go a long way toward challenging society's accumulated myths and fears about disability as these attitudes are as discriminating and limiting as any physical limitations that a person with a disability has.

PDA's members have made it clear that the days of unequal treatment, accepting handouts or minimal support are no longer appropriate and are therefore demanding change in attitudes, in the way services and supports are distributed, in the way governments and other decision makers view people with disabilities, and changes within people with disabilities themselves as they grow and prosper as equal citizens in their own country.

APPENDIX

PDA Guiding Philosophies

The experience of people with physical disability:
Regardless of individual differences, it can be said with confidence that people with a physical disability, particularly those with significant mobility impairments.

1. experience discrimination within the community in some form;

2. have great difficulty gaining access to public and private buildings because of physical barriers such as steps, steepness of site and lack of parking;

3. Face greater costs than other people because of their disability (such as equipment, modifications to vehicles, household appliances and housing, home maintenance, transport, personal, medical and health care costs and managing a household) which impacts substantially on their financial situation

4. Generally cannot access public transport and are reliant on taxis, with varying levels of subsidy throughout Australia. Or are reliant on private vehicles with little or no assistance for installing hand controls and wheelchair hoists, or alternately family sized vans for those who cannot drive.

5. Face significant discrimination in finding/securing a job and obtaining promotional opportunities, despite the avenues for redress provided through disability discrimination legislation

6. Have lower incomes than their equivalent age/educated peers due to greater difficulties in getting employment and in achieving equal promotion opportunities.

7. Have fluctuating income if their impairment is associated with medical conditions leading to episodic periods of hospitalisation and/or absence from work. (Such people include some people with spinal cord injury, multiple sclerosis, muscular dystrophy, cerebral palsy, motor neurone disease and more)

8. Lack access to affordable, secure and appropriately designed housing, which is a critical issue for people with a physical disability. Lack of access to such housing has a major impact on our capacity to participate fully in the life of the community and to live as independently as possible within our own households.

ACCESS TO PREMISES

The new standards for access to public buildings for people with a disability were a significant step towards making our buildings safer and more accessible for everyone. This move has been applauded by PDA as many of our members are significantly affected by lack of access to public places in their community. PDA sees this as a significant step forward, but it is not enough.

Access to premises benefits everyone, people with disabilities, the ageing population, parents with small children and prams, and those who are temporarily disabled by sickness or accident and delivery persons for businesses. It makes sense; it is safe and very definitely an advantage to the whole community.

The Premises Standards will take effect from 1 May 2011 and will apply to new buildings and new parts of existing buildings undergoing renovation or upgrade. It is anticipated the BCA will be changed to reflect the content of the Premises Standards at the same time. This will ensure consistency between the requirements of building and discrimination law in relation to the construction of buildings.

ACCOMMODATION, SUPPORTED ACCOMMODATION, HOUSING

People with disability are ordinary people, and like ordinary people want a home of their own and a place to feel secure, safe and comfortable. Unfortunately in Australia this is not always easy to achieve.
Currently there is a housing shortage in Australia, especially in public housing and rental housing for lower income earners, which is the primary area or resource for people with disabilities, as their income is often insufficient to purchase a home of their own.

In March of this year, The Housing Industry Association (HIA) report said, *' the current shortage of 109,000 houses could increase to 466,000 over the next decade*.'. This is supported by a report from Department of Families and Housing, Community Services, Indigenous Affairs (FaHCSIA).

Australia urgently needs to expand the stock of affordable rental housing. The housing supply gap is having a direct impact on housing affordability for both renters and home purchasers. Most of this impact is on low and moderate income earners who were not home purchasers before the housing boom commenced in the late 1990s.

The affordability of the private rental housing market has declined in the last 12 years, particularly for those households on low or fixed incomes.[1] *Between September 2006 and*

September 2009, real rents increased by 12 per cent.[2]*Key workers and households on moderate incomes are having difficulty saving with rising rents and increasing house prices.* [2]

PDA believes that all persons with disability are entitled to affordable, appropriate housing or accommodation in the community of their choice; and that

- Every person with a disability, who requires support to live independently in the housing or accommodation of their choice, should have the opportunity to be supported to do so.
- All housing options should be developed in consultation with people with disability as well as appropriate professionals to ensure consistency and continuity to a National Standard
- All Housing / Accommodation options should be developed in the wider community with inclusion and access to all areas of the community being the first principle.
- Young persons with disabilities should never be placed in Nursing Homes or other institutional settings, in lieu of their own home, at any time.

Physical Disability Australia believes that all accommodation should be affordable and accessible to the wider community, including people with disability, ageing communities, young people, single people and those with families.

AIDS AND EQUIPMENT

Equipment/Aids for people with physical disabilities are not an optional extra or a luxury, but rather, are essential for day to day mobility purposes and for daily living and increased independence. For instance a wheelchair may be the only mobility method that many people have. It is their legs, and the only way a person is able to move about in most cases. Without a wheelchair many would have to stay in bed, or worse be admitted to Nursing Homes in order to be assisted with feeding, bathing, toileting and more. These same people could not work, play or learn or ever be fully integrated into all aspects of Australian society.

This is the same for other equipment. A specific type of bed may be required to enable a person to sleep uninterrupted by pain and to assist in rising in the bed, a walking frame to assist walking and movement, a hoist to assist a person to transfer from one place to the next, or a reaching stick may assist in picking up items from the floor or reaching higher places. Bathroom equipment includes transfer boards or hoists (portable or fitted to the ceiling) enabling movement from one place to another (from wheelchair to toilet for example) or a shower stool to allow sitting whilst bathing.

These and many other types of equipment allow a person with physical disability to be as independent as possible, maintain personal dignity and will also assist those who provide supportive assistance, such as paid support workers or family members. [3]

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[2] *Regulation and Growth of the Not-For-Profit Housing Sector: Discussion Paper – FaHCSIA – April 2010*

[3] *PDA policy paper Equipment and Aids required by people with physical disability. 2009.*

Many people with physical disabilities require differing aids and equipment to assist them to live ordinary lives, and contrary to popular belief do not just include wheelchairs and crutches. Without this equipment people are unable to:

- Communicate, either verbally or by e-technology
- Physically leave their bed or their home.
- Prepare meals and live independently
- Dress independently
- Transfer from one position to another, such as wheelchair to toilet or shower or to bed
- Drive a car using hand controls, wheelchair roof hoist and other modifications
- Attend a movie or visit a friend, or interact in their community
- Do the shopping, cooking and cleaning, or other daily tasks
- Make friends or be with their families and visit other people, go to church, go to the library, attend a show or a movie, etc.
- Be employed in open employment
- Study or learn
- Interact in many other activities taken for granted by those without disability.

The Rudd government made a commitment to work toward streamlining and simplifying the Aids and Equipment system nationally and PDA believes that this is urgently needed.

This would be an improvement on the current myriad of systems and schemes in place across Australia. These schemes differ in the amount of funds available from one state to the next, waiting times and lists, availability of equipment, shortages of staff qualified to assess for equipment needs and many other issues that result in a person with a disability using out-dated equipment.

ATTITUDES

PDA believes that everyone is born equal and people with disability are people, first and foremost. We believe:

- People with disabilities can and do take up the same range of opportunities as anyone else. We work, play and contribute to our community. We are parents, sons or daughters, but mostly we are individuals.

- Like others, people with disabilities are sexual beings and have the right to enjoy sexual relationships and express their sexuality in the same way as other people.

- Patronising or avoidance behaviour can occur when people do not understand people with disabilities. Active listening, asking the person with the disability, and awareness training can help in these instances.

We believe that disability is normal and difference is human.

ABUSE AND NEGLECT

People with physical disability are often vulnerable to physical, emotional and sexual abuse, and to being neglected and abandoned.

Physical Disability Australia believes for Abuse and Neglect:

- Physical Disability Australia is committed to advocating for the prevention of all forms of abuse and neglect against people with disabilities.

- Physical Disability Australia encourages any person experiencing any form of abuse or neglect, or suspecting another person is experiencing or committing abuse or neglect, to report the situation to the relevant authorities or to seek help to do so.

Physical Disability Australia believes that abuse and neglect of people with disability is unacceptable in any situation.

ADVOCACY

The rights of people with disability as members of the Australian community must be respected and upheld, and therefore PDA believes that advocacy is the right of all Australians, and must be independent and individual centred.

EDUCATION

Education is central to the life chances and potential and potency of people with physical disabilities to be part of the community.

Physical Disability Australia believes:

- An inclusive education is the right of all Australians, including those with disabilities.

- Inclusive education includes personal support, note takers, peer support and mentors, modifications and equipment resources, as well as full environmental access and accommodations provided by the educational facility of the individual’s choice.

- Equitable education provides opportunities for personal, social and academic growth and development, and sets the stage for later life experiences, most especially in employment.

- Further reading on PDA's position on education can be obtained from the PDA (formerly PDCA) *Submission* ***to the Senate Inquiry On Education of Students with disabilities see:*** ***http://www.pda.org.au/published-papers*** ***under published papers.***

EMPLOYMENT

PDA supports employment of people with physical disability in open employment with award based conditions, and room for promotion and/or advancement.

PDA believes for Employment:

- All people with physical disability have the right to work with award-based wages and conditions consistent with Australian work practices and opportunities.

- Physical Disability Australia does not support people with physical disability being employed in Business Services (*Sheltered Workshops*).

Early Interventions - PDA believes that a work ethic must be instilled in all people at the school level, and whilst this is not to overtake education, it must become an everyday practice that all students, including those with a disability are introduced to the concept of working, and follow through with the opportunity for skills training introduced within the final years of schooling.

Vocational Education - Opportunities must be increased for all people. Today in Australia there are fewer and fewer school leavers taking up Cadetships and Apprenticeships than ever before, yet these are essential to our future as a nation. People with disability are more than capable of undertaking Cadetships and Apprenticeships, yet this is seldom an opportunity that is offered to people with disability.

Australian Public Service - *'The decline in employment of people with disability continued this year, with the proportion of employees now down to 3.0%. In absolute terms, the number of employees with disability fell for the fifth consecutive year. The fall this year represented a decrease of 4.2%, compared with an increase in overall ongoing employee numbers of 1.6%. The decrease in absolute terms (199 ongoing employees) is the largest drop since 2002–03.'* [4]

Job Seekers with Higher levels of disadvantage – A former Labor government (Keating) initiated 'More Intensive Flexible Services' (MIFS) in Queensland, as a pilot programme for those with higher levels of disadvantage, and despite this programme being successful in its ability to place in employment and support those with higher levels of disadvantage, the Howard government scrapped this and other programmes that actually worked.

Performance Management Principles- PDA believes that disability employment services place too much emphasis on getting short term outcomes for funding reasons, and are becoming larger and therefore less in touch with their client base and place less importance on sustainability in employment, job satisfaction and career advancement.

Administration costs - In addition to the recommendation above, PDA believes that Administration takes the largest share of grant funds in any employment services. This was evidenced by the writer who worked in such an organisation where funds were channelled into overall rent and administration of an existing organisation. There seems to be no goodwill within larger organisations

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[4] *Australian Public Service State of the service Report - State of the Service Series 2008–09*

that this is a service offered within the community, but rather these have become businesses in their own right and chasing the funds.

Personal Support in the workplace - PDA recommends that funds be allocated under the NDIS to the individual as part of their path to employment.

Supported Wages - PDA does not support supported wages in its current configuration, and recommends that a review of this process be undertaken as part of any NDIS.

Workplace equipment provision - PDA believes that any equipment allocated for support reasons should always remain with the individual if changing employment and not remain with the previous employer.

MENTAL HEALTH

People with physical disability may have mental health conditions which may or may not be related to their disability, and be a temporary or lifelong condition.

Physical Disability Australia believes:

- We have the right to equitable access, confidential and flexible support, information and treatment.

- Flexible support includes longer appointments with counsellors, in-home support, and appointments where supporters and/or advocates are welcomed.

- Health Professionals must be educated regarding the mixing and side effects of medications in relationship to a person's disability.

PERSONAL SUPPORT

Personal support refers to a person, employed (paid or not) for the purposes of assisting another. In this instance, people with disability are often vulnerable to the whims and actions of those who provide the support, including service providers.

More often than not, there are insufficient hours or dollars to pay for this support and most service providers do not supply services out of hours. This is particularly true for those who live in rural and remote communities.

This means:

- People with physical disability have the right to support that enables and encourages a "good life".
- Adequate funding for the support.
- Support that is responsive to a person's needs.
- Having consistent protocols, 24 hours a day, 7 days a week.
- After hours support for emergency reasons
- Respect and dignity - "my body, my rules" and/or "my house, your workplace".

- Safety as an employer and an employee of support persons
- Adequate training for the person with the disability as an employer of support people, and training for their employees.
- Uphold the rights and choices of the person.

Physical Disability Australia believes that without these things, some people will not survive.

TRANSPORT

All public transport, including rail, road, air and water, should be accessible to allow people with physical disability to travel as all other passengers: anywhere, at any time, and without restrictions.

Physical Disability Australia believes for Transport:

- All fares and charges, conditions and services should be equitable to all passengers

- Future design changes should be done in consultation with Disability Advisory Committees to enable more transparent and accessible passenger services, including:

  - Visible meters in taxi vehicles;
  - Travel facing in the direction of the vehicle, not sideways or back to front;
  - A view for passengers in wheelchairs to enable sightseeing and way finding;
  - Safety Design Standards, including tie downs and seat belts;
  - Booking services online for people with disability as well as the general public, which are efficient and responsive to requests

- Information on rights and responsibilities is made available to all passengers.
- People with disability requiring attendant support when travelling should not be charged an additional fare for their support person and a National Companion Card Scheme should be in place.

Physical Disability Australia believes that public transport is for all Australians, and should meet the needs of all Australians.