



30 July 2004

The Secretary
Senate Community Affairs References Committee
Suite S1 59
Parliament House
Canberra ACT 2600

Dear Committee Secretary

National Disability Administrators' Projects Relating to Aged Care.

I wish to advise the Senate Community Affairs References Committee of the work of the National Disability Administrators (NDA) that relates to aged care.

The National Disability Administrators is responsible under the Commonwealth-State/Territory Disability Agreement 2002 – 2007 (CSTDA) for the CSTDA Performance Reporting Framework, CSTDA Research and Development Program and the CSTDA Implementation Plan.

A project of the NDA Work Plan for implementation of the CSTDA is "Access to Services for People with a Disability who are Ageing." The jurisdiction with responsibility for leading and coordinating the project is the Australian Government – specifically the Office of Disability of the Department of Family and Community Services. The Australian Government provided a status report on the project to the NDA meeting in May 2004, which is attached for your information.

A research project under the NDA Research and Development Program of the NDA is designed to inform the above Work Plan project. The research project "Disability and Ageing" is designed to provide advice to all jurisdictions in respect to appropriate, best practice, service and funding models for the range of services provided to meet the specific needs of people with disabilities who are ageing. The research will act as a status or progress report, in relation to people with a disability who are ageing overall, those living in the community or in disability supported accommodation but also in terms of specific sub-populations. The jurisdiction with responsibility for leading and coordinating the project is Western Australia – specifically the Policy, Planning and Information Directorate of the Disability Services Commission. A research brief has been developed for that project, and is attached for your information.

Disability Services Queensland

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A further research project is being undertaken by the NDA relating to the matters referred to the Committee by the Senate. The project "Support Needs and Service Models for Younger People with High Clinical Care Needs" aims to progress discussions of the issue and inform initiatives under bilateral agreements with regard to young people in nursing homes and people with disabilities with high clinical care needs. The jurisdiction with responsibility for leading and coordinating this project is New South Wales – specifically the Community Partnerships Branch of the Department of Ageing, Disability and Home Care. A research proposal for the project is attached.

I trust that this information is of interest and assistance to the Committee in their Inquiry into Aged Care. Please contact me if the Committee require further information on the activities of the NDA that relate to Aged Care.

Yours sincerely



Bette Kill
Chair
National Disability Administrators

Assistant Director-General
Disability Services Queensland

NDA MEETING

21 MAY 2004

BRISBANE

D i s  i l i t y

AGENDA ITEM NO. 3.2

SUBMITTED BY: Australian Government

TITLE: CSTDA IMPLEMENTATION PLAN – Access to services for people with a disability who are ageing – Proposal

Decision Paper

RECOMMENDATION/S:

That you consider the following paper on proposed work on access to services for people with a disability who are ageing.

Author: Debbie Wade Telephone: (02) 6244 6614
Jurisdiction: Australian Govt Submission Date: 21 May 2004

NDA Meeting - Brisbane – 21 May 2004

PURPOSE OF THE PAPER:

- To table a proposal for the progression of the NDA workplan in respect of access to services for people with a disability who are ageing.

BACKGROUND:

- At their July 2003 meeting, disability Ministers agreed to 14 key policy priorities under the current CSTDA. One of these was access to services for people with a disability who are ageing.
- At its November 2003 meeting, NDA adopted a workplan, including agreed actions, timeframes and progress reporting.
- Under the NDA workplan, the Australian Government accepts a leadership role, working with the Western Australian government, in respect of the policy priority area of access to services for people with a disability who are ageing.
- The number of people with disabilities who are ageing is increasing. Longer life expectancies and changing expectations of people with disabilities (and their carers) means the disability sector is, for the first time, "facing a constellation of issues associated with an ageing demographic"¹. The situation is compounded by the fact that people with certain disabilities may experience the effects of ageing earlier than others with disabilities or the general population.
- There are many issues that people with disabilities will face as they age. One is access to services and support when they are no longer engaged in employment. The other is access, at an appropriate time, to community and residential aged care services.

ISSUES:

Retirement issues

The main issue is the availability of support either under the CSTDA or through other programs such as HACC to meet the need of people with disabilities retiring from employment or ATE

Factors contributing to this gap include:

- group homes and other accommodation services may be unable to meet the needs of residents who are not 'at work' from Monday to Friday;
- need for the provision of support to ageing carers, especially once they can no longer access the 'respite' side effect of an employment service;
- the emerging needs of people with disabilities who are ageing – a new experience for the sector; and

¹ From Disability and Ageing project research brief CSTDA 3/NDA 002

- lack of suitable processes for transition to more appropriate support options.

This issue is important to the successful implementation of many of the bilateral agreements between the Australian Government and the various state and territory governments. However, there are currently also a number of projects underway which are integrally linked and should inform decision making and policy application in this area. It is proposed that activities under the NDA workplan have the opportunity to take into account learning from these vitally important projects and previous related activities, for example: the Fyffe, Gordon and McCubbery report for the NDA on Ensuring Successful Ageing: Report of a National Study of Day Support Services Options for Older Adults with a Disability:

- initiatives from the 2004-05 federal budget in relation to older carers. In particular data gathered in the initial stages would provide a more comprehensive understanding of the demographics of the population in focus;
- the Business Services Assistance Package (*Security, Quality Services and Choice for People with Disabilities Funding Package*) recently announced;
- the NDA Research and Development project on Disability and Ageing (CSTDA 3 / NDA 002);
- the Community Care Review being conducted by the Australian Government Department of Health and Ageing;
- Department of Health and Ageing Innovative Pool projects on disability and ageing issues; and
- ongoing sector developments.

In addition, a number of state and territory jurisdictions have developed, or are developing, service coordination structures, such as the Local Area Co-ordination programs in Western Australia, Queensland and the ACT. Other states such as New South Wales are undertaking work in relation to joint ageing and disability planning.

Aged care issues

People who are ageing with a disability may prefer to 'scale back' or cease their involvement in employment or ATE services, in much the same way as other Australians who are ageing. However, this may occur when the person is not old enough to be considered for aged care services, or are not otherwise showing signs of ageing.

In addition, people may be presently accommodated in group homes or other supported accommodation arrangements, suggesting that they would be a low priority for consideration for aged care places or services.

State and territory jurisdictions need to plan for the provision of services to people 'retiring' from work, but not yet requiring aged care services.

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 Jurisdiction: Australian Govt Submission Date: 21 May 2004

At the same time, it is known that there are a large number of younger people with a disability who currently occupy residential aged care places, and who may be inappropriately placed in residential aged care.

OPTIONS:

Retirement issues

The Australian Government, as lead state for the key priority area of access to services for people with a disability who are ageing, proposes that it works with Western Australia to examine a range of activities that may provide greater insight into the area of 'positive retirement'.

As an interim measure, the Australian Government proposes to work with the Western Australian government to identify an appropriate 'service mix' to meet individual need as a major contributor toward 'positive retirement'. This includes examining issues such as:

- Developing a coordination role at a community or local area level which takes into consideration, on an individual basis, various service mixes that can contribute to 'positive retirement'; and
- Examining options making up the 'service mix' for people with disabilities, for example: day options, leisure/recreation activities of personal choice, accommodation, transport and general community services as appropriate.

As previously outlined, work is currently underway in a number of related areas that will impact on work to retirement issues. These include the Community Care Review and projects funded under the CSTDA Research and Development funding.

The Australian Government 2004-05 Budget outlines a package to assist ageing carers by guaranteeing four weeks of respite care annually. Once this program is in place demographic data collected will also provide a better understanding of issues in relation to the elderly carers of people with disabilities who are approaching retirement.

It is proposed that this project be conducted at a stage when further information is available through these initiatives.

It is proposed that the Australian Government, in conjunction with the Western Australia government, comprehensively scope this project and develop a paper for discussion at the planned NDA meeting in November 2004.

Aged care issues

It is understood that the Australian Government Ministers for Family and Community Services and Health and Ageing are to meet shortly to discuss a range of interface issues, including the provision of aged care services for people with disabilities and the issue of younger people with disabilities living in residential aged care facilities.

It is expected that a number of options will be discussed at that meeting. The Australian Government will work in collaboration with the Western Australian government in progressing the outcomes of this meeting, and will provide a joint report to the next NDA meeting.

National Disability Administrators

Project Ref: CSTDA 3 / NDA 002

Disability and Ageing

Steering Committee Research Proposal

6th May 2004

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Introduction

People with disabilities are ageing in significant numbers along with the rest of the population. Changes in the disability sector, including the move to community based residential services, longer life expectancy and changing expectations by people with a disability means that the sector has not previously experienced the current constellation of issues associated with an ageing demographic.

There is a need to conduct a comprehensive and systematic exploration of this population, their changing needs (nature and extent) and the capacity of the disability and aged care sectors to support them to age positively.

The aim of this research project is to provide advice to Australian Governments in respect to appropriate, best practice, service and funding models for the range of services provided to meet the specific needs of people with disabilities who are ageing.

To achieve this, information is sought on several issues:

- the profile of people with disabilities who are ageing;
- an understanding of the existing models of support, services and funding, as they are managed in and between the various sectors who provide for this group;
- the existence, or potential development of, alternative models of support and funding;
- the identification of key concerns and specific amendments to existing funding and service models to allow for appropriate change which will benefit this group.

The research would involve a review of service models and approaches that target people with disabilities who are ageing, giving consideration to the interface with health and aged care services. The research would provide evidence to progress national discussions on policy and funding issues impacting on people with disabilities who are ageing.

The research presents an opportunity to look at the current capacity of services to meet the needs of people with disabilities who are ageing and their likely capacity in the future to meet the needs of people with disabilities to age positively. The research will act as a status or progress report, in relation to people with a disability who are ageing overall, those living in the community or in disability supported accommodation but also in terms of specific sub-populations.

This project is being managed by the Western Australian Disability Services Commission, in conjunction with a project steering committee, on behalf of the National Disability Administrators (NDA). The National Disability Administrators comprise Heads of Departments of the Australian and the

States/Territories governments who are responsible for the administration of the Commonwealth State / Territory Disability Agreement (CSTDA).

Background and Context

Principles Underpinning the Research

The following principles, based on the United Nations Principles for Older Persons are proposed to underpin this research:

1. As an overarching principle the NDA understands that ageing is a natural phase in a person's life and values older people for their uniqueness and their contribution to the richness and diversity of community life;
2. People with disabilities who are ageing should have access to individually designed services and supports that enhance their autonomy, protection and care;
3. People with disabilities who are ageing should be able to age in place with appropriate supports. Ageing in place refers to people being able, should they so choose, to continue to reside in the dwelling they currently live and to live with others who have comparable experiences and interests (Gething, 1999);
4. People with disabilities who are ageing should be able to participate in determining when and at what pace withdrawal from the work force takes place;
5. People with disabilities who are ageing should be able to participate in leisure/recreation activities that are adaptable to personal choices and changing capacities;
6. People with disabilities who are ageing should have access to health and allied health care to help them to maintain or regain their optimum level of physical, mental and emotional well being and to prevent or delay the onset of illness; and
7. People with disabilities are representative of the diversity found within the general population and should not be seen as a homogenous group. Linguistic and cultural requirements need to be addressed where required.

Background and History

By 2031, the ABS estimates that 21% of the population will be aged over 65 years. Indeed, Australia's ageing population has been a key focus for planners and policy-makers during the past decade. This ageing of the population is coupled with ongoing social, economic and technological change

which will have a considerable effect on family and community structures, retirement earnings, housing and other lifestyle matters (Andrews, 2002).

Among this population is a cohort of people with disabilities who are ageing. As a result, Australia has encountered an increase in both the total numbers and ratio of people with a disability who are ageing. (Bigby, 2002). This is the first significant population of people with disabilities who are growing older with the rest of the population (Bigby, 2002).

The source of this cohort is primarily due to the 'baby boomer' phenomenon, but also there are increasing numbers of people with disabilities who are living longer due to medical and technological advances (Doka and Lavin, 2003). Changes in the disability sector, including improved standards of health care, deinstitutionalisation and the move to community based residential services, have contributed to an increased life expectancy for people with disabilities (Doka and Lavin, 2003).

A related and important issue is that, for some forms of disability, the effects of ageing are experienced at an earlier age, for example, Downs Syndrome and Fragile X Syndrome (Hogg, et al., 2001). These people may need to access aged care services at an earlier age.

This, in addition to shifting expectations by people with a disability, mean that the disability sector is, for the first time, experiencing this constellation of issues associated with an ageing demographic.

This presents a considerable challenge for the aged care and disability sectors in, what Doka and Lavin (2003) refer to as, a 'paradox', whereby as people with disabilities age, their intellectual and physical capabilities decline, their need for services increase, and their family and community support systems may be less accessible.

As the needs of ageing people with disabilities change, the profile of the services that they need will also change and may lead to a lack of clarity around the interface of services in areas such as disability, medical and nursing, guardianship/advocacy (especially with aged carers as well), aged care and home care. As a consequence, there is a possibility that aged people with early onset disabilities may be included or excluded from either sector (Bigby, 2002) – these interface issues need further documentation in this study.

This issue has implications for forecasting demand for services and resources, training and development of support staff (Doka and Lavin, 2003), and discerning the future source of personal and financial responsibility for this population.

This complex array of needs, services and responsibilities mean that challenges can arise at the Australian Government / State and Territories interface when dealing with aged care, health and disabilities. Currently, aged

care services in Australia are administered by two Australian Government Ministers in Health and Aged Care. The Minister for Aged Care has specific responsibility for aged care services (ABS, 2002); the Minister for Health and Aged Care has overall responsibility for health. Each state and territory jurisdiction also has Ministers responsible for health services and sometimes a separate minister for disability services. The Department of Health and Ageing has responsibility for providing accommodation and care for older Australians. Accommodation for people with disabilities under 65 years is a State / Territory administrative responsibility.

The potential impact of the increased population of people with disabilities who are ageing has been discussed extensively in the literature, but to date, there has been very little understanding and investigation of how service demand and provision has progressed to meet the changing needs of people with disabilities who are ageing. Therefore, it is important that the assumptions underpinning our current understanding of the effects of the ageing population are addressed, in order that we have an accurate understanding of the issues that we face.

Jurisdictions have recognised the issues and challenges associated with ageing and are putting in place a range of strategies and responses to support people with disabilities to age positively. However, there is a need to conduct a comprehensive and systematic exploration of current ways in which the disability sector supports positive ageing to inform the development of these responses.

Existing Research

Literature reviews in the field (e.g. AIHW, 2000; Hogg, et al., 2001) have highlighted a great many related issues. These tend to be discussed in terms of:

1. Demographics
 - a. the identification of the population
 - b. a more in-depth understanding of the sub-groups within the population
 - c. gender- specific issues (Harrison, 2003)
 - d. culture and ethnicity
 - e. people with disabilities aged over 65 who have their own children
 - f. people living in remote or rural areas;
2. Diagnosis
 - g. premature ageing
 - h. the high rate of psychiatric and physical disorders (Cooper, 1999)
 - i. life expectancy and ageing processes
 - j. diagnosis-specific prognosis;
3. Process of caring for these people
 - k. health care needs
 - l. family support
 - m. financial situation; and

4. Services
 - n. Appropriate accommodation
 - o. day options and employment
 - p. quality of life.

Policy Context and Related Projects

The issue of providing appropriate services for people with disabilities who are ageing has implications across three CSTDA Policy priorities – access to generic services, across government linkages and improving strategies to manage demand. It is also likely to inform Australian Government Aged Care policies and service purchasing policies in all jurisdictions.

A project of significance to this proposal is the work funded by the NDA under the CSDA II on Disability and Ageing. This was carried out by the Australian Institute of Health and Welfare in 2000. The research focused on using the snap-shot day data from the 1997-1998 National Minimum Data Set and the ABS survey of Disability and Ageing (ABS, 1998). The report provides an overview of demographic data as it was available in 1997-1998. This project provides an opportunity to update earlier demographic information, with new NMDS and ABS data, as well as provide much greater analysis of possible service responses.

Research Scope

Project Objectives

The objectives of the project are to:

- understand the demographics and characteristics of people with disabilities who are ageing;
- understand their specific situation, the nature of their needs and barriers to their accessing services to meet those needs;
- to present a comprehensive review of existing practices, trends and issues, with a view to the development of best or new practice models;
- understand the barriers for CSTDA services to support ageing in place;
- understand the services provided in relation to the needs of the population; and
- understand the appropriateness of aged care facilities for people with disabilities who are ageing.

The Research Problem

The research problem is:

- to provide an objective analysis of the current level of need that has changed as a result of ageing;
- make informed estimates about the future need;
- assess how CSTDA services are meeting this need now and their capacity into the future; and

- to identify policy directions and models of service provision that will assist in meeting these needs taking into account the role of other sectors including health and aged care services.

Target Population

People with disabilities who are ageing and whose needs are changing in receipt of CSTDA services. Sub-groups within this population are likely to be identified based on age, diagnosis, geographical, cultural, demographic and other considerations.

Project Scope

In order to meet these objectives the Steering Committee believe that the research should consider, but not limit themselves to the research tasks, as described below.

Population

- Review the current demographics of the population with disabilities who are ageing, who are in receipt of CSTDA services extending on the work of the AIHW (2000);
- Consider the relationship between severity of disability and ageing for this population;
- Identify the life expectancy and ageing processes associated with this population, and address the differences in ageing within sub-populations – this should include consideration of: health and well being; life expectancy; whether the ageing population of people with disabilities in receipt of CSTDA services is still quite young on the whole;
- Identify the needs that are changing as a result of ageing for these sub populations. To what extent are needs changing as a result of ageing;
- A significant focus of this research will be on people in disability supported accommodation services who are ageing and whose needs are changing, however it will also be important to know to what extent people with disabilities who are living in the community who are accessing CSTDA services are able to access appropriate HACC and aged care services when they need them; and
- Develop percentages of the overall population, that is, determine the relative populations of the various sub-groups.

CSTDA Service Responses

- Develop an understanding of the situation for people with disabilities who are ageing in CSTDA services, how this creates unique service needs and how these needs are being met (from a range of sources such as: formal, informal, purchased and provided, etc.);
- Make an assessment of the adequacy with which changed needs that arise as a result of ageing are being met by current CSTDA service and how CSTDA services are or are not being augmented by other services;
- What are the costs (financial and other) that are being borne by CSTDA services to meet these changed needs;

- Identify the barriers and difficulties that prevent positive ageing in place and assess the gap between changed needs and current service provision; and
- Examine access to generic community services by people with disabilities who are ageing in the community.

Examples of Practice

- Identify and highlight current initiatives (here and overseas), with reference to best or new practice that facilitates positive ageing in place.

Interface with Aged Care sector

- Document the extent to which people with disabilities in receipt of CSTDA services are able to access residential and community aged care services and community care services;
- Document how well the disability sector is handling the transition from disability to the aged care sector and how well the aged care sector is responding;
- Examine how people with disabilities who are ageing are assessed under the HACC eligibility criteria; and
- Develop an understanding of the appropriateness of aged care facilities for people with disabilities who are ageing.
- This includes the situation of people with disabilities who are growing older living in the community who are no longer able to be supported by their families.

Policy Directions

- Assess current policies in related areas health, aged care, housing, financial support, guardianship / decision-making which may or may not be supporting ageing in place for this population.

Methodology

Consultants would be invited to propose a methodology. The steering committee has reviewed a range of methodologies which might be considered in order to address these questions. These include:

1. a state by state and national survey of people with disabilities who are ageing and the sub populations that are ageing in CSTDA services.
2. a state by state and national survey of CSTDA services providing services to people with disabilities who are ageing;
3. case studies;
4. a longitudinal, empirical study of a sample of people with disabilities who are ageing – focusing on abilities, strengths and needs – which issues arise, and what are the best methods of dealing with them;
5. analysis of ABS and MDS datasets;
6. short literature review of relevant trends and issues (as a precursor to, or as informed by empirical research);
7. consultation with people with disabilities eligible for CSTDA services
8. consultation with Australian Government, State and Territory representatives in the key areas of: aged care; disability; health care;

- pensions; and accommodation to identify current and future policy objectives and directions;
9. consultation with peak service bodies such as the National Disability Advisory Council;
 10. consultation with CSTDA service providers; and
 11. access professional or other appropriate advice on the likely progress of relevant disabilities, including likely implications for future needs and understanding of the interaction between ageing processes and their disability.

Requirements

The following requirements are likely to be addressed in the final deliverables, based on the methodology as proposed by the consultant:

- a report covering the issues outlined in the Project Objectives and that addresses points identified under the project scope (it is not anticipated that the report will make specific recommendations, but rather it will comprehensively document and analyse the learning from the research undertaken);
- any data collected from surveys and other methodologies would be provided to the client in a de-identified form in an appropriate software medium; and
- the report should be fully referenced as per Australian Government Publishing requirements.

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Appendix 1: Glossary of Terms

For the purposes of this document, the following terms can be understood according to their definitions as outlined below. These have been derived from a combination of sources including: WHO; UN; ICF; CSTDA; the Australian Department of Health and Ageing National Strategy; and the ABS. Others were developed by members of the steering committee based on their understanding of the issues associated with the project.

People with Disabilities	People with disabilities attributable to an intellectual, psychiatric, sensory, physical or neurological impairment or acquired brain injury (or some combination of these) which is likely to be permanent and results in substantially reduced capacity in at least one of the following: self care/management; mobility; or communication; requiring ongoing and/or long-term episodic support and which manifests itself before the age of 65 (CSTDA).
Ageing	The process of growing older and showing the effects of increasing age.
People with Disabilities who are Ageing	People with disabilities whose support needs are changing as a function of increased age and whose disability was not acquired as a result of ageing. That is, people who will reach their older age with a pre-existing disability (Bigby, et al., 2001, p3)
Life Expectancy	The average age at which a given population or cohort can be expected to live according to mortality tables. Or the age to which 50% of a given population or cohort survive according to mortality tables.
Aged Care Sector	The welfare system focused on the needs of older Australians.
CSTDA Services	Services as specified in the Commonwealth State Territory disability Agreement.
Service Models	A system devised for the effective and efficient delivery of support to people who are eligible and have a particular need.

Age Positively	Becoming older in a productive, constructive, beneficial and positive way, maximising and enabling enhanced life expectancy of a person. The broad concept of positive ageing can include four aspects: healthy ageing; good quality care; independence and self-provision; and attitude, lifestyle and community support.
Acquired Disabilities	Disabilities consequent upon trauma, or progressive or degenerative disease or disorder.
Lifelong Disabilities	Disabilities which are experienced before the age of 18 years, where both the impairment and the consequent disability were present before the age of 18 years.
Community Based Residential Services	Either of: services designed to sustain a non-institutional residency and to support the person to remain in their current family or community setting; or a non-institutional out-of-family-home placement.
Health Condition	A health condition is an umbrella term for disease (acute or chronic), disorder, injury or trauma. A health condition may also include other circumstances such as pregnancy, ageing, stress, congenital anomaly, or genetic predisposition. Health conditions are coded using ICD-10. (ICF, 2001)
Generic services	Those services which are not specifically directed at persons with disabilities. That is, those services which are directed and are accessible and intended for all persons.

National Disability Administrators

Project Ref: CSTDA 3 / NDA 003

Support Needs and Service Models for Younger People with High Clinical Care Needs

Steering Committee Research Proposal

12th July 2004

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Introduction

There are growing concerns around the number of young people in residential aged care. These concerns relate to the appropriateness of such accommodation for younger people; the availability of more appropriate support models for younger people with high support needs, including those who may require medical or clinical support; and access for younger people with disabilities in nursing homes to other disability support services such as recreation and day options. This issue highlights a number of complex interfaces across jurisdictions, specifically across the aged care, health, disability and housing programs.

Under the Commonwealth State Territory Disability Agreement (CSTDA), all jurisdictions, except the Northern Territory, have entered into bilateral agreements with the Australian Government which includes a commitment to work together to reduce the inappropriate placement of young people with disabilities in aged care nursing homes. This includes examining more flexible funding approaches, the consideration of alternative support models for young people in nursing homes and exploration of the capacity to transfer younger people who may have been inappropriately placed in nursing homes to more appropriate accommodation.

The aim of this research project is to progress discussions by the National Disability Administrators (NDA) and to inform initiatives under the bilateral agreements with regard to young people in nursing homes and people with disabilities with high clinical care needs.

The research will do this by:

- developing a national profile (including pathways and trends in referral patterns) of younger people with disabilities who reside in residential aged care facilities;
- mapping existing models of support, services and funding for this target group; and
- identifying alternative support and funding models.

This project is being managed by a project steering committee and coordinated by the Western Australian Disability Services Commission on behalf of the NDA. The NDA comprises the Heads of Departments of the Australian Government and the States/Territories responsible for the administration of the Commonwealth State Territory Disability Agreement (CSTDA).

Scope of Research

Target Group

For the purposes of this study, the main target group will include people 50 years and under:

- who are eligible for services as defined under the CSTDA;
- who require high levels of nursing or related supports; and
- who live in residential aged care services; or,
- who have been ACAT assessed and approved as eligible to enter Residential Aged Care.

Scope of Work

1. Mapping the Prevalence and Demographic Profile of Younger People in Residential Aged Care Facilities

The project seeks to identify and map the characteristics of younger people in residential aged care, as follows:

- demographic profile including age, gender, geographical location, cultural background and aboriginality;
- differentiating characteristics, if any, of younger people in residential aged care, in comparison to people with similar disabilities and needs who do not reside in residential aged care facilities;
- factors contributing to the referral and / or entry of younger people into residential aged care and exit pathways;
- support needs and disability profile across key age and demographic groupings;
- age at initial entry and length of time resident in residential aged care; and
- trends and patterns of referral over time.

2. Review of Alternative Service Models

a) Literature Review

The project is to include a literature review of local and international service and funding models which specifically support younger people with high clinical care needs. This needs to canvas models from within and across the disability, health and aged care sectors. There are several current, key documents in the area which form the basis for current understanding of issues for this project.

These include:

- Stanton and Jessop (1994): 'Acquired Brain Injury: Accommodation and Support Needs'
- 'Disability and Ageing' (AIHW, 2000)

- Fyffe, McCubbery and Honey (2003): 'Young people with ABI less than 65 years requiring nursing home level care'
- Fortune and Wen (1999): 'The definition, incidence and prevalence of acquired brain injury in Australia'.
- Disability Service Commission (WA) (1998): 'The young people in residential aged care facilities project evaluation'
- Moylen, Dey and McCalpine (1995): 'A national research project examining the placement of younger people with a disability in residential aged care facilities for the aged'.

b) Identification and Analysis of Existing and Alternative Models and Pathways

The project is to include a description and analysis of existing service models specifically designed to meet the needs of younger people with high clinical care needs across the disability, health, community and aged care sectors. This review should include a demographic profile of consumers, and map alternative pathways for younger people with disabilities with high support needs. It should also identify aspects of the model which contribute to its effectiveness compared to other models.

Models should be assessed and analysed according to the following:

- client outcomes (such as quality of life, community access and social participation);
- service capacity (that is, the number of people supported);
- financial sustainability;
- interface between disability, health, aged care and housing; and
- the use of other support services while in residential aged care.

Examples of models to be reviewed include:

- Cyril Jewell House, funded by the Department of Health and Ageing, with additional funding provided by the Victorian Government under its disability program, to provide community access for 15 young people with multiple sclerosis;
- Fern River, and other projects funded by the Western Australian Disability Services Commission under its Young People in Nursing Homes project;
- individual community based accommodation support options funded under disability programs;
- pilot projects funded under the Australian Government's Innovative Pool funding;
- models jointly funded by health and disability programs to support young children and adults with respiratory support needs or who are ventilator dependent; and
- disability services funded specialist community residential services with aged care "top up" funding to address nursing care requirements.

Reference List

- Australian Institute of Health and Welfare (AIHW) (2000). *Disability and Ageing: Australian Population Patterns and Implications*. AIHW cat. No. DIS 19. Canberra: AIHW (Disability Series).
- Fortune, N., & Wen, Z. (1999): *The Definition, Incidence and Prevalence of Acquired Brain Injury in Australia*. Canberra: AIHW.
- Fyffe, C., McCubbery, J., & Honey, K. (2003): *Young People With ABI Less Than 65 Years Requiring Nursing Home Level Care*. Melbourne, Victoria: Disability Services Division, Department of Human Services.
- Jones, G., & Lawn, R. (1999). *The History of the YPINH Project from 1995 to 1997: Report One of the Young People in Nursing Homes Project Evaluation*. Perth, Western Australia: Disability Services Commission.
- Moylen, M., Dey, P., & McCalpine, E. (1995). *A National Research Project Examining The Placement Of Younger People With A Disability In Residential Aged Care Facilities For The Aged*. Sydney, New South Wales: Aging and Disability Department.
- Stanton, J., & Jessop, M. (1994). *Acquired Brain Injury: Accommodation and Support Needs*.