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A submission from the Physical Disability Council of Australia Ltd (PDCA) on Young People with Disabilities in Nursing Homes.

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Overriding Principles

People with disability have a right to live as valued individuals receiving support to:

- live in safety and security, free from neglect, abuse and harm;
- experience opportunities for positive growth and development;
- be contributing members of their community.

These rights are stated in international conventions on the rights of people with disability and are further enshrined in the Disability Services Act in each State and Territory.

The following system of support must be in place for people with disability to live valued lives in accordance with these principles:

- A lifetime guarantee of support for individuals with disability as and when needed;
- Planning and resources to provide a coherent and comprehensive system of support, i.e. a planned, resourced and effective service delivery and specialist support system through government and non-government agencies, including effective staff training; a planned and resourced system to allocate funding packages to individuals; a planned and resourced system for allocating funds to meet developmental and changing needs of individuals;
- Service planning and design that identifies and highlights ongoing opportunities for learning and development;
- Infrastructure and specialist support to effectively support the individual, particularly as needs change;
- A planned, resourced and effective system of monitoring supports and services to ensure quality of service for the individual;
- A commitment to continuous improvement in service quality and effectiveness, including responsiveness to individual and changing needs;
- Community environments that are accessible and welcoming to, and inclusive of people with disability.

People with disability may experience vulnerabilities and therefore safeguards and protections are required. These are particularly critical when the individual is experiencing a major life-change. It is essential that the following safeguards are provided within the system of support for people with disability:

- Meaningful choice within the framework of the Disability Services Act, including:
    - a right to be consulted and participate in any change process;
    - choice of service provider and choice of how support is provided;
    - responsiveness to an individual's choice of life-style;
- Access to independent consent mechanisms, including guardianship;
- Access to independent advocacy support;
- Access to independent complaints and appeals processes;
- A responsive process, which assesses the recurring daily support needs of individuals and which includes an understanding of, and means of recording, the identified potential support needs of individuals to grow, develop and change.

Statistics

In 1998, 3.6 million people in Australia had a disability (19% of the total population). A further 3.1 million had an impairment or long-term condition that did not restrict their everyday activities. Of those with a disability, 87% (3.2 million) experienced specific restrictions in core activities, schooling or employment.

Self care, mobility and communication are fundamentally important activities underlying all aspects of everyday life. Most people with a disability (78%, or 15% of the total population) were restricted in one or more of these core activities. Depending on the level of assistance needed or difficulty experienced, restriction in core activities was profound (3% of the total population), severe (3%), moderate (4%) or mild (6%) (Table 2).

Participation in education and the labour force contributes to personal development and independence. Of those with a core activity restriction, 47% (1.3 million) people were also restricted in schooling or employment. A further 327,900 people without a core activity restriction were restricted in schooling or employment.[2]

Regardless of individual differences, it can be said with confidence that people with physical disability, particularly those with significant mobility handicaps:

- have great difficulty gaining access to public and private buildings because of physical barriers such as steps, steepness of site and lack of parking
- face greater costs than other people because of their disability such as specific and essential equipment, modifications to vehicles, household appliances, modifications to housing including internal and external, home maintenance including gardening and lawns, transport, personal and health care including pharmaceutical's and items not included on the PBS, and managing a household and family in many cases
- generally cannot access public transport and are reliant on purpose built taxis, with varying levels of subsidy throughout Australia, or on private vehicles
- face significant discrimination in finding a job and obtaining promotional opportunities, despite the avenues for redress through disability discrimination legislation. The Australian Public Service does not employ people with disability in the same numbers as it once did [2]
- have lower incomes than their age/education peers due to greater difficulties in getting employment and in achieving promotion
- 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 people with spinal cord injury, multiple sclerosis, muscular dystrophy, polio, cerebral palsy, arthritis etc).
- Often require support by way of home attendant support, nursing services and other medical assistance
- Are required to live in Nursing Homes if alternate accommodation is either not available or affordable.

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2 ABS Disability and Carers 1998

2 (1998 ABS Disability and Ageing

Position Statement

PDCA believes that younger people with disability should not be admitted to residential aged care facilities at any time; and that those currently living in residential aged care facilities should be relocated to community based placements with the appropriate supports.

The focus of this submission will be based solely on younger people with disability living in residential aged care facilities, and based on the understanding that residential aged care facilities were always intended for older people and are not appropriate for younger people with disability.

In Australian society, we generally talk about families as being the main carers or advocates for other family members, especially those who have a disability. However, this is not always the case as some people may not have family members able to advocate and alternatively partners, friends or others such as organisations may act as advocates or carers.

Why are younger people with disability in residential aged care facilities?

It appears that younger people with disability end up living in residential aged care facilities partly because there are no other options available. Even if there are other options, people end up in aged care facilities because these options are not sought and explored. In the past some of the reasons why younger people with disability entered residential aged care facilities included:

- Medical practices resulting in more young people surviving accidents and illnesses that would once have resulted in death;
- No funds to provide alternate housing and care;
- A lack of other accommodation and support alternatives to hospitals and nursing homes;
- Ageing carers 'bringing along' a family member with a disability when moving into the nursing home;
- Residential aged care facilities perceived by many as the only 'secure' option;
- Residential aged care facilities known to people while other alternatives are not generally well known and understood;
- A Residential aged care facility may be the only facility close to family members;
- Expectations of a need for 'high quality' medical/ nursing care in residential aged care facilities, where community based home care will provide the same care; and
- Residential aged care facilities are seen as a 'final' alternative for people with high medical/ nursing care needs.

How many younger people with disability are in residential aged care facilities?

From Department of Health and Ageing Reports, the following table shows that he number of YPINH has nearly doubled in the last decade and the rate of increase is likely to grow further in line with the 12% demand increase predicted by the AIHW over the life of the 3rd CSTDA.

Date	ACT	NSW	NT	QLD	SA	TAS	VIC	WA	Total
1990	33	1541	31	601	323	72	604	326	3531
1992	39	1766	39	712	371	106	789	387	4209
1994	71	1951	58	892	350	125	1035	445	4927
1996	53	2027	63	948	344	129	1177	428	5169
1998	57	2167	65	1141	312	153	1410	477	5782
2000	37	2299	67	1205	325	149	1433	497	6012
2001	41	2279	61	1219	346	139	1414	485	5981
Total	331	14030	384	6718	2371	870	7862	3045	35611

Source: Dept of Health and Ageing Reports

The problems

While nursing homes generally serve the needs of the frail elderly, they create lifestyle and care problems for younger people. The main problems with nursing home for younger people are

- Nursing home staff not trained to meet the needs of younger residents
- Nursing staff are often not skilled in spinal injuries and care;
- Few nurses these days are experienced with the late effects of Polio and treatment;
- Other disabilities require specific information and training, not always available to those who work in nursing homes;
- The environment is to manage the end of life not the living of life
- Little peer support: isolated by age from the predominant resident group
- Few opportunities to participate in community life
- Care service revolves around personal care only
- Costs of Care can be high and not always appropriate to need;
- Little or no access to required therapy services contributing to upstream bed blockages in acute hospitals
- Distress and depression experienced by residents and families, especially being exposed to death and illness, when the person concerned is not actually ill;
- Nursing home environments do not lend themselves to visits by the friends of younger people, nor encouraging of an external social life, which increases the effects of social isolation.

The costs of care of a younger person in a nursing home

Studies have shown that an inappropriately placed person with Multiple Sclerosis, Acquired Brain Injury or high support need physical disability, residing in nursing homes can cost the community up to $100,000 per resident per year.

The Australian Nursing Homes and Extended Care Association estimate that the full extent of the Commonwealth Subsidy for nursing home beds to be approximately $70,000 per bed per year, taking various allowances and accommodation subsidies into account.
Clearly many younger residents are missing out on much of their necessary care. Unless families and advocates can get other health services involved in a person's care, they will not receive the care and community access they require.

Funding and Programme barriers

There are a range of programme barriers, including barriers within and across Governments, both state and Federal. Residential aged care facilities are funded by the Federal Government through the Department of Health and Aged Care but this funding is not part of the Commonwealth State (and Territory) Disability Agreement (CSTDA).

In the early '90s an attempt was made to relocate younger people with disability from residential aged care facilities through the provision of funds to State governments. Since then, a combination of pressures for discharge from hospitals (such as the improved treatment of people sustaining catastrophic injuries, such as brain injuries, as well as medical advances in treatment and maintenance of degenerative conditions) has meant that whilst the medical care has improved, younger people with disability continue to be placed in residential aged care facilities due to lack of forward planning for appropriate community based care options researched and funded by State/Territory and Federal governments.

In NSW, community aged care packages in particular have been used to provide community care to younger people with disability. Although the program targets older people in the community who have complex care needs, younger people with disabilities can also receive packages if their care needs fit the criteria of the program and if there are no other appropriate services operating in their area. In 2000, the total number of CACP recipients was 16,000. Of those about 7% went to people aged under 65, and only 1% of care recipients were under the age of 50.

It is estimated that the cost to accommodate a younger person in a nursing home in NSW is $319 per day. The difficulty arises in enabling these funds to 'follow' a younger person with disability if they move into the community. This involves a transfer of funds from the Commonwealth Department of Health and Aged Care to pay for community based care as part of a disability accommodation funding program, which is considered a State responsibility under the CSTDA. Clearly there needs to be a transition programme which assists the individual to move from a nursing home into the community that is not measured by cost efficiency in state budgets.

Lack of clarity of government responsibility

In order to provide appropriate supports to younger people with disability with high support needs currently living in residential aged care facilities, any approach must necessarily involve Commonwealth, State/Territory and local government agencies; particularly:

- Departments of Ageing, Disability and Home Care
- Health Departments
- Department of Housing
- Planning Departments
- Transport Departments
- Local Government community service and planning sections
- Commonwealth Department of Family and Community Services
- Commonwealth Department of Health and Aged Care

The barriers to a joint approach range from resource constraints to an unwillingness to engage in

and take responsibility for younger people who are inappropriately placed in nursing homes.
For example, in providing services to younger people with high intensity needs, there is clearly an interface between their acute care needs and their need for accommodation and non-medical supports. The medical needs of people fall under the jurisdiction of Health Departments whilst community support services to people with disability are generally provided in the community or through state government disability services. Where people with disability have high medical needs it is unclear whether the primary responsibility falls with Health or Disability Departments or both.
In addition, there has been a policy vacuum between the Commonwealth and State governments regarding the responsibility for younger people with disability currently living in residential aged care facilities

The 1997 Commonwealth Aged Care Act provided subsidies and services for older people in residential aged care facilities. These provisions are intended for older people, generally over 65 years, although the legislation is not limited to that age group. Residential aged care facilities provide a range of levels of care for people in need of more intensive nursing care. People with disability in residential aged care facilities are taking places originally intended for older people requiring a degree of intensive nursing care.

While the supports younger people need may mirror those of older people, they are not the same, nor should they be provided in the same way at the same location. Responsibility for ensuring that residential aged care facilities are providing services for the target group for whom they are funded should be clearly identified by government. In addition, as the Australian population ages, the places taken by younger people in nursing homes are needed for the ageing population.

While there is no clarity of responsibility between State and Commonwealth governments, younger people with disability living in residential aged care facilities do not have access to the same provisions as people with disability receiving services under the various Disability Services Acts.
These Acts state that people with disability are entitled to the same basic human rights as other members of the community and to access the same opportunities, so far as possible, as people of the same age without disabilities. The placement of younger people in residential aged care facilities is inconsistent with the provisions of the DSA´s. Responsibility for ensuring that young people with disability receive services which accord with the principles of the DSA´s should be clearly identified by government.

Lack of options, information and certainty

Younger people in nursing homes and other residential aged care facilities reside there because of a lack of available, reliable and appropriate alternative service options. It could be argued that if such service options were generally known and available, no younger person with disability with high support needs would enter a residential aged care facility.

Case study – Carol

Carol lives in Brisbane and in 10 years she will turn 65. If you ask Carol, she says her concerns about ageing ¨lie predominantly with finances right now¨ which is an understatement when you hear

her story!

Carol was involved in a car accident in 1981 and sustained injuries that left her a high level quadriplegic. This means that all 4 of her limbs are paralysed. Carol is a very tall woman and uses a large electric wheelchair for mobility. Her wheelchair is propelled by Carol using a mouth stick to operate the controls.

In 1984 Carol received 3rd party insurance compensation based on the doctors/court calculations that she had approximately15 years to live. If Carol had died in 1996, all would have gone to plan.

However , due to the fact that she had to employ full time carers 7 days per week and 24 hours per day, her funds ran out early in 1999. Carol shopped around for nursing homes because she couldn't find any alternatives. A social worker from the Spinal Injuries Outreach Team helped her to fill out an application for assistance from the State Government, and with direct intervention by her state parliamentarian she was successful in receiving funding through an Adult Lifestyle Support Package.

Whilst waiting for the funding to come through Carol sold her wheelchair accessible van, then most of her furniture and then her house bought from compensation monies, to pay for the 24 hour care she needed.

The Department of Housing at that time bought her home which she had designed herself and had it built specific to her needs. The conditions of sale were that she would move when she found suitable alternate accommodation.

Around 18 months after the sale, Carol received word to say that the Department of Housing were building 2 two bedroom apartments and one of these was designated for her. The unit turned out to be tiny and dark and difficult to manouvre the wheelchair around, and she could not get her computer table into the bedroom because the doors were too narrow. When Carol is confined to bed, her computer, controlled by voice recognition software is her only method of communication with the outside world. In other words she can still socialise, undertake her voluntary work whilst staying sane at the same time.

Carol moved in, but stressful times ensued in the apartment and after some consideration Carol decided to take on the Housing Department again and with the help of her parliamentarian once again, she moved back into her former home and negotiated an arrangement that will allow her to stay in this house in perpetuity.

Carol considers she is more fortunate than most and life is secure for her at least where her housing is concerned, but consider the other costs for Carol to live in this home independently and the cost cutting measures which include:

- cancellation of her daily subscription to newspapers ;
- cancellation of $35 monthly subscription to Foxtel;
- no longer paying to rent a video. She only watches what she can borrow or what friends pay for;

- Carol can only socialise with friends/family if they travel to her house, pay for a maxi taxi trip or can meet 'them' somewhere travelling by train
- She has not bought any new clothing since last July
- Carol has a 'budget' for food supplies and once that's been spent she has to do without
- Staff/Carers use small freezer bags instead of plastic gloves to touch any area of me that exudes bodily fluids eg emptying catheter bag, applying cream.
- reducing catheter changes and bladder washouts to once a month to save the extra cost of using a catheter bag weekly
- 'recyclying' catheter bags by 'sterilising' them in Milton solution. This is not always successful and is not very hygenic

Some of Carol biggest expenses besides nursing staff are:

- The cost of extra incontinence aids
- The cost of repairs to medical equipment [eg repairs to her manual height adjustable bed cost me $470.48 in the last 2 months]
- The cost of repairs to technology aids eg replace power cord to TSP Phone was $90 plus postage. [Carol can use a traditional phone handsfree during the day but uses and relies on a TSP phone as a safety measure at night, if anything goes wrong such as staff being sick, a fire or burglary) this means she can call for help.
- The cost of electricity. Because Carol is a high level quadriplegic and is not able to regulate body temperature, she needs air conditioning to maintain a cooler body temperature in Summer and heating to maintain a warmer body temperature in winter.

What concerns Carol as she gets older is:

- a change of government could see her homeless despite promises made by housing. In other words she is at the whim of governments and public servants;

- due to cost increases in medical equipment and spiralling costs to maintain equipment, Carol often has to do without getting faulty equipment repaired. For example a castor on her bed broke a few weeks ago and this had to be repaired. The castor itself cost $13.48 but the total bill with call out fees and labour charges came to $101.48!

- due to lack of finances, Carol has had to give up any form of social life outside my own environment/house

- due to increases in electricity costs, (July increase 2.5%) Carol will now have to survive without air conditioning

- increases in telephone bills prevent her from maintaining contact with her immediate family who all live in rural/regional communities where this was once a regular routine
- increasing fees by service providers take more than5.5% of the total support package

- increases in carer's wages are growing faster than the funding by DSQ for carers

Because of the above, Carol sees a nursing home not as an option but an inevitability.

Carol would like to see a future that includes:

- being able to stay in her current house
- to have enough funding for necessary carers and not have to worry about funding every year
- to be able to work from home - part time or full time - without losing financially
- big businesses such as BHP, CSR etc to help support social welfare costs through taxation
- NOT having to worry about staff or equipment etc.; and
- to grow old disgracefully

Carol is in a unique situation with her service provider and the state government because she already employed her own staff when she initially received funding in 2000/2001. She employs most of her own carers herself and sends the wage sheets to the service provider organisation who check the sheets and electronically reimburse her. She employs her carers using an Enterprise Bargaining Agreement and manages her staff which saves her money.

Carol is not a stay at home person. With the help of a friend from school days Carol´s Internet and email connection is paid for by him and he is also extremely generous with his [and his staffs] time when it comes to fixing her computer.

She is extensively involved in the disability sector in Queensland and sits on the Disability Advisory Council of Lifeline and on the management committee of Queenslanders with Disability Network (QDN). She has built and manages a website for people with disabilities, parents, guardians, carers and health professionals to exchange information statewide in Queensland which is now being used worldwide.

Carol volunteers at the Independent Living Centre in Brisbane and writes and co-writes various papers and video scripts for conferences as well as in house training of Occupation Therapists on how to use the new technology she employs to undertake these tasks. She also plays 'crash test dummy' for various new devices and/or technology for people with disabilities

So what does the future hold for Carol? Will she be better off living in a Nursing Home?

The International Experience

In the United States there is a similar push for alternates to nursing homes, and a paper worth reading from comes from the website of (ADAPT - see website below) entitled ¨ A Disability Perspective on Home Health Care by Stephanie Thomas.

¨One group leading the push for community based services is ADAPT (American Disabled for Attendant Programs Today). Started as a project of the Denver based home health agency and independent living center, the Atlantis Community, ADAPT's focus is to enable people with severe disabilities to get the support services they need to function independently out in the community, instead of being forced into nursing homes and other institutions to get these support services. In fact the Atlantis Community was founded in 1975 by group of activists, ex-nursing home staff and

residents, who were bound to prove there was a better way to provide support services than institutionalizing people. Many ADAPT members have been willing to go to jail in the civil rights struggle for this freedom.

The traditional stance in our culture is that "normal" is the "Pepsi generation" version of youth and physical fitness, and anything diverting from this is an abnormality which should be corrected. In the disability community this is sometimes referred to as the "medical model" for service provision. As people with disabilities began to question this attitude, they also began to demand a place in society as equal citizens. As people sought the same things in life that their non-disabled peers were seeking and receiving, a new picture arose. They came to realize that disability, different from illness, is not a temporary state of abnormality, but rather is another way of being normal.

More and more people with severe disabilities are living in their own homes in the community. According to the research of the World Institute on Disability, W.I.D., almost eight million Americans need assistance from another person to accomplish every day tasks, and three million of them are not getting the assistance they need. A 1986 Lou Harris poll of people with disabilities found over half (56%) of those whose activities were limited attributed that limitation to a lack of attendant services. Of those who were able to get assistance W.I.D. found 79% must rely on volunteers. As our population ages, and, through medical advances, more people with disabilities are being kept alive these numbers will only grow.[a] ¨

Recently the ABC Radio National programme presented news that ¨A West Australian District Court judge recently ruled that a young man injured after a car accident has the right to receive one-on-one care in his own home, rather than in a nursing home, and awarded him $7.2 million as a result.¨ It's great news for him, but where does it leave the 6,000 young people currently living in nursing homes for whom a case of negligence can't be made?

One argument used to justify admitting younger people with disability to residential aged care facilities is that the disability services sector does not have the capacity to provide for their needs. It is clear, however, that the real issue is much more likely to be about insufficient resources and in rural and regional areas a lack of resources and services. This lack of resources is underlined by the ability of people with sufficient funds (private or compensable) who have high and complex nursing care needs to purchase appropriate support services privately in the community.

Despite their complex needs these people do not move into residential aged care facilities because they can meet their needs with their funds. Therefore the availability of services is based on purchasing power which proves that with sufficient resources, capacity can be generated and alternative solutions can be found.

Often families have no information about the range of support options available through community care and other home supports which may delay the need for more intensive services. In fact for many individuals and families it may be their first experience with disability.

Families may also not have the experience or access to support to identify and plan appropriate community based care for their family member. Families feel they require certainty of service

[a] http://www.adapt.org/homehealth.htm

provision and decide that residential aged care facilities provide that certainty, despite not being the best service option for the younger person with disability.

Placing a younger person in a residential aged care facility may be in response to a crisis and may appear to be the only option in the absence of more appropriate services available. High levels of unmet need for disability services also add to this crisis. Despite the best intentions for seeking appropriate placement, the admission of the younger person into a residential aged care facility immediately reduces their crisis in accommodation and support.

This lowers the priority rating for that younger person which in turn means that by being placed in the residential aged care facility the person is off the crisis/ priority list and therefore the person does not constitute a crisis for the government any longer.

Cultural Issues

While the problems experienced by any younger person with disability residing in a residential aged care facility also apply to Aboriginal and Torres Strait Islander (ATSI) peoples with disability and people a from non-English speaking background (NESB) with disability, the emphases are different.

For many younger indigenous people with disability living in a nursing home the sense of isolation is enhanced when the person lives far from their own land, their home ground, their people.

The cost of travel for visits may be prohibitive for many families. In general, a family member with disability having to live in a residential aged care facility, away from their family, could exacerbate their sense of desolation and marginalisation. The inability of the family to provide for the person with disability may add to the pressures and guilt of families already affected by dispossession and oppression and can result in cutting all contact with the family member with the disability.

For some people from a Non English Speaking Background (NESB) with disability one of the key issues is the perception that highly bureaucratic systems (such as residential aged care facilities) provide better care and support than families and non-institutionalised systems. In part, this belief is based on a perception of the efficacy and efficiency of 'white, western bureaucracy'. The dominance of those kinds of bureaucracies is seen by many as a pinnacle of civilisation, especially by those who arrive in Australia from countries with very few and not very well- developed bureaucratic systems. [b]

This belief is also fuelled by a perception that professionals know best, which can result in a complete severance of any relationship between the younger person with the disability and their family.

In addition, the availability of ethno-specific cluster residential aged care facilities makes them a seemingly attractive alternative to disability services, which only provide very limited ethno-specific services. If there is any choice available to people, they have to choose between a culturally appropriate service and an age appropriate service.

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[b] National Ethnic Disability Alliance (NEDA)

Finally, the lack of extended family support systems (including the difficulties in obtaining carers' visas for family members from overseas) and the overall lower socio economic status of migrant families adds to the limited ability of families to support people with disability.

Incompatibility of systems: younger people with disability in an aged care system

Currently assessments for eligibility to residential aged care facilities are undertaken by Aged Care Assessment Teams (ACATs). These teams are made up of professionals trained and focused on the assessment of older people.

Whilst ACAT assessments are one of the key pathways by which many people with disability enter residential aged care facilities, the capacity, skills and knowledge of these teams in assessing younger people with disability may be limited, due to the focus on older people. However, due to the high levels of unmet need in disability support and accommodation services and the number of people in 'crisis' seeking assessments by ACATs, there is significant pressure on ACATs to assess a younger person with disability for placement in residential aged care facilities.

It may also be possible that in those assessments the physical care needs of a person with disability are focused on and maybe overemphasised, whilst cognitive, behavioural, support, cultural and personal issues, in particular issues relating to sexuality, are overlooked, underestimated or discounted.

There is grave concern that residential aged care facilities are not obliged to respond to the changing needs of younger people with disability, either via monitoring and reassessment or development of an Individual Service Plan as required of disability services in some states, such as NSW. It is possible that any focus on the cognitive, behavioural and social needs of a younger person with a disability occurs only when problems arise for the provider due to the person's expressed behaviours. For example, the nature of the disability of the younger person (e.g. alcohol related dementia) may cause additional problems if there is no access to any age-appropriate social life, no appropriate mechanism for sexual expression, no peers to talk to or to share interests with. A response by residential aged care providers is likely to be similar to the responses to people with age-related cognitive decline (for example, dementia and Alzheimer's disease).

In addition, deaths are a reality in residential aged care facilities. However, while death may be expected for older people who are in end stages of life, death ought not to be a frequent event in the environment of a younger person with disability. The placement of younger people in aged care facilities where death is an accepted and expected occurrence may contribute to the false perception that they are in end stages of life 'awaiting death' and this may influence the care received.

Issues and Questions

Below are a set of issues and questions which need to be debated and resolved in order to move on the issues of younger people with disability living in residential aged care facilities. The list of

issues and questions has been divided into several themes, may be seen as a starting point only and can and will be developed further as understanding about this issue increases amongst the communities, non- government agencies and the relevant government agencies.

1. Needs:

- What do younger people with disability need to ensure they are supported adequately to live the fullest life possible?
- What about workable solutions for people with high complex care needs? In providing services to younger people with high intensity needs, how can their needs for acute care, accommodation and non-medical support be met in a 'seamless' way, across the various governments, government and non- government agencies responsible for meeting those different needs?
- What happens for the people in similar circumstances and levels of need?

2. Transition:

- How can younger people currently living in aged care facilities be moved into more appropriate accommodation?
- What happens when the ACAT no longer access people with disability at all?
- What strategies must be implemented when a policy of no - new admissions is introduced?

3. Models:

- What is the best practice currently available to younger people with intense / support needs who are already living in the community?
- Are there examples of innovative programs elsewhere in Australia and internationally that might be adapted or accessed for this group of people?
- What examples are available to show successful community based services in practice?

4. Capacity Building:

- How to build the best services?
- Are there appropriate services and supports available and are those supports and services available in non- metropolitan areas?
- How can the service sector build capacity to respond to cultural diversity?
- How can we replicate current best practice consistently across the whole State?
- What barriers exist in current service provision that prevent best practice from becoming state wide standard practice?
- What examples of good practice are currently being pilot funded?
- What pilot projects have been evaluated?

5. Funding:

- Where will the money come from?
- What will happen to the dollars spent on younger people with disability currently living in aged care facilities?

6. Government:

- What level of Government is responsible?
- Who will monitor the services?

- Older people with high support needs receive Commonwealth service provision, younger people with disability may have similar high support needs but requiring different supports – does this indicate a Commonwealth responsibility?
- Should people with disability currently residing in residential aged care facilities be included in Stage 2 of the NSW Devolution commitment and where will the money come from?
- If in the case of people with disability with high intensity support needs there is a joint state government responsibility for support services to people with disability, how can this responsibility be extended to younger people in nursing homes for re-location and no further admissions?

Towards Solutions

Maintaining the status quo is not an option. Doing nothing now means more and more younger people with disability have no alternative but to enter a residential aged care facility.

We believe that in order to move this issue forward the following steps should to be taken:

1. A policy of no new admissions into residential aged care facilities for younger people with disability.

2. Development of an action plan to move all younger people with disability currently living in residential aged care facilities into community living, giving priority to the youngest. Such a plan must be based on a flexible approach that takes advantage of opportunities arising regardless of age.

3. Establishment of a transition programme with funded staff whose sole purpose is to assist individuals to move from a nursing home into the community

4. Development of pathways for people with disability which exclude residential aged care facilities as an option.

5. Urgent resolution of the State and Commonwealth Government dispute about who is responsible and of the cross-government issues. (We believe this should not be a political issue)

6. Establishment of alternative community living options which are rights based and equitable, to enable those in nursing homes to move into the community.

7. Development of community living programmes that are not measured by cost in state budgets or Federal budgets, but are measured by the positive outcomes for Australian citizens, currently living in nursing homes;