Atkin, Margaret (REPS)

From: Michael Woodhead [michael@adacas.org.au]
Sent: Thursday, 20 May 2004 11:27 AM
To: Committee, Ageing (REPS)
Subject: Fw: Late submission - Ageing inquiry

Committee Secretary
Standing Committee on Ageing
House of Representatives
Parliament House

Please find attached a late submission to the Committee's inquiry into long term strategies to address the ageing of the Australian population over the next 40 years.

This submission is from the ACT Disability, Aged and Carer Advocacy Service (ADACAS). I am the Acting Manager of ADACAS and have signed the submission on the organisation's behalf.

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We understand that the closing date for submissions was some time ago but, after discussions with the Committee Secretary, hope that there may still be a chance for members of the Committee to consider our submission.

Yours sincerely

Michael Woodhead

Submission No 193

Inquiry into long-term strategies to address the ageing of the Australian population over the next 40 years.

Submission by the ACT Disability, Aged and Carer Advocacy Service (ADACAS)

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The ACT Disability Aged and Carer Advocacy Service (ADACAS) provides advocacy for people living in aged care facilities, as well as for people with disability. Both of these advocacy programs are funded by the Commonwealth Government.

YOUNGER PEOPLE WITH DISABILITY IN AGED CARE FACILITIES

Background

Nationally, there are many hundreds of younger people with non-age related disability living in Commonwealth funded aged care facilities.

They are there because of a lack of support services, even though the Commonwealth State Disability Agreement, (CSDA) clearly places the responsibility for meeting the accommodation support needs of people with disability with the State/Territory governments.

Consequences for younger people with disability, for people who are ageing and for the Australian population

Cost
There are significant cost implications of this practice. A younger person, say aged 18, who has brain injury or spinal injury as a result of drowning or diving accident, will spend possibly the next 40 to 60 years living in an aged care facility. He or she will be occupying a bed that will never be available to older people. This means the Commonwealth needs to build an additional bed to compensate, in addition to meeting the ongoing support costs, which should have been met by the state/territory government.

Quality of Life
Clearly a geriatric facility is not suitable for young men and women, who have decades of life yet to experience. Aged care facilities have a focus on meeting the health care needs of residents. Activities, where there are any, are geared towards the majority resident group: people aged 70 and over.

The care and support provided is geared towards the most frail, meaning that some residents, even those people who have age related disability, are technically "over-supported", and lose skills and knowledge through inactivity.

In addition, whilst rarely acknowledged publicly, most residents in aged care facilities die there. Therefore, there is not a strong emphasis on rehabilitation and skills development and maintenance. The result is that younger people with disability become increasingly dependant, and their support needs increase as does the cost of meeting them. With decreasing skills comes increased vulnerability, and the inevitable perception of incompetence and low social value.

Characteristics
Whilst people with many different types of disability can live in aged care facilities, the majority are people with an acquired brain injury, a severe spinal injury, or a degenerative illness eg Multiple Sclerosis. Their needs can vary from some nursing procedures, eg change of catheters and administration of (some) drugs, to general personal care support and lifestyle development.

Concerns for the future

Of major concern is the rumour that State/Territory governments are lobbying for the Commonwealth to allow, and possibly fund extensions to existing facilities, to enable younger people to be moved from "aged care beds" into purpose built nursing homes.

If this goes ahead, it will effectively reverse the policy initiative of previous Governments, which transferred Special Purpose Nursing Homes from administration by the Aged Care Program to the Disability Services Program.

This transfer occurred with the implementation of the *Disability Services Act 1986* (DSA), and in the following years many of the facilities were closed. The residents were supported to move into more suitable community based accommodation, in line with the Principles and Objectives of the DSA, and consistent with their wishes.

Since the implementation of the DSA, and more recently the CSDA, the numbers of younger people with disability living in Commonwealth funded nursing homes has increased. In addition, the funds available to support community based living have been inadequate to meet even urgent demand.

The Commonwealth has not rescinded eligibility for younger people to access nursing homes, arguing that they should be there as "last resort" placements. However, this option seems to be being promoted by state/territory governments, who administer the Aged Care Assessment processes where-by access to aged care facilities is approved.

Possibilities for a different approach

Any response that enables people with disabilities to be supported in the community will require additional resources, but more importantly coordination of existing resources and programs, and early intervention. Many of these, if in place, would have a direct impact on reducing the ongoing cost of support. For example:

- use of state housing authorities to advance low or interest free loans to modify housing to make it accessible to the disabled family member and to enhance independence;
- early intervention to maintain as much physical mobility, independence and intellectual capacity as possible, again a state/territory responsibility, eg physio, occupational, and speech therapies;
- case management from time of injury through to some months after satisfactory return to their home;
- ongoing support and/or case management to respond to changes in lifestyle; (such as Local Area Coordination)
- brokered package of support funds.

There are a number of examples nationally of successful programs where younger people have been assisted to leave a nursing home, or to not go into one in the first place. Some examples are currently operating in Western Australia and South Australia.

In addition, the Commonwealth's Attendant Care Scheme, piloted in the mid-1980's, provided examples of different models of administration and support including a system where payment was made directly to the client, who then organised their own support.

Suggestions for implementation

The resources supporting younger people with disability in nursing homes are currently solely the responsibility of the Commonwealth.

Funding possibilities could include an extension of the Commonwealth's Extended Aged Care in the Home (EACH) scheme. Additional funds and services could then be provided by State and Territory governments through, for example, housing authorities, HACC and Disability Services Grants programs.

However, the initial critical objective should be an unequivocal statement that aged care facilities are not appropriate placement options for young people with disability. This should be followed by consistent and coherent policy making and resource decisions.

The key features of any program to support people with disabilities, irrespective of where they live should be:

- separation of tenancy from support;
- flexibility;
- responsiveness to the individual's support needs;
- developmental, least restrictive options;
- portable to different housing options;
- involve the people with disability in decisions affecting their lives;
- maximise the control by the person with disability, and their family where necessary.

Supporting documents

ADACAS believes that it is important to develop policies that enable younger people in aged care facilities to be supported to return to community living.

To this end, ADACAS has previously provided a proposal to the Department of Health and Aged Care that would enable this to happen in a way which is, effectively, cost-neutral to the Commonwealth Government. That proposal also aimed to deliver longer term positive outcomes for younger people with disability, and older people living in the community. A summary of the proposal is **Attachment A.**

ADACAS has also developed a position statement, entitled *Permission to Shine*, designed to promote discussion on this topic. The statement is **Attachment B** to this submission.

Michael Woodhead
A/g Manager

Attachment A

Summary of ADACAS proposal to Department of Health and Ageing regarding younger people with disability in aged care facilities

The proposal is to re-categorise the places occupied by younger people with disability as Extended Aged Care in the Home (EACH) places.

The funds for these places would then be brokered to community based organisations providing support to people with disability, to develop and provide the required level of support to enable the person to live in the community.

In return, the vacated places could receive approval as aged care beds in the next round of new places funding. (However, if there were concerns about the quality of care provided in the facility, then approval should be withheld.)

The project could be trialled within the ACT, and extended nationally following evaluation. ADACAS research has indicated that there are more than 50 younger people currently living in ACT facilities, with others on waiting lists. The majority are people with Multiple Sclerosis, but there are other people with acquired brain injury and spinal injury.

Not all residents want to leave the nursing home, possibly because of fear about ongoing support, and lack of options and demonstration projects to raise awareness of alternatives to institutionalisation.

Rationale

Cost shifting

- Unless and until the Commonwealth Government changes its policy on the eligibility of younger people with disability to access aged care facilities, then it is likely the demand will increase. The main reason for this is that the Residential Aged Care Program has automatic funding/places growth.

- The Commonwealth/State Disability Agreement, (CSDA), places responsibility for meeting the accommodation and support needs of younger people with disability with State and Territory Governments. Funding for these programs is not automatically linked to demand, and was significantly under-resourced when the CSDA came into effect in 1991-2. Several studies undertaken by

State/Territory Governments, and by the Australian Institute of Health and Welfare, indicate a significant shortage of accommodation places for people with disability.

- The States and Territories are going to use whatever options are available to them to make funds stretch further. The Aged Care Assessment Teams, which gate-keep access to aged care facilities, are administered by State and Territory Governments.

- If the Commonwealth allows younger people into aged care facilities, it will be meeting those support costs until the person dies, or they find an alternate accommodation option. For some people, this could be 4 or 5 decades, or longer.

- As funds for disability accommodation support are scarce, and prioritised to those most in need, people currently "adequately" supported in aged care facilities are unlikely to get priority. If the numbers of younger people in aged care facilities increase, the Commonwealth could eventually be spending the majority of its aged care budget on younger people.

- Commonwealth is meeting infrastructure costs which are effectively State/Territory obligations: The Commonwealth can make Residential Care grants to meet the establishment costs of aged care beds.

- The number of new beds is governed by a formula, (a certain number of beds per 1000 people over 70 years of age) which has been determined as reasonable to meet the demand from older people for aged care beds. As long as a younger person occupies an aged care bed, then that bed is not available for use by an older person, and consequently the Commonwealth is not meeting the quota.

- If the formula for aged care beds is valid, then the Commonwealth should increase the formula to compensate for the deficit. The more younger people there are in aged care facilities, the more the Commonwealth will have to spend to establish new beds to meet the quota, and demand from the older population. These are effectively infrastructure and support costs that should, under the CSDA, be met by the States and Territory Governments.

Cost neutral

- The proposal is cost neutral to the Commonwealth. The Commonwealth would have continued to be responsible for the support costs for the younger person anyway; so continuing this funding through an EACH place requires no increase in Commonwealth funding.

- Growth places would have been allocated anyway. The difference is that some of the new places are pre-determined, ie to those facilities where a younger person has been discharged into the community.

Policy coherency

- The proposal is coherent with current approaches to support for people with disability; accommodation in institutions is not. In 1987 the Commonwealth Government transferred responsibility for administration of special purpose nursing homes, (SPNH), from the Residential Aged Care Program to the Disability Services Program.

- This move reflected a philosophical shift in delivery of support to people with disability, which was consistent with the *Disability Services Act, 1986, (DSA).* The Principles and Objectives of the DSA were developed following extensive consultation within the community, as well as research on contemporary, and leading edge approaches to support. As a result, this policy shift had a significant level of support from people with disability and their families; especially from those people already living in SPNH's.

- As a consequence of the internal transfer of administrative responsibility many, but not all, SPNH's were de-institutionalised, with residents being returned to the community with appropriate levels of support.

- To re-establish SPNH's, or to construct wings in existing aged care facilities, would be to return to policies almost three decades old.

Constraints

If this proposal were to be implemented, there are other factors which need to be considered, and put into place, in order for younger people with disability to be adequately supported in the community. These include:

- access to modified housing, and/or funds to modify existing housing;
- access to therapies to maximise physical and mental functions;
- access to nursing care as required;
- access to aids and equipment;
- access to other supports if the EACH funding is insufficient;
- access to ongoing case management/coordination.

All of these are the responsibility of the State/Territory Government. However, the Commonwealth has some influence on these through:

- Home and Community Care Program;
- Commonwealth State Disability Agreement;
- Commonwealth State Housing Agreement;
- Medicare Agreement.

There is also general concern in the community about the general lack of these resources, for people with disability, for older people, and for their families and carers. In particular, availability of accessible housing, and/or the lack of access to low interest or interest free loans for housing modifications, is a continual source of frustration for people with disability, (and older people) wishing to continue living in the community. There are also issues about lack of, or insufficient access to coordination, and a lack of mechanisms to tailor packages of individualised support, as opposed to "off-the-shelf" service responses.

Thus a project that is able to demonstrate outcomes in these areas will not only deliver improved outcomes for the people concerned, but also, in a wider context, improve the community's infrastructure and social capital.

In the longer term, there are issues around early intervention to maintain people in the community, rather than projects to return people to the community from an institution. The latter is more resource intensive as links to the community have to be re-established. This proposal will demonstrate ways to overcome these constraints.

Attachment B

A POSITION STATEMENT
FOR THE
"PERMISSION TO SHINE PROJECT"

OCTOBER 2002

1. Introduction

Purpose of this Position Statement

This position statement has been prepared as part of a submission for Government funding concerning younger people with disabilities in residential aged care facilities (or nursing homes) in the ACT to promote discussion and to contribute to the overall robustness of the final submission.

Reason for the Position Statement

The position statement is motivated by a heartfelt concern for the well-being of younger people with disabilities currently living in residential aged care facilities in the ACT and a desire to strengthen and secure more positive life pathways for these people.

Structure of the Paper

This paper is structured as follows. It first provides a detailed description of the subgroup of people with a disability who are the focus of this position statement. It then outlines the policy context that operates in the ACT and identifies the main barriers experienced by younger people with disabilities in residential aged care facilities. The key premises central to the position statement follows this. It then identifies and operationalises seven high-level principles which underpin the position statement. The last section provides an overview of what actions need and could be taken to progress the Permission to Shine Project.

1. *TARGET GROUP – WHO ARE WE TALKING ABOUT?*

The group of people at the centre of this position statement includes younger people with disabilities under the age of 65 who are:

- currently permanent residents in residential aged care facilities in the ACT, totalling 41 persons (25 men and 16 women) at 30 June 2001[1]; and

- currently eligible or likely to become eligible for permanent placement in a residential aged care facility in the ACT.

It excludes younger people with disabilities with a terminal medical condition, those who receive a supported accommodation service through

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[1] Australian Institute of Health and Welfare (AIHW) (2002) *Residential Aged Care Services in Australia 2000–01: A Statistical Overview,* AIHW Cat. No. AGE 22, Canberra, AIHW (Aged Care Statistics Series No. 11).

or funded by Disability ACT and those who currently receive or are eligible to receive a package through the Community Aged Care Package Program.

Consistent with the *ACT Disability Services ACT 1991*, **DISABILITY**, in respect of a person, means a disability that is attributable to a permanent intellectual, psychiatric, sensory or physical impairment or a combination of those impairments, which results in a substantially reduced capacity of the person for communication, learning or mobility and the need for continuing support services.

2. *POLICY CONTEXT OPERATING IN THE ACT*

It is well known and generally accepted in the disability and aged care sectors that residential aged care facilities are inappropriate environments for younger people with disabilities. Despite such placements being used as an "option of last resort" by the ACT Government, the number of younger people with disabilities in these facilities is unacceptably high and the outcomes for this group are far less than ideal.

Notwithstanding sound arguments around deficiencies in existing government programs and funding allocation, the principal reason for the unacceptably high number of younger people with disabilities in residential aged care facilities in the ACT is that they are powerless to chart their own pathways in life. Indeed, a national research project investigating the placement of younger people with disabilities in residential aged care facilities conducted by the NSW Department of Community Services in 1995[2] found that the relative support needs of those remaining in these facilities were not significantly greater than former younger residents of such facilities who had been relocated to more appropriate residences in the community.

There is also a critical absence of information about younger people with disabilities in residential aged care facilities at both the national and State/Territory level. The data currently available only tells us about the overall number and proportion of permanent and respite care residents and admissions in the ACT, by gender (see Table 1 over the page). Putting anecdotal evidence to one side, there is no government publication from which to paint a personal picture about the lives of younger people with disabilities in the ACT. We no little or nothing about:

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[2] In AIHW (2001) *Australia's Welfare 2001*, Canberra, AIHW.

- the appropriateness of the placement of younger people with disabilities in residential aged care facilities;
- the personal characteristics and experiences of younger people with disabilities;
- the life pathways younger people with disabilities and those who are closest to them would choose for themselves; and
- the diverse options available to sustain their life choices.

Without such information, the task of developing public policies concerning younger people with disabilities becomes a precarious exercise. Consequently, the effective-ness of such policies would most certainly be severely compromised.

Therefore, understanding the personal characteristics, experiences, life goals and aspirations of younger people with disabilities along with a knowledge of the range of sustainable diverse alternative life pathways available to them is of vital importance to ACT public policy makers, but also to service providers, younger people with disabilities and those who are closest to them as they are directly affected by the actions of policy makers.

Table 1: Resident type by gender, persons aged under 65 and the total population, residential aged care facilities, ACT, 30 June 2001(A)

Resident Type	Persons Aged under 65	Total Population
All residents	44 (3.1%)	1,434
Female	19 (1.8%)	1,059
Male	25 (6.7%)	375
Permanent residents	41 (2.9%)	1,401
Female	16 (1.5%)	1,035
Male	25 (6.8%)	366
Respite residents	3 (9.1%)	33
Female	3 (12.5%)	24
Male	0 (0.0%)	9
All admissions(B)(C)	79 (7.0%)	1,136
Female	49 (6.7%)	734
Male	30 (7.5%)	402
Permanent admissions(B)(C)	24 (5.1%)	471
Female	10 (3.2%)	315
Male	14 (9.0%)	156
Respite admissions(B)(C)	55 (8.3%)	665
Female	39 (9.3%)	419
Male	16 (6.5%)	246

Note:

(a) Derived from information held on the Commonwealth System for the Payment of Aged Residential Care and from supplementary data provided by the Commonwealth Department of Health and Ageing.

(b) Refers to admissions to residential aged care facilities between 1 July 2000 and 30 June 2001.
An individual can have more than one admission during the period.
Transfers are excluded.

(c) Separations from residential aged care facilities (i.e. death, return to the community, to hospital,
to another aged care service) are not available for persons aged under 65.

Source: Australian Institute of Health and Welfare (AIHW) (2002) *Residential Aged Care Services in Australia 2000–01: A Statistical Overview,* AIHW Cat. No. AGE 22, Canberra, AIHW (Aged Care Statistics Series No. 11).

4. Key Premises Of The Position

Central to this position statement are a number of key beliefs:

1. Residential aged care facilities:
    - are inappropriate for younger people with disabilities as they are designed for frail older people;
    - provide a minimum standard of physical care, which is not necessarily commensurate with the level of care actually needed by younger people with disabilities;
    - are detrimental to the psychological and social well-being of younger people with disabilities as their living conditions are regimented, they are subjected to group treatment and are isolated from community life; and
    - are the antithesis of human dignity, self-determination and integration into full community life as articulated in the *ACT Disability Services Act 1991* (see Attachment A, Schedule 1 of the Act).
2. Younger people with disabilities in residential aged care facilities are a diverse subgroup of the general population of people with a disability, with varying backgrounds, capacities, needs, life goals and aspirations.

3. Younger people with disabilities in residential aged care facilities need encouragement, personalised opportunities and supports[3] in order to live an ordinary life and to be part of their local community.

4. The meaning of ordinary life and community living for every person with a disability is unique to that person.

5. The life pathway/s chosen by a younger person with a disability need to be respected and actively reflected in the assistance that is provided to that person.

6. Government policy and the service delivery culture need to be facilitative, responsive and flexible to the dynamic capacities, needs and life choices of younger people with disabilities.

7. A much higher priority and more resources need to be given by both the Federal and ACT Governments in order to make a substantial difference to the quality of life of younger people with disabilities.

5. HIGH-LEVEL PRINCIPLES

The position statement is underpinned by seven high-level principles:

1. Unique Supports;
2. Empowerment and Self-determination;
3. Ever-changing Lives;
4. Equity of Opportunity;
5. Right Relationships;
6. Quality Service; and
7. Culture Change and Community Development.

1. Unique Supports

There is no model, or preconceived notion of the best life pathway/s for younger people with disabilities. In identifying what these diverse alternative life pathway/s might be, this process needs to be characterised by:

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[3] This could include personalised opportunities and supports in areas such as: physical care and well-being; emotional well-being; independent advocacy support; personal relationships/family; cultural; sexuality; housing; therapy; telecommunications, aids and appliances; education, vocational training and employment; recreation and leisure.

- Assisting younger people with disabilities and those who are closest to them to build visions of a desired life pathway/s.

- Assisting younger people with disabilities and those who are closest to them to think creatively to locate solutions that will enable them to pursue their desired life pathway/s.

- Fully respecting the wants, needs and life choices of younger people with disabilities and those who are closest to them.

- Including all life's needs (refer to footnote 3).

- Identifying and securing, where possible, the required resources to enable younger people with disabilities and those who are closest to them to pursue their own life pathway/s.

- A whole of government approach.

2. ***Empowerment and Self-determination***

Younger people with disabilities will drive the process. This requires:

- Acknowledgment that younger people with disabilities have a right of self-determination; that is, they are free to determine their own life pathway/s.

- Acknowledgment that many younger people with disabilities have had little or no real decision making opportunities for some time.

- Acknowledgment that younger people with disabilities have decision making experiences that have not created positive circumstances or outcomes for them or those who are closest to them.

- Acknowledgement that the life pathway/s chosen by younger people with disabilities will be strongly influenced by their perception of whether or not their personal safety is adequately provided for.

- A process that acknowledges and proactively responds to the changing needs, circumstances and life pathways chosen by younger people with disabilities over time.

- A process that provides adequate safeguards and protections for younger people with disabilities and those who are closest to them, particularly in times of change.

- Acknowledgment that opportunities in life are part of a process, not an outcome.

3. Ever-changing Lives

The lives of younger people with disabilities and those who are closest to them are typically dynamic and fluid, not static. To this end, an array of different pathways may be accessed at any point in time. This requires that:

- "Visioning" and "dreaming" of a desired life pathway/s is constantly evolving and is not a one-off decision or experience.
- Resources must be linked to the younger person with a disability to enable them to develop and be happy.
- The meaning of an ordinary life is defined by and is unique to the younger person with a disability and those who are closest to them.
- The ever-changing aspects of living as reflected in the decisions younger people with disabilities make must be in place as safeguards.

4. Equity of Opportunity

For a number of reasons not all people begin life's journey on an equal playing field. As a consequence, people have different levels of emotional support, strengths of personal support networks, needs and supports due to the nature of their disability, etc. It is necessary, then, that:

- The process identify that different types and levels of resources will be needed over time.
- The initial stage of deciding upon an alternative or enhanced life pathway/s may necessitate providing younger people with disabilities with information, experiences and support.

5. Right Relationships

It is important to honour the natural relationship between a younger person with a disability and those who are closest to them. This requires that:

- It may be necessary to work with the immediate or extended family of the younger person with a disability to re-establish the primary relationship of parent, partner, sibling, friend, etc, as opposed to a relationship primarily identified as carer/care recipient.

- Younger people with disabilities and those who are closest to them dominate
  the decision making process and make their own decisions at all times.

- It may be necessary to assist some younger people with disabilities to form alternate natural loving and supportive relationships.

- It may be necessary for some younger people with disabilities and those who are closest to them to have the support of an independent advocate.

6. Quality Service

Younger people with disabilities and those who are closest to them should be in the position to define what quality service (including quantity) means to them. This requires that:

- Public policy makers and service providers look beyond the concept of minimum service standards to meeting the needs of younger people with disabilities.

- Quality service needs to be defined by the younger person with a disability and those who are closest to them. The outcomes of standardised assessment tools and formal assessments conducted by allied health professionals need to complement (not replace) the service and supports needed as defined by the younger person with a disability and those who are closest to them.

- The process fosters the right relationships between younger people with disabilities, service providers and other formal and informal support networks.

- Any funding is attached to the individual and is portable.

- There is an emphasis on education and information.

- Some younger people with disabilities may require the support of an independent advocate.

7. Cultural Change and Community Development

The process identifies that being a valued member of the community is the rightful starting point, not an outcome. The process must:

- Challenge assumptions that the community is not welcoming.

- Challenge assumptions that public policy makers, allied health professionals and workers in aged care facilities know what is best for younger people with disabilities and those who are closest to them.

- Work to establish/re-establish the networks for younger people with disabilities that give value to being part of the community.

6. WHERE TO FROM HERE?

It is essential that immediate action be taken to assist younger people with disabilities currently living in residential aged care facilities in the ACT to locate appropriate and positive living options and resume lives that have a purpose and value. It is equally important that other younger people with disabilities do not find themselves in the position of being unable to locate any positive life pathways. These are over-whelming imperatives in the lives of the individuals who find themselves in these situations.

It is also clear that an infrastructure must be developed to sustain a service and support system that will respond to the lives of younger people with disabilities in a positive and proactive manner.

Four actions have been discussed that will assist with:

- **the improvement of information on younger people with disabilities in the ACT;**

- **generating a wealth of insights into good practice for working with younger people with disabilities and those who are closest to them; and**

- **the development of an infrastructure that could sustain the level of system change required.**

ACTIONS -

1. CONDUCT A THOROUGH INVESTIGATION **into:**

    - the locations and circumstances of younger people with disabilities currently living in residential aged care facilities in the ACT, and people who are in other residential facilities who are eligible for placement in such facilities;

    - the extent of issues experienced by younger people with disabilities in residential aged care facilities in the ACT;

- the options currently considered available for these people;
- current national and international practices, including best practice;
- financial costs to sustain current practices; and
- non-financial costs to sustain current practices.

2. **DEVELOP AND TRIAL A PROCESS** that would:
   - investigate the personalised opportunities and supports required by younger people with disabilities to sustain a positive health status *and* to maximise and maintain personal relationships and other social and community connections;
   - identify service providers with the capacity to support younger people with disabilities and then link younger people with disabilities with them;
   - identify community organisations with the capacity to provide financial support to younger people with disabilities;
   - liaise and network with service providers and community organisations to inform and educate them about the needs of younger people with disabilities; and
   - build links with a range of service providers and community organisations to improve access for younger people with disabilities.
3. **BUILD PARTNERSHIPS** with relevant policy government departments, service providers and community organisations to contribute to robust policy that will sustain positive practice:
   - at a funding and accountability level;
   - at a service/support collaboration level; and
   - at a service/support practice level.
4. CONDUCT EDUCATIVE ACTIVITIES **to enable these three actions to eventuate in a positive and collaborative manner.**

Further discussion is necessary between younger people with disabilities and those who are closest to them, the ACT Government, the Federal Government, service providers and advocates in order to pursue any of these actions and/or other actions that may be necessary to strengthen and secure more positive life pathways for younger people with disabilities and those who are closest to them.

It is also necessary that action not be hindered by a lengthy period of negotiation. The discussion must take place immediately. It must be focussed and outcome directed.

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ATTACHMENT A

SCHEDULE 1 OF THE ACT DISABILITY SERVICES ACT 1991:

Human rights principles to be furthered
in relation to people with disabilities

1. All people with disabilities are individuals who have the inherent right to respect for their human worth and dignity.

2. People with disabilities, whatever the origin, nature, type or degree of disability, have the same basic human rights as other members of society and should be enabled to exercise these basic human rights.

3. People with disabilities have the same rights as other members of society to realise their individual capacities for physical, social, emotional and intellectual development.

4. People with disabilities and carers of people with disabilities have the same right as other members of society to services that will support their attaining a reasonable quality of life.

5. People with disabilities have the same right as other members of society to make and actively participate in the decisions that affect their lives and are entitled to appropriate and necessary support to enable participation in, direction and implementation of the decisions that affect their lives.

6. People with disabilities have the same right as other members of society to receive services in a manner that results in the least restriction of their rights and opportunities.

7. People with disabilities have the same right of pursuit of any grievance in relation to services as have other members of society.

8. People with disabilities who wish to pursue a grievance also have the right to adequate support to enable pursuit of the grievance; and be able to pursue the grievance without fear of discontinuation of services or recrimination from any person or agency who may be affected by or involved in the pursuit of the grievance.