

Advocacy Tasmania Inc
NATIONAL DISABILITY STRATEGY
SUBMISSION
November 2008

About Advocacy Tasmania Inc

Advocacy Tasmania Inc. (ATI) is an independent, statewide, non-profit, advocacy service for older people, people with disabilities, people with mental health disorders and their families and carers.

Advocates are available for people in the following client groups:

- People with disabilities
- People living in aged care facilities and potential residents, and people receiving Community Aged Care Packages (CACPs and EACH)
- People in receipt of or eligible to receive Home and Community Care services
- People living with dementia and memory loss
- People with a mental illness or mental health disorder
- Carers and relatives of all the above groups

Advocacy Tasmania also operates a scheme which provides free, trained volunteers to represent people with mental illness in hearings before the Mental Health Tribunal across the state.

The Service's Mission Statement is:

“Advocacy Tasmania Inc., acting independently at all times, works to both empower and uphold the rights and interests of older people and people with disabilities”.

The Service's Aims are:

- To provide an equitable, high quality service to all people who use the service across the State.
- To assist clients to exercise their rights by providing information and support to self advocate and individual advocacy representation.
- To protect and enhance the rights and interests of our client groups through promotion, education and community development.
- To identify systemic issues affecting our client groups and to take effective action.

- To manage the human and financial resources of the organisation efficiently and effectively, overseen by good governance.

In 2007/08 Advocacy Tasmania provided individual advocacy to 1323 clients represented 206 people at Mental Health Tribunal hearings and provided information and education sessions to 4950 participants – a total of 6479 Tasmanians assisted.

The recommendations provided in the following National Disability Strategy submission draw upon our extensive and contemporary experiences of assisting hundreds of people with disabilities and their families across the state each year. Comments have been sought from people with disabilities and their families who have used our advocacy services; from ATI Board members, all of whom identify as people with disabilities or carers; and our staff.

The list is not exhaustive but represents the most immediate priorities that were raised during our internal consultations for our submission to the Strategy.

Consultation Questions

1. What do you think should be included in the National Disability Strategy

What are the greatest barriers that people with disability face to participating fully within the community and what specific local or national actions could be taken to overcome these barriers?

Barriers to Participation

Education

- The high cost of education for people on the DSP precludes many people from post secondary education
- Lack of adequate support services required to participate in education
- Lack of affordable and appropriate transport
- Many education facilities say they do not have the resources to provide support to students with disabilities
- Lack of understanding by facilities, just how difficult it is for people with disability to meet the requirements of their course without adequate supports.
- Difficulty in getting work placements due to access and support issues, which hampers transition from school to work
- Poor physical access in many schools, colleges, TAFEs, and universities
- Some people with a disability need more time to complete their studies. If they take twice the time it costs them twice as much in fees, transport and other costs to complete their studies than for a non-disabled peer.

Employment

- Many people with disability don't continue in post secondary education due to the multitude of barriers which, in turn, reduces their employability

- There are not enough incentives or promotional programs to inform employers of the advantages of employing people with disability.
- The current paid incentives to employers (13 weeks) are inadequate and usually do not result in ongoing employment.
- Mentoring is generally not available for people with disability
- Some people on DSP are so fearful of losing their entitlements, or not being able to get back onto the DSP if their employment fails, that they will not seek employment. Many families are also fearful and so discourage their relative with a disability from seeking employment.
- When people on DSP apply to Centrelink to find employment, automatically, their DSP is re-assessed - this also discourages people from seeking employment.
- Specialist Disability Employment Services: People with disability often complain that it is not clear what their entitlements are to support and training from the employment services and that each client does not receive the same access to education and training via such services.
- People with disability are encouraged to do one training program and then to “move on” to employment and often one training program does not fully equip them to be employment ready. There is no ongoing learning ethos or strategy in the sector for people with disability
- In the late 80’s and early 90’s government had a stronger commitment to assisting people with disabilities from supported employment (ie sheltered workshops/business services) to competitive employment. Such models as enclaves and workcrews were advocated. There was much more active engagement with this group to explore options for competitive employment. Business services nowadays seem to have returned to operating as a separate world with little movement of workers into open employment.
- Because there is little or no flow through in Business Services, there are very few vacancies for new employees to commence work in supported employment as a first step to open employment. Some Business Services appear to wish retain the productive workers so they can remain financially viable as a business.

Centrelink

- People with disability are at higher risk of being “breached” by Centrelink due to lack of flexibility and understanding of their circumstances in situations where due to their disability they may not be able to report (e.g. mental health illness).
- Centrelink is “daunting”, “intimidating” and “confusing” for the vast majority of people even if they do not have a disability. They need to become friendly, accessible and flexible so that their services are “accessible”.
- Centrelink does not provide people with clear and easy to understand details about what service and benefits to which they may be entitled.

Social Inclusion

- People with more profound disability are the most socially isolated in the community. They often live in group homes or have drop-in support, but support is provided for the essentials and not community access and involvement.

- Many Day Options Programs which people with more severe disability attend, are not creative or flexible in providing programs that maximise social inclusion.
- Lack of social options for people with physical disabilities. Generally expected to participate in mainstream social activities but unable to due to cost, lack of transport, lack of access to person care; lack of confidence.

Episodic Disability

- There is insufficient flexibility in Centrelink and DSP arrangements to adequately address episodic disability which will allow people with disability to work when they are able and then automatically go back onto benefits when they are unwell.

Anti-Discrimination Legislation

- Relies on people with disability or their families to make complaints to draw attention to breaches of the Act. This places a lot of demands on complainants.
- There needs to be obligations under the DDAAct that need to be adhered to and which are evaluated for compliance.
- The Govt needs to be proactive to bring about change to the advantage of people with disability (in areas of discrimination, access etc).
- The DDA Access Standards and Building Codes are inconsistent with each other.

Continence Aids

- The subsidies provided for continence aids either under CAAS or by State governments are totally inadequate to meet the needs of the majority of people requiring continence aids. The \$400 pa subsidy does not even meet 50% of the needs of a person with a disability who is a paraplegic - costs for people in this situation are usually \$1,000-\$1,400 pa just for continence pads alone.
- Due to inadequate subsidy for continence aids people with disability report that they have to 'ration' the occasions that they access the community.
- The continence aids subsidy is not sufficient to support a person with a disability to attend full-time employment.
- Continence aids subsidy needs to be provided according to assessed need rather than an across the board maximum subsidy for all.

Equipment

- In Tasmania the contribution that the State Community Equipment Schemes provide to a person with a disability to purchase an electric wheelchair is \$6,000 and this subsidy has been the same for many years - with the average electric wheelchair costing at least \$16,000, it is impossible for a person on the DSP to save the other \$10,000 needed every 5-7 years (which is how often wheelchairs have to be replaced).

- People with disability now have no other avenue to seek funding for expensive equipment such as electric wheelchairs as fewer and fewer charity and community organisations are willing to fund such equipment.
- People with disabilities who move into residential aged care facilities lose access to the state funded equipment scheme.

Poverty and Disability

- There needs to be an understanding and acceptance by government of the cost of disability to the person, their family and the community.
- There have been suggestions that some of their costs might be better alleviated by providing more subsidies (ie for rates, electricity, bus fares etc).
- There has been considerable research into this issue in recent years, but it has not been translated into changes in government policy.

Mental Illness

- It needs to be universally accepted that mental illness is a disability - mental illness is accepted as a disability in some areas but not others.

Specialist Services

- Unmet Needs in Tasmania - currently 454 Tasmanian are waiting for support services from State Disability Services. The latest waiting list figures for disability support are 292 waiting for individual support packages; 123 waiting for community access or day support packages; and 39 waiting for accommodation support. There are no waiting list figures available for respite.
- Many people who are on waiting lists for supported accommodation, individual support packages, and community access or day support packages have been waiting 2-3 years.
- The Tasmanian government, in June this year following the budget, gave a commitment to provide 75 more individual support packages, 50 extra community access packages and 12 more accommodation placements - this will only meet just over one-quarter of the waiting list, when growth in demand for disability support services is rapidly escalating in this State.
- Many people who are receiving individual support package funding or HACC services are living marginal lives due to underservicing (ie they receive some but not an adequate number of support hours). This commonly involves people receiving minimum personal care support only, which results in severe restrictions to the person's life (eg having to spend long hours in bed). Such situations commonly break down resulting in the person having to go to hospital or a nursing home (even if they are young). This is a far more expensive option than providing the few additional support hours per week that is required. This also results in cost shifting from State to Commonwealth but more importantly it results in the person having to go into institutional care rather than continuing to live independently in the community.
- Commonly reported problems with personal care services;
 - Often inflexible in the hours that are provided. Clients requesting a change of timing are commonly refused.

- Poor standard of worker. Difficult to recruit workers with right attitude and aptitude given the low wages paid.
- Clients in rural areas often can't get workers to provide care
- Where rural clients do receive care travelling time of workers is deducted from the clients hours
- Lack of coordination and integration of services – needs of person with a disability not looked at holistically

Transport

- The cost of transport or the lack of availability of transport often means that people with disability cannot access education, employment, services or the community. It is a pivotal support service which is often not available which then excludes the person from many or all aspects of their community.

Affordable and Accessible Housing

- There are currently approximately 3,000 people on the Housing Tasmania waiting list. Many are people with disabilities. They face long waits to be housed as not all public housing is accessible.
- The private rental market can be very difficult for people with disabilities to access due to high costs, lack of physical access, discrimination and the competitive rental market in all major cities.
- A strong commitment to public housing from Commonwealth and State Governments is the key to provision of accessible and affordable housing to people with disabilities

Community Attitudes

- More often than not people with disabilities are seen as 'recipients of services' and a 'burden' rather than equal members of the community who have a valuable contributions to make.

Actions to Take

Communication and Information

- Commonwealth, State, Local Government need a communication and information strategy so they can optimise information about services, supports, rights and entitlements for people with disabilities and their families.

Provision of Individualised Funding

- Overwhelmingly people with disabilities and families tell ATI that they want to directly receive government funding so they can purchase their own services. This will provide people with greater control over supports, give them more flexibility, and would contribute to improved quality of service delivery. Overall, this would allow people with disability to have wider choice and live with greater dignity.

Centrelink Reform

- Reform of Centrelink is needed that will:
 - Make eligibility and "access" easier

- Become more flexible and simpler in their systems
- Significant increase in the DSP with costs of disability being recognised.
- Have systems that ensure financial security for people with disability
- Simplify letters and forms so that they can just “confirm” previous information rather than have to fill out a whole new form again.

As a Society

- We CAN afford the basic services and supports that people with disability require to live a decent life in the community. Such basic supports should be provided as an entitlement. This is needed if Australia is serious in its intention to meet our obligations under the UN Convention on the Rights of Persons with Disabilities.

Young People with Disabilities in Nursing Homes

- Nursing Homes continue to accept younger people as residents because it is seen as there are no other accommodation options - **this is not acceptable.**
- When younger people go into nursing homes, they no longer have access to the community services such as transport, the state community equipment scheme and community access services.
- A properly funded national program needs to be put in place to end this situation

Leadership from the Commonwealth Government on Affordable and Accessible Housing

- An enhanced national commitment to public housing
- Having a decent proportion of affordable housing being accessible.

Advocacy

- ATI believes that disability advocacy is undervalued in the contribution it makes to the lives of people with disabilities
- The National Disability Advocacy Program has had some enhanced funding from the Commonwealth to fill some regional service gaps, but overall the NDAP is poorly funded.

Criminal Justice

- Needs to be a national strategy to address
 - Disproportionate representation of people with disability in prison – especially autism, ABI and Mental Illness.
 - Prison becoming an alternative accommodation option for those with disability who do not fit into current service models.
 - More training for prison staff and police in disability
 - Criminal justice system does not understand disability
 - Access to legal representation for all people with disability who have legal issues - civil as well and criminal

Charter of Rights

- A National Charter of Rights would benefit all citizens, including people with disabilities

Cost of Disability

- Recognition of the true costs of disability and mechanisms to compensate

Continence

- Continence aids subsidy needs to be provided according to assessed need rather than an across the board maximum subsidy for all.

Transport

- Increase the Taxi subsidy
- Better use of transport resources through improved coordination

Positive Attitudes to People with Disabilities

- A public awareness campaign that emphasises the positive social and economic contribution that people with disabilities make to the community

Employment

- Increase subsidies to employers from 13 to 52 weeks
- Better publicity of availability of subsidies and entitlements
- Enhancement of supports so that people with disabilities can participate in work experience, job trials and ongoing employment
- Renewed emphasis on options for people to move from business services to competitive employment
- Government setting the standard by employing more people with disabilities in the public service

National Abuse Prevention Strategy

- Needs to be a national strategy to address this issue
- What is presently in place is very piecemeal
- National Abuse Hotline is perceived as taking little or no real action in relation to abuse. They do not investigate all complaints (if they are anonymous). Needs to be a greater capacity to investigate and then refer for action.
- The Aged Care Complaints Investigation Scheme has a process in place for investigating complaints and allegations, even if anonymous. The Disability Sector needs something similar.
- Police processes need to be in a timely fashion and appropriate to disability
- National Awareness Campaign required (e.g. California "Face it: It's a Crime" Campaign)

Consultation Questions

What areas of research do you think should be a priority to better inform the National Disability Strategy

Research

Innovation

- Funding of pilot projects often piecemeal and short-lived. Need a better approach

Ageing and Disability

Advocacy and it's benefits

- Little or no research ever undertaken in Australia as to the benefits of advocacy

Cost of Disability

Transitions

- Overcoming the problem of service silos and concomitant problems of managing important life transitions e.g. school to work; family to independent living; aged care; prison to community

Models of Support for clients living independently who have complex support needs.

Individualised Funding and Personalised Budgets

Consultation Questions

2 We are interested to know about your personal experience.

Advocacy Tasmania Inc consulted with a number of people with intellectual disability as part of the preparation of this submission. Their comments are reproduced below

National Disability Strategy Plain English Questions and Answers Comments by eight people with intellectual disability given to advocates of Advocacy Tasmania November 2008

What are the main things that stop you doing what you want to do in the community?

Safety – not able to walk on my own and need to be careful

I am independent enough to do things on my own

Not enough pension (DSP) to go out much and get stuck (for money) on off pension week

People are rude to me when I am out – like school kids

Not many good working public toilets and some are for both men and women which I don't like

Cost and reliability of taxis - they don't come when you want them

Bit hard if you have no money

No one to take me to local sports events

I like to go out but can go only sometimes

Don't always have (staff) support to go out

What are the good things in your community?

Going out for walks and to the shopping centre

Going to the local bank on pay (pension) day

Going out for tea in the community with other people with disabilities

Going to an interest group, monthly

Going to my day service

Going to dances, for people with disabilities

Going for walks, to the social club and to dances

Being close to shops and Doctor when I need that

Using the local buses

Going out for drives

Going out for a meal at the local pub

Going to the local shopping centre

Going to the markets on the weekend – something to do as I like to always have something to do

Going to day activities Monday to Friday

Visiting my family and going out with them for a seafood meal

Going out dancing

What are the main things that stop you having outings?

Not enough support (staff) to go out

Not wanting to have support with me when I do go out, like to the markets

When other people I live with don't want to go out

Money – often have to borrow money to go out

Transport issues – cant catch buses as cant read and not safe

No transport – can't get out

What are the main things that stop you getting a job?

Got "work" in a supported employment day service

I do work part time (8 hours/2 days) and that's enough, and then I do activities like candle making and 10 pin bowling on other days

My disability stops me, but I like "supported" work at my day service where I can do what I want to do and don't have to wear a uniform

Staff – they don't want me to leave my day service

Used to work at a laundry but retired and now go to a day service where I like to help and keep busy

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