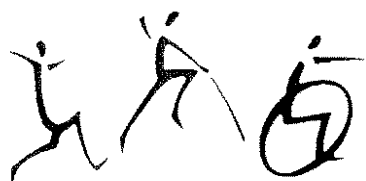


Provided at hearing
22/2/05 DisAction
(Revised Sub 232)



DISABILITY ACTION INCORPORATED

Rights, Equality and Empowerment for People with Disabilities

**Submission to the
Senate Community Affairs Committee**

Inquiry Into Aged Care

February 2005

**Authors: David Morrell
Suzanne Mackenzie
Phillip Beddall**

Disability Action Inc.
295 Torrens Road
Croydon SA 5008
Ph: 08 8346 8288
Email: systemic@disabilityaction.asn.au
www.disabilityaction.asn.au

Summary

This submission addresses the third term of reference:

“the appropriateness of young people with disabilities being accommodated in residential aged care facilities and the extent to which residents with special needs, such as dementia, mental illness or specific conditions are met under current funding arrangements; ”

Disability Action argues that the presence of young people with disabilities in nursing homes is a serious violation of their human rights. It is a major failure on the part of Australian governments to uphold the commitments they have made in international and domestic law.

Discussion of the finer details of the issue can all too easily lead to an attempt to make the inexcusable tolerable. Disability Action understands that the solution to the problem is likely to be complex and multi-faceted. However, fundamental human rights must not be traded off in the quest for what is possible.

We illustrate the poor performance of the South Australian government in providing the accommodation services that would divert younger people away from nursing homes.

We then present a discussion based on the United Nations Declaration on the Rights of Disabled Persons and on the Disability Services Acts that exist in the Commonwealth and many State jurisdictions.

We conclude with some recommendations to improve resources, accountability and objectives in accommodation policy for people who have disabilities.

Disability Action Incorporated Its Advocacy for Young People in Nursing Homes

Disability Action Inc. fights for the rights of people with all forms of disability. That includes people with psychiatric, physical, intellectual and sensory disabilities as well as people who have a brain injury. Disability Action is an advocacy organisation. Advocacy is speaking for or with a person or group, usually to achieve a goal which has been agreed on.

This means we:

- Work to change laws, policies, rules, decisions and practices which disadvantage people with disabilities. This is called systemic advocacy;
- Help individuals to have their wishes and opinions heard, get their needs met and have their rights respected through individual advocacy, which is done by paid staff and the many dedicated volunteer advocates in our DARE program;
- Provide information and resources on rights and advocacy through our publications and advocacy resources.

Disability Action has sought improvements in accommodation options for people with disabilities since its earliest days in 1987.

In mid 2003 Disability Action agreed to facilitate the SA Engine Room for the Young People in Nursing Homes project. Our representatives collaborated with Engine Rooms in other states and made a submission to a State Parliament inquiry into supported accommodation.

Our representatives have been actively involved in the national Young People in Nursing Homes Alliance and in national level advocacy.

For some of us, this issue is very personal. For example, in 2004 Disability Action volunteer advocate Suzanne Mackenzie told a national radio audience how she was almost forced into a nursing home against her will.

Pursuit of rights, equality and empowerment for people with disabilities is at the core of Disability Action's work. Many issues connected to young people in nursing homes provide rich examples of the importance of improving protection for the human rights of Australians who have disabilities. In pursuit of this broader goal, Disability Action actively supports work towards replacing the present Declaration on the Rights of Disabled Persons with a binding Convention. We have pursued this work in collaboration with other members of the Australian Disability Rights Alliance.

South Australians With Disabilities

In South Australia compared to the nation, there is both a higher demand for nursing home accommodation arising from older people and more people with disabilities.

The South Australian population is older than in most other states. While 12% of all Australians were older than 65 in 2001, 14.5% of South Australians were older than 65.¹ This is 21% above the national average, or 225,000 South Australians.

South Australia, Tasmania and Queensland had the highest disability rates in 2003 (23%).² This is 15% more than the national average of 20%. That's 357,000 South Australians who have a disability.

Yet South Australia performs very badly in funding the disability accommodation services that might provide alternatives to nursing homes. For example, in 2001-2002 no other state spent less per resident on accommodation services than South Australia.³

Spending per Resident (\$)

	SA	Qld	Vic	WA	NSW	Tas	ACT	NT	Aust
Inst'n	60 803	66 375	74 597	96 313	111 834	90 609
C'ty	63 507	94 601	73 684	90 900	107 434	98 732	78 612	..	86 360

Low spending is reflected in low availability of accommodation services. In 2002 accommodation services were used by 0.66 South Australians per 1,000 of the population, compared to a national average of 1.06.⁴

WA	NT	SA	Qld	NSW	Tas	Vic	ACT	Aust
0.50	0.57	0.66	0.82	0.97	1.75	1.88		1.08

¹ "Australian Social Trends 2002: Population - Population Composition: Regional population ageing" ABS 2002

² Publication 4430.0 "Disability, Ageing and Carers, Australia: Summary of Findings" Australian Bureau of Statistics 15 September 2004

³ Report on Government Services 2004 Table 13A.24, Productivity Commission 2004.

⁴ Report on Government Services 2004 Table 13A.18, Productivity Commission 2004.

South Australians with disabilities are already steered towards congregate / institutional care more strongly than in any other state.⁵ The capacity of such services to absorb people coming out of aged care nursing homes is therefore likely to be less than in other states.

Consumers of community-based or in-home accommodation support services as a proportion of all accommodation consumers, (per cent)

	SA	NSW	WA	Tas	Qld	Vic	ACT	NT	Aust
2002-	59.5	65.6	74.0	75.7	76.3	81.0	100.0	100.0	72.9

This situation has been made worse because of long standing failure by the South Australian government to meet its obligations under the Commonwealth, State and Territories Disability Agreement.

Increase in Spending on Accommodation Support Services 1998 – 2003 (pct)

SA	ACT	NSW	Qld	Tas	WA	Vic	NT	Aust.
3.0%	4.8%	6.3%	6.5%	7.5%	8.8%	11.2%	64.8%	8.0%

These factors produce the second highest occupancy rate of nursing home places in Australia, with 98.2% of available places for people with high care needs being occupied in 2003.⁷

The system clearly has no useable capacity to absorb increased demand. Yet demand will increase.

The population is expected to get older. Over the last 100 years, the proportion of the population aged 65 years and over has risen from 4% to 12% (in 2000). It is projected to rise to about 18% by 2020.⁸

Disability is highly correlated with age. Therefore, unless medicine and rehabilitation make great strides in technique and affordability, the proportion of the population with disabilities will also increase.

Some long term projections show the South Australian population declining as people pursue better economic opportunities on the East coast. However, this trend is not likely to affect the numbers of older people or people with disabilities to a great extent as many of them are not in the labour market. If anything, it will tend to elevate them as a proportion of the South Australian population.

The Bottom Line

There is a simple message that must never be forgotten amid the complexities of young people in nursing homes. It is a brutal message which is therefore often couched in niceties.

Let us dispense with those.

⁵ Report on Government Services 2004 Table 13A.6, Productivity Commission 2004.

⁶ Report on Government Services 2004 Table 13A.20, Productivity Commission 2004.

⁷ Report on Government Services 2004 Table 12A.7, Productivity Commission 2004.

⁸ Australian Social Trends 2002: Population - Population Composition: Regional population ageing" ABS 2002

Nursing homes are places where old people go to spend their last days in some comfort and dignity. They support people who are at the end of their life's journey.

Young people are at the beginning of their life's journey.

They plan for the future. They want to grow and develop and learn. They want to have relationships and sex and perhaps children. They want to work, have money, buy things. They want to have fun, go out to dinner, come home when they're ready and not when the curfew bell rings.

Young people do not give these things up unless all hope is denied. Surely there could be no greater denial of hope than to be forced against your will into a place where people go to spend their last months or years.

The intended residents of nursing homes do not expect to live in them for more than a few years at most. They expect to be among others in a similar position. In contrast, young people forced into nursing homes can expect a much longer future. They can also expect to experience isolation from most of the older people who share their home and frequent losses among whatever older friends they may make. In short, they can expect loneliness, grief and depression.

The Human Rights Dimension

Australia has signed the "Declaration on the Rights of Disabled Persons" and has given some effect to it in domestic law.

"The (Commonwealth) Human Rights and Equal Opportunity Commission Act 1986 established the Human Rights and Equal Opportunity Commission. ... and gives it responsibility in relation to seven international instruments ratified by Australia. These instruments are (in part) ...

Declaration on the Rights of Disabled Persons ...

*Declaration on the Rights of Mentally Retarded Persons"*⁹

Disability Action therefore believes that our nation's performance of its obligations should be examined as it applies to young people living in nursing homes.

The questions are simple. The answers are so indisputable as not to require any great degree of analysis or scholarship.

Article 3 of the Declaration on the Rights of Disabled Persons says:

"3. Disabled persons have the inherent right to respect for their human dignity. Disabled persons, whatever the origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow-citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and full as possible."

Being forced to enter a nursing home because your country has not provided adequate supported accommodation alternatives cannot be mistaken for a show of respect for human dignity.

Being forced into the company of sick old people cannot be mistaken as according to young people the same fundamental rights as their fellow citizens of the same age.

Being subjected to the restrictions and social isolation of life in a nursing home does not amount to observance of the right to enjoy a decent life, as normal and full as possible.

⁹ Human Rights and Equal Opportunity Commission web site

Article 6 of the Declaration on the Rights of Disabled Persons says:

“6. Disabled persons have the right to medical, psychological and functional treatment, including prosthetic and orthotic appliances, to medical and social rehabilitation, education, vocational training and rehabilitation, aid, counselling, placement services and other services which will enable them to develop their capabilities and skills to the maximum and will hasten the processes of their social integration or reintegration.”

Young people are forced into nursing homes precisely because the rest of the disability, education employment and medical services cannot provide the things described in article 6.

Nursing homes are about medical maintenance, palliative care and, at the end, dying. Their purpose is not to provide “...services which will enable them (people with disabilities) to develop their capabilities and skills to the maximum and will hasten the processes of their social integration or reintegration.”

They are typically under – resourced to achieve even their intended mission, let alone act as a surrogate for all of the other services that should have prevented admission to a nursing home in the first place.

Article 9 of the Declaration on the Rights of Disabled Persons says:

“9. Disabled persons have the right to live with their families or with foster parents and to participate in all social, creative or recreational activities. No disabled person shall be subjected, as far as his or her residence is concerned, to differential treatment other than that required by his or her condition or by the improvement which he or she may derive therefrom. If the stay of a disabled person in a specialized establishment is indispensable, the environment and living conditions therein shall be as close as possible to those of the normal life of a person of his or her age.”

Nursing homes are not places in which young people with disabilities may “...live with their families or with foster parents...” Nor are they places in which young people may easily “... participate in all social, creative or recreational activities.” Most such activities likely to interest younger residents are only available outside the nursing home. Transport and carer support to take part in off-campus activities is often not available.

It might be argued that enforced residence in a nursing home is justifiable because it is “... required by his or her condition or by the improvement which he or she may derive therefrom.” Perhaps this could be used as a thin an argument to justify detention of some young people in institutions with others of around their own age. However, this argument can not possibly be used to support detention of younger people in nursing homes meant to ease the last days of frail old people. It cannot be used to support a claim that Australia is showing respect for the right of people with disabilities who need intensive support to an “... environment and living conditions ... as close as possible to those of the normal life of a person of his or her age.”

Finally, let us turn to the Declaration on the Rights of Mentally Retarded Persons. This appears to be relevant in as much as some people detained in nursing homes are there because of brain injuries, some of which would affect cognition and memory.

Article 7 says:

“7. Whenever mentally retarded persons are unable, because of the severity of their handicap, to exercise all their rights in a meaningful way or it should become necessary to restrict or deny some or all of these rights, the procedure used for that restriction or denial of rights must contain proper legal safeguards against every form of abuse. This procedure must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic review and to the right of appeal to higher authorities.”

There are no safeguards on detention of younger people in nursing homes.

They are forced into them out of desperate necessity. There is no statutory authority to issue a Community Treatment Order after due process has been observed. There are no detention orders with limited duration and mandatory independent expert review processes. There is nowhere to lodge an appeal.

Claims to natural justice such as those in the preceding paragraph cannot even be made at all on behalf of nursing home internees whose mental processes are not impaired.

The Commonwealth and State Disability Services Acts are intended, in part, to give effect to Australia's obligations under the various human rights treaties it has signed. This is especially true of the disability service standards which form part of the Commonwealth Act and many State Acts.

Let us consider these briefly.

“Standard 1— Each consumer seeking a service has access to a service on the basis of relative need and available resources.”

The intent is to ensure rationed access to services. However, there is a presumption that there will at least **be** some possibility of access. Forcing young people out of disability services into aged care services is an ultimate admission by governments that they have failed to provide resources to meet even their own standard.

“Standard 2— Each person with a disability receives a service which is designed to meet, in the least restrictive way, his or her individual needs and personal goals.”

A nursing home cannot be taken to be the ‘... least restrictive way...’ when there are community based models for delivering support services. Therefore this standard is breached at once.

“Standard 3— Each person with a disability has the opportunity to participate as fully as possible in making decisions about the events and activities of his or her daily life in relation to the services he or she receives.”

It is pointless to discuss this standard further because, in very many cases, the desire of younger people **not** to accept nursing home services has been over-ridden.

“Standard 4— Each consumer's right to privacy, dignity and confidentiality in all aspects of his or her life is recognised and respected.”

Congregate care facilities may do their best to demonstrate respect for this right. However, the right can never be as strongly supported in congregate facilities because of the very fact that residents live in close proximity to each other when more normal, home-like environments are possible.

“Standard 5— Each person with a disability is supported and encouraged to participate and be involved in the life of the community.”

Anyone detained in a nursing home is starting from far behind the eight ball in this regard simply because they live apart from the rest of the community.

“Standard 6— Each person with a disability has the opportunity to develop and maintain skills and to participate in activities that enable him or her to achieve valued roles in the community.”

The ultimate goal in a nursing home is a dignified death.

“Standard 7— Each consumer is free to raise and have resolved, any complaints or disputes he or she may have regarding the agency or the service.”

Observance of this standard relies on good will and charity when the agency against whom a complaint might be made holds a monopoly on provision of the essentials of life

itself. This circumstance is highly likely to prevail when a person with high support needs has been forced into what will often be the only nursing home that has a space to take them.

Bed blockers

Disability services do not have enough resources to enable young people with high and complex needs to live in a place of their own choosing.

There is a way to unblock this very expensive, inefficient and dehumanising mis-application of resources.

An ever growing number of these young people end up in nursing homes intended for older people against their will.

The intended residents of these nursing homes cannot get in. They may remain living in their homes, coping as best they can but often at risk and often making demands on aged care services. They may also be found in hospitals or other acute care settings which cannot discharge them because there are neither the community support services nor the nursing home facilities.

Resources that could be available to bring down the hospital queues and get waiting lists off the front pages of the newspapers are tied up with people who should be in nursing homes.

A decent investment in community based disability support and health services could solve a lot of problems in a very cost – effective manner.

However, the curse of Australia's federal political structure must be confronted if this is to be achieved.

Community based services are primarily a state responsibility, while nursing homes are primarily funded by the Commonwealth. From the States' point of view, it makes good political sense to push people with resource – intensive needs into the nursing home system and spread their community support resources around among the largest possible number of people with lesser support needs. This strategy forms part of the general strategy of rationing community support services so that they enable only a bare subsistence. Community support services can almost never enable people with disabilities to undertake all of the social roles that someone without a disability might take for granted e.g. parent, lover, partner, worker, friend, artist / musician, sports person.

What Should Be Done?

Without more money a great deal of time and ingenuity will continue to be spent finding solutions within the constraints of what is possible. And, as now, the result for people with disabilities will reflect a very poor return on the effort invested.

Mr. David Holst, leader of the Dignity for the Disabled campaign, has estimated that an extra \$100m per year is needed to allow the system to function with some degree of effectiveness and efficiency.

It should be noted that this is only approximately 1.4% of the South Australian State budget.

The South Australian government must greatly increase its contribution to funding of disability services of all kinds.

State and Commonwealth government disability service funding agencies (e.g. Disability Services Office in South Australia) should not fund services that do not comply with the standards forming part of the Acts under which they operate.

“Recommendation 1: That the Commonwealth and State Governments amend their respective Disability Service Acts and other relevant legislation to clearly bind the crown and service providers to the objectives of the Acts and, to give people with disabilities clearer legal frameworks to pursue better quality services when necessary.”¹⁰

With the legislation amended, Disability Action urges that it be policed.

“Recommendation 2: That the Commonwealth Government establish an independent process to review service standards in large residential settings on an annual basis with a strong focus on human rights and service quality, and at a compliance level consistent with legislative principles and objectives.”¹¹

Disability Action also has a message about what nursing homes should be doing for young people detained there.

“Recommendation 6: That family reunification possibilities for adults and children become a case management focus for all funded accommodation agencies as a part of funding and service agreements with Commonwealth and State Governments.”¹²

¹⁰ From “Position Paper On Deinstitutionalisation” Disability Action Inc. December 1999

¹¹ From “Position Paper On Deinstitutionalisation” Disability Action Inc. December 1999

¹² From “Position Paper On Deinstitutionalisation” Disability Action Inc. December 1999

