Senate Community Affairs References Committee

Inquiry into Aged Care.

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

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SUBMISSION TO SENATE COMMUNITY AFFAIRS COMMITTEE INQUIRY INTO AGED CARE

TERMS OF REFERENCE: C

THE APPROPRIATENESS OF YOUNG PEOPLE WITH DISABILITIES BEING ACCOMMODATED IN RESIDENTIAL AGED CARE FACILITIES

ADACAS believes unequivocally that residential aged care facilities are not appropriate places for younger people with disabilities to live because these facilities are the antithesis of human dignity, self determination and integration into full community life.

For the purposes of this submission, ADACAS has taken the term "residential aged care facilities" to include respite care, hostels and nursing homes.

Nationally, there are many hundreds of younger people with non-age related disability living in Commonwealth funded aged care facilities and this group is increasing in size. They are a diverse subgroup of the general population of people with disabilities, with varying backgrounds, capacities, needs, life goals and aspirations. 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.

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

Consequences for younger people with disabilities

There are a range of serious consequences arising from the accommodation of younger people in residential aged care facilities.

Firstly, there are significant lifestyle issues that arise for younger people who are institutionalised in aged care facilities. A geriatric facility is not suitable for young men and women, who have decades of life yet to experience. Aged care facilities generally 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 in these facilities is also geared towards those people who are the frailest. This means that some residents, even those people who have age related disability, are technically "over-supported". This results in a level of inactivity, which in turn leads people to lose the skills and knowledge that they have accumulated because they are no longer required to use them. When a person's skills decrease, they also become increasingly vulnerable and this inevitably leads others to perceive them as incompetent and of low social value.

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 disabilities become increasingly dependant. Their support needs increase as does the cost of meeting them.

There are also significant cost implications of accommodating younger people in residential aged care facilities. For example, a younger person (say aged 18), who has acquired brain injury as a result of a diving accident, could potentially spend the next 40 to 60 years living in an aged care facility. This person would be occupying a bed that would never be available to older people. This means the Commonwealth would need to build an additional bed to compensate, in addition to meeting the ongoing support costs, which should have been met by the relevant State/Territory government.

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 previous policy initiative which transferred Special Purpose Nursing Homes from administration by the Aged Care Program to the Disability Services Program.

This transfer occurred with the introduction of the Commonwealth *Disability Services Act 1986* (the DSA). In the following years, many such 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.

Unfortunately, since the introduction of the DSA, and more recently the CSTDA, the numbers of younger people with disability living in Commonwealth funded residential aged care facilities 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 residential aged care facilities, 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.

Other options

ADACAS strongly advocates for people with disabilities to be able to live within, and as part of, the community. Despite common (mis)assumptions about what is possible or appropriate for people with disabilities, many people with high support needs live full, contributing and rewarding lives in the community. Those people with disabilities who live in residential aged care facilities often experience violations of their rights and are rarely able to reach their potential and live quality lives.

Special purpose nursing homes, cluster housing and other forms of segregated, congregate accommodation are contrary to the objects of the DSA and are not acceptable alternatives for younger people with disabilities.

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; (perhaps using the Local Area Coordination model)
- brokered package of support funds.

There are a number of examples nationally (and internationally) of successful programs where younger people have been assisted to leave aged care facilities, or to not go into one in the first place. Many of the Australian initiatives had their origins in the Commonwealth's Attendant Care Scheme, piloted in the mid-1980's. The scheme provided examples of different models of administration and support, including direct payment to the client, who subsequently organised their own support.

The resources supporting younger people with disability in aged care facilities are currently solely the responsibility of the Commonwealth. Funding possibilities could include therefore, an extension of the Commonwealth's EACH scheme, (Extended Aged Care in the Home), with additional funds and services being 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;
- portability of support 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.

Position statement – "Permission to Shine"

Following this submission is a position statement that was prepared as part of a submission for Government funding concerning younger people with disabilities in residential aged care facilities in the ACT.

The paper provides a detailed description of the subgroup of people with a disability who are the focus of the position statement; 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 position statement is underpinned by seven high-level principles:

- Unique Supports
- Empowerment and Self-determination
- Ever-changing Lives
- Equity of Opportunity
- Right Relationships
- Quality Service; and
- Culture Change and Community Development.

ADACAS commends the position paper to the Committee. In particular, ADACAS recommends that the Committee endorse the seven high-level principles as a basis for developing policy in this area.

Kym Duggan
Chairperson
ACT Disability Aged and Carer Advocacy Service Inc,
(ADACAS)

6th August 2004

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

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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).

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:

- 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

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

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.

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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.

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:

- 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 –
    (a) adequate support to enable pursuit of the grievance; and
    (b) 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.

SUBMISSION TO SENATE COMMUNITY AFFAIRS COMMITTEE INQUIRY INTO AGED CARE

TERMS OF REFERENCE: D

THE ADEQUACY OF HOME AND COMMUNITY CARE PROGRAMS IN MEETING THE CURRENT AND PROJECTED NEEDS OF THE ELDERLY

ADACAS wishes to explore the differing approaches to aged care and disability services, with particular emphasis on the Home and Community Care Program, (HACC). The paper will compare 7 different aspects of the HACC and Disability Services Programs. Having done this, we will then go onto outline significant implications for people with disability unless the HACC program undergoes significant reform. Finally the paper challenges some assumptions about the quality of life for older people, and the role HACC services has in supporting older to have a full and rewarding life in the community.

The differing approaches to aged care and disability services

1. Philosophy

There have been significant reforms to the provision of support for people with disability living in Australia in the last 30 years. These mirror international reforms and are primarily articulated in and promoted by the Commonwealth and State/Territory Disability Services Acts, (DSA's).

Specifically, the Objects of the DSA's are:

- to assist persons with disabilities to receive services necessary to enable them to work towards full participation as members of the community;
- to promote services provided to persons with disabilities that:
  (i) assist persons with disabilities to integrate in the community, and complement services available generally to persons in the community;
  (ii) assist persons with disabilities to achieve positive outcomes, such as increased independence, employment opportunities and integration in the community; and
  (iii) are provided in ways that promote in the community a positive image of persons with disabilities and enhance their self-esteem;
- to ensure that the outcomes achieved by persons with disabilities by the provision of services for them are taken into account in the granting of financial assistance for the provision of such services;
- to encourage innovation in the provision of services for persons with disabilities;

(Commonwealth's ***Disability Services Act, 1986*****)**

By contrast, the "Objects" of the Home and Community Care Act, are:

- to develop a comprehensive range of integrated home and community care services for frail or at risk aged persons and younger disabled persons in order to facilitate the maintenance of those persons in their own homes; and
- to provide moneys, on a co-ordinated basis, to assist in the provision of those services.

(Commonwealth's ***Home and Community Care Act, 1985*****)**

So before we delve deeper into documentation with respect to both Programs a fundamental difference of purpose is already apparent:

- the HACC Program is about developing a range of services to meet people's (maintenance) needs, without any emphasis on people's ability to fully participate in the community or achieve positive outcomes; and
- the DSA Programs are to meet people's needs by developing services designed to assist people to participate and integrate in the community.

Whilst some may see this as semantics, the outcomes for consumers of the Programs are very different. We argue that this is because of the difference in the underlying philosophies of the two Programs. Philosophies are often underpinned by assumptions, and one may ask "what are the stereotypical assumptions which have dictated the different philosophical approaches in the 2 Acts?"

Based on the analysis of the Objects, purposes of the DSA and HACC Acts and Programs, it seems to ADACAS that one of the assumptions is that older people have little value for the community and are simply a drain on resources, that they have little capacity to continue to grow and develop, and to contribute to and participate in their community. This assumption in turn influences every aspect of the HACC Program, from the services it funds, to the people deemed eligible for access, and finally the how it evaluates the effectiveness and quality of the services provided with HACC funding.

2. Service types

The philosophy underpinning each Act influences the kinds of activities, or "service types", eligible for funding.

The HACC Program has developed a set of clearly defined service types, and if your needs meet these service types, then they can be met, (the "menu" approach). The DSA approach is to identify a person's needs and then create a service designed around the individual.

Whilst there are "service types" in the DSA's they are defined within "broad life functions" eg accommodation support. Approaches funded under the DSA's recognise that every human being is different, and meeting their needs can and does require different and holistic approaches. It has greater capacity to see the consumer has a whole person, and therefore more likely to identify needs that fall outside the service type, develop more flexible responses etc.

HACC, on the other hand, clearly defines some (only) aspects of "daily living", and classifies them as "service types". Whilst the more recent development of Community Options Projects has resulted in a more holistic approach to identifying and responding to the needs of HACC consumers, never-the-less, the bulk of HACC funding is provided to designated service types, eg meals [on wheels], transport, home maintenance etc.

3. <u>Thrive or survive?</u>

Looking at the HACC program documentation, the Act is further clarified by the National Program Guidelines for the Home and Community Care Program, 2002.

These state:

> "The HACC Program is a key provider of community care services to frail aged people and younger people with disabilities, and their carers. The overall objective of the HACC Program is to enhance the independence of people in these groups and to avoid their premature admission to long term residential care.
>
> "The Program aims to:
>
> - provide a comprehensive, coordinated and integrated range of basic maintenance and support services for frail aged people, people with a disability and their carers;
> - support these people to be more independent at home and in the community, thereby enhancing their quality of life and/or preventing their inappropriate admission to long term residential care; and
> - provide flexible, timely services that respond to the needs of consumers.
>
> "The Program operates within a regional framework with the purpose of improving responsiveness to the needs of consumers and helping achieve equitable access to HACC services. Critical elements for achieving this goal are improved regional planning and accountability, and making more transparent the relationship between the funding of regions and service providers and the level and quality of services.
>
> "Service providers funded by the HACC Program are part of the wider care network in which an organisation's service may be one of several services a person receives. Therefore cooperative and coordinated working arrangements between service providers are essential for the people they serve.
>
> "The HACC Program encourages flexible service delivery and a suitable mix of services to meet the needs of individuals and regions."

The use of the terms “premature” and “inappropriate” (admission to long term residential care) imply an inevitability that people will go into residential aged care, and that this is appropriate. ADACAS does not support this assumption, and further believes that as current generations age, institutional care will be less and less acceptable in any shape or form. This would have significant consequences for the HACC Program

The key phrase which dominates the practical application of the HACC Program seems to be “basic maintenance and support services” (for the purposes of preventing premature admission to long term residential care).

Some of the rhetoric mirrors the Objects of the DSA’s, (eg “meet the needs of individuals” and “support these people to be more independent at home and in the community” etc), and indeed there are service types which imply support and skill development, (eg **“Other Food Services:**This refers to assistance with the preparation and cooking of a meal in the client’s home and the provision of advice on nutrition, storage or food preparation”).

However, it is clear that the focus of the HACC Programs is to enable people to <u>survive</u> as opposed to an expectation that, in spite of increasing disability due to age, a person might prefer and be supported to grow, learn and maximize their participation in their community. Indeed the majority of services provided by the HACC Program could be described as enabling people to merely survive.

By contrast, based on the Objects of the Commonwealth DSA, as discussed above, the key aspects of services funded under the DSA’s are that they will be delivered so that people with disability:

- have full participation as members of the community;
- are integrated into their community;
- use generic services wherever possible;
- achieve positive outcomes eg increased independence, employment, community integration;
- are promoted in a positive manner, ie not as a burden, in need of charity etc.

In short, the expectation is that people with disability will <u>thrive</u>, and become and continue to be participating members of their community, and that the role of funded disability services is to facilitate this.

4. <u>Assessment</u>

Again we believe that the underlying philosophical differences between the 2 programs has been instrumental in developing their approaches to assessment. The HACC Program’s approach to assessment identifies what activities of daily living people can’t do, and attempts to provide assistance with those activities, or at least some of them. This approach could be categorized as “deficit based” assessment.

For example, from the National Program Guidelines for the Home and Community Care Program, 2002:

> "Access to services in the HACC Program is based on the assessed needs of individuals seeking assistance to remain at home in the community. Assessment is a systematic way of establishing the type and extent of consumer support needs and following on from this, the identification of a range of <u>appropriate home and community care services</u> to meet those needs."

This implies "menu" lives: that is selection from a pre-determined range of service types, (based on basic survival) rather than an organic process of determining what a person wants to do with their life, what the barriers (caused by their age-related disability) are to achieving those goals, and how HACC services might assist someone to achieve them.

By comparison, the DSA's approach could be classified as "holistic, bottom-up". Whilst the DSA's have service types and definitions, they are couched in general terms, eg "accommodation support", are governed by the overarching Objects of the Acts, and therefore have capacity to be inherently flexible in identifying and responding to a persons needs within various life domains or purviews. So instead of "what can't you do?", DSA based assessment focuses on questions like : "what do you want to do with your life, what's stopping you doing it, what can specialized services do to assist?"

Surely this approach is equally valid, irrespective of what age the consumer is? If an older person does not want to be encouraged or actively engaged in their community, then the response from their HACC service could be designed accordingly.

Elsewhere, the HACC Guidelines state:

> "…eligibility for services is based on frailty related to handicap and that individuals do not qualify for HACC services solely on the grounds of advanced age.
>
> "Thus, individuals over any particular age do not qualify for HACC services on the basis of their age alone, but because they have difficulties in carrying out tasks and need assistance due to a moderate, severe or profound disability.
>
> "A person considered to have a moderate, severe or profound disability has a functional disability which makes it difficult to perform the tasks of daily living without help or supervision. '<u>Tasks of daily living' include dressing, preparing meals, house cleaning and maintenance, and using public transport</u>. Some people may need only one service (for example nursing services or personal care), while others may need a combination of services."

Whilst life is lived in the mundane, most people would believe that "living" (a quality life) is more than getting up in the morning, preparing (and eating) meals, doing the housework and being able to catch a bus. Also, the HACC Program seems to see all a person's needs met by formal human services and, unlike the DSA's, ignores the broader capacity of generic services to respond.

5. Inclusion, integration: rhetoric versus reality

One of the most stark differences between HACC and DSA funded services is the approach to segregated, congregated services. Not-with-standing the rhetoric in the Act and HACC Guidelines, ("…flexible service delivery and a suitable mix of services to meet the needs of individuals…", and "The overall objective of the HACC Program is to enhance the independence of people…" etc), centre-based services are endorsed even encouraged by HACC.

Research undertaken in the last 25 or more years has clearly established that services where large numbers of people are congregated together on the basis of their disability are less likely to receive programs tailored to meet their individual needs and maintain or acquire new skills. This research has driven the de-institutionalisation of services for people with disability for well over 30 years.

It is not clear why Government Programs designed to respond to the needs of people who have become frail through age-related disability eg HACC, Residential Aged Care, ignore this research. They still include in their Program-related documentation for centre-based services, requirements for funded services to achieve outcomes for their consumers, eg enhance independence, meet individual needs, yet they have been shown to be not achievable in congregated, segregated settings. One answer could be that, not-with-standing rhetoric elsewhere, there is a view that older people, especially if they are frail, cannot, or do not want to have a full and rewarding life.

6. In/eligible service types

The HACC Guidelines define some service types as "ineligible" under HACC, specifically "supported accommodation". Following the de-institutionalsiation programs from the 70's onwards, many people with disability now live in group homes, defined by the HACC Program as "supported accommodation". In more recent years most jurisdictions in Australia, and indeed internationally, have recognized the limitations of group houses. As a result, State and Territory Governments are progressively allocating funding on an individual, portable basis.

As a result, people with disability are choosing where and with whom they live. Whilst this living arrangement may still have the appearance of a "group home", it is fundamentally different. Essentially, there may be 2 or more people with individual support packages choosing to share housing for "economies of scale", friendship, or in an intimate relationship etc.

The HACC Program does not exclude people receiving individual support packages from being able to access HACC services, as long as it is not to increase the level of support provided under their DSA funding. So for example, a person might receive DSA funded support for independent living skills training in their own home, personal care etc, but receive HACC meals on wheels, gardening and home maintenance, transport etc.

These reforms in funding of DSA services have been underway for well over a decade, and yet, when releasing the National Program Guidelines for the Home and Community Care Program, in 2001, this fundamental change in service provision for people with disability, and the impact on HACC, was ignored. This creates significant continuity of care issue for people with disability as they age, and these are discussed below.

7. Advocacy

Both the DSA and HACC programs fund advocacy. The National Disability Advocacy Program, effectively funded and administered by both levels of Government, has well developed foundations for advocacy to enable consistency of approach. This process has also assured that advocacy is seen for what it is, a human rights and social justice program, which recognisees the vulnerability of people with disability because of their disability. That is, their vulnerability will be experienced in all walks of life, not just in the context of the formal, specialised disability services they may receive.

HACC on the other hand, sees advocacy only in the context of the HACC Program, ie people who are consumers of HACC services, about HACC issues, eg quality of service, complaints, eligibility, access etc. This presents major barriers for older people as many aspects of their lives cannot be protected from abuse and discrimination by HACC funded advocacy programs, even though the consequence of not receiving the advocacy may be premature institutionalisation, the prevention of which is a specific objective of the HACC Program. For example: elder abuse, housing, health, debt etc., any one of which if not addressed could result in the older person entering an aged home, (assuming they have a level of disability which makes the eligible for entry).

In addition, not all States and Territories have HACC funded advocacy, and even those that do, have only a few funded agencies. Therefore, there is a significant under-resourcing of advocacy for older people especially in Australia, which leaves their voice, especially at the individual level, largely unheard.

People with disability accessing HACC services now, and as they age

ADACAS' experience is that many of the expectations of younger people with disability accessing HACC services are not generally met. In particular, the degree of self-determination, service flexibility and respect for them generally, is felt to be lacking, especially when compared to DSA funded services. Specifically, people with disability report experiencing a more patronising attitude from HACC service staff, especially those services that are only HACC funded, ie have no DSA funds, and provide the more home based services eg cleaning, shopping etc.

In particular, people with psychiatric disability and/or mental dysfunction report being less well treated within the HACC system. Indeed, ADACAS experience is that the HACC Program, at least in the ACT, is regarded by the Government as not an appropriate option to meet the needs of people with psychiatric disability. There is a view that Mental Health Services should meet all the needs of people with psychiatric disability, which we regard as contrary to the National Mental Health Strategy, (NMHS).

There has been a recent focus on the way HACC services respond to the needs of people with disability, and the first round of HACC standards assessments have only just been completed. It is possible therefore that over time there will be an improvement in how HACC services and their staff interact with people with disability.

Another concern though, is the impact of increasing numbers of people with disability accessing HACC services as they age, and what will happen at the "transition date" of age 65. As a result of de-institutionalisation, and improvements in health care, many people with disability (eg intellectual disability, cerebral palsy etc) are living into old age, and are living in the community.

As mentioned above, many people with disability live in group housing, (whether as a group home, or as a group of individuals choosing to live together), a service type ineligible under HACC. This model of service often provides "24/7" support. The current HACC Program cannot respond to this need as it is currently operating.

Compounding this situation is the lack of growth provided through the Commonwealth-State/Territory Disability Agreement. This places pressure on State/Territory Governments and service providers with respect to high demand from younger people, whilst at the same time the future of older people living in supported accommodation is unclear. Obviously also, this situation would be causing great concern for people with disability and their families, who are faced with uncertainty about where and how support will be provided for them as they grow older.

In the ACT the Residential Aged Care, (RAC), Program, (Commonwealth) and the ACT Government are discussing an option where-by the RAC program will provide a subsidy to the ACT Government so the people in their group homes can remain where they are as they age. However, it is not clear what arrangement might be available for people being supported by community based agencies.

Should older people just survive, or should they thrive?

In closing we would like to return to a view expressed earlier in the paper: that is that the basic assumption which appears to be underpinning the HACC Program is that older people should be provided with basic maintenance services in order for them to survive, rather than thrive, in their community. It is true that not all HACC services operate this way, but there are significant structural barriers inherent within the HACC Guidelines, as discussed above, which make it very hard for them to meet the needs much less the aspirations of their clients holistically.

ADACAS challenges this assumption. Whilst it is possible that some older people are, and will continue to be satisfied with meals on wheels etc and do not want more comprehensive service involvement in their lives, as the HACC Program supports people with more complex needs, it has to be able to respond more holistically and comprehensively.

ADACAS believes significant reform is needed to enable the HACC Program to respond to the changing demands / expectations of an ageing population.

In addition, whilst we support many aspects of the Government's proposed reforms to Community Care, as outlined in the discussion paper, (March 2003), we disagree with the continued focus on deficit based assessment. This is especially the case if, as was proposed in the discussion paper, ALL community based services, including CS/TDA funded services for people with disability, will be included in the new access, eligibility and assessment arrangements. If this were to occur it is our view that services for people with disability will be set back 30 years or more, and an opportunity to make community services for older people more relevant and in tune with community views and expectations will have been lost.

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