Mercy Aged Care Services

SISTERS OF MERCY AUSTRALIA
BRISBANE CONGREGATION

Registered as the Corporation of the Trustees of the Order of the Sisters of Mercy in Queensland

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Committee Secretary
Senate Community Affairs References Committee
PO Box 6100
Parliament House
Canberra ACT 2600

Inquiry into Planning Options and Services for People Ageing with a Disability.

Attached please find our submission to the inquiry.

Mercy Aged Care Services has a focus on providing care for people with an intellectual disability who are ageing. We believe that, like all other citizens, these individuals need timely and appropriate access to a continuum of services and supports.

Representatives of our organisation are available to attend hearings of the committee to provide further details in relation to the submission. The committee is also welcome to visit our service during the inquiry.

Thank you for your consideration of this matter. Please contact me on 3260 9555 if you require additional information.

Yours sincerely

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MERCY AGED CARE SERVICES
SERVICE PLANNING FOR PEOPLE WITH A LIFELONG DISABILITY WHO ARE AGEING

Senate Community Affairs References Committee Inquiry into Planning Options and Services for People Ageing with a Disability

SUMMARY

1. *The State and the Commonwealth Governments have yet to implement policies to guide their funding and planning response to the reality of adults who are ageing and who have a lifelong disability.*

People in this population are disadvantaged by the division of responsibility and associated program boundaries between the States and the Commonwealth. For example, many people with intellectual disability 'age' in their mid 50s. This age group is seen as the responsibility of the States and are expected to 'fit' into the current models of accommodation and support.

2. *Functional abilities, not age, should be the factor in determining the suitability of services and supports for adults who are ageing with a lifelong disability.*

'Ageing is place" is happening by default in the community and there is a of lack of alternative and appropriate service responses. Current supported accommodation models for people who have a disability are generally funded to support people who have day activity or employment options. Organisations that provide support for people who are ageing in these accommodation models are not adequately resourced or structured to manage the changes in functional ability of people or the complex clinical and nursing care associated with ageing. However, acute care facilities and main stream residential aged care services are also not always the most appropriate alternatives.

Service provision should be based on collaborative cross sectoral planning across aged care, disability, health and generic community services. It should be person centred, with whole of life planning and transition preparation rather than simply having to manipulate a 'fit' with existing accommodation (State Govt. responsibility) or Aged Care (Commonwealth Govt. responsibility) program guidelines.

Like all other citizens, these individuals need access to a continuum of services and supports and like all good practice, this access should be timely, appropriate and responsive to the presenting need.

Program guidelines should support a continuum of flexible, person centred responses that include support to age 'at home' or to age 'in place', to access specialised services like 'Allambe[1]', to access transition planning and to access medical, psychological, psychiatric assessment and intervention.

Funding should reflect the cost of care and recognise the particular and complex behavioural and clinical needs of people ageing with a lifelong disability.

Funding should be available to support cross sectoral training in the aged care and disability support sectors to support planned transitions for this population.

[1] Please see description of Allambe in later text.

Funding should accommodate a network of specialised health, disability and aged care services specifically responsive to the care and support of people ageing with lifelong disability.

There is a significant deficit in the provision of capital funding for accommodation and care services for people ageing with a lifelong disability. The majority of people in this group do not have the capacity to pay accommodation bonds (the standard form of financing capital development in aged care). Current capital subsidies cover only part of capital development costs.

Commonwealth or State capital funding would quickly be recovered through a reduction in the number of people occupying acute and sub acute bed.

We ask the Commission to include in its final report a specific recommendation

1. to include cross sectoral based transition planning for people who are ageing and who have a lifelong disability in the quality service standards requirements;
2. to fund the planning activity;
3. to allocate individualised service and support funding accordingly;
4. to provide an additional supplement in the Aged Care Funding Instrument (ACFI) to cover the additional costs associated with providing aged care for people with an intellectual disability;
5. to increase and expand the scope of capital funding grants and to increase recurrent capital subsidies to reflect the real cost of capital development.

MERCY AGED CARE SERVICES
SUPPORT FOR PEOPLE AGEING WITH INTELLECTUAL DISABILITY

Mercy Aged Care Services is a ministry of the Sisters of Mercy, Brisbane congregation and provides residential and community based aged care for 189 residents and clients in the North Brisbane region. The service has a focus on integrated dementia care, complex clinical and palliative care, and care for people with intellectual disability.

The aged care service is part of a network of services sponsored by the Congregation including Mater Health Services, Mercy Disability Services and Mercy Family Services and has a capacity to develop collaborative responses within the group.

The service has supported people ageing with intellectual disability in main stream aged are, in community care and a specialist residential aged care service 'Allambe'. Allambe is a modern facility, completed in 2009, based on a small family group environment. Capital funding ($260,000 per room) was provided by the Sisters of Mercy Brisbane Congregation. Recurrent funding is provided through the Commonwealth Aged Care Program.

The objective of the service is to provide the highest level of accommodation and care for this group. Planning of the facility was based on consultation and research undertaken by Community Ventures and Alliances in 2005. The research indicated a continuing need for a specialist facility and identified support for the concept and model of care within the disability sector and resident relatives.

Residents typically are people who have exited (disability) supported accommodation services or State mental health institutions. Many have multiple disabilities and multiple cognitive conditions including mental heath issues, intellectual disability and dementia.

While recurrent funding is provided through the Commonwealth aged care program this funding does not cover the cost of care. In particular the (ACFI) behaviour supplement is inadequate. (Research (MH 2009) indicates that equivalent levels of care and accommodation can exceed total aged care funding by greater than 100%)

The facility has two 'unfunded' places. The purpose of these places is to provide flexibility in responding to care needs through transitional care and respite care. The places have been used to provide respite care for people ageing with intellectual disability who have been funded under non aged care programs.

SERVICE MODEL OF CARE
The service model of care, based on resident lifestyle planning/case management, was developed through a project facilitated by Dr. Marie Knox in 2003. The model has been refined since particularly in relation to dementia care for this group.

The model recognises that, while the group has high clinical care needs, quality of life and social involvement can be maintained through proactive lifestyle planning and maintaining relationships. The approach focuses on enhancing resident social networks and activities while responding to complex clinical conditions and high nursing care needs.

The facility has a separate identity as a small family group environment. Its co-location with the larger Emmaus aged care facility provides access to specialist clinical support, primary health care, dementia services and therapies and infrastructure services.

Mercy Aged Care Services has a focus and particular expertise in dementia care based on an integrated (not segregated) model. As most people with intellectual disability will develop dementia, links to this expertise are important.

FUTURE SERVICE PLANNING

Mercy Aged Care recently completed a research and consultation project to identify need and to guide future service responses for ageing adults who have a lifelong intellectual disability. The Project sought to assist service planning for people ageing with intellectual disability and, in particular, to inform decision making relating to future development of the Allambe facility. The objectives of the study were to examine future demand for services and to review the costs of alternative approaches to care and accommodation for this group.

The Project included an extensive literature review, consultations with government and service providers in the disability and health care sectors and review of models of care and accommodation in Queensland and interstate. Consultations associated with the study established links with government agencies and service providers in other sectors that will be developed in planning future service provision.

Key outcomes indicated that:

Future service planning for the group should be based on collaborative partnerships with acute health care services (Mater Health Services), mental health services, primary health care services, disability support services (Mercy Disability Services, Endeavour) and community housing services.

Service provision should be based on collaborative inter sectoral person centred whole of life planning (planning for transitions) rather than attempting to ‘fit’ people into existing (State and Commonwealth) program guidelines.

Service provision should be flexible and include a range of accommodation responses including community care, assisted living, respite and transitional care, residential aged care and specialised aged care services. Future development and expansion of the facility should support this approach.

There is scope to develop (aged care and disability support) inter sectoral training programs.

Issues identified in the Project are now discussed.

Future demand for Care Services

The Project Report provided ample evidence of a need for appropriate care services for people ageing with intellectual disability. For example, one of the largest Statewide Disability Service Providers has approximately 70 clients over the age of 65 and approximately160 clients between 60 and 65.

Carers Queensland data indicated a significant number of people aged over 50 with an intellectual disability who are living with carers. (See also CSTDA data for Greater Brisbane Area for people in supported living arrangements).

Disability service providers are responding to these needs by supporting increasing age related frailty, in some instances, without having adequate expertise or resources.

The translation of identified need into future demand for places (at Allambe} is problematic. Future demand will depend on relationships and linkages with the disability service sector, the adoption of a collaborative and integrated approach to care planning and the capacity of the service to be flexible and responsive to changing needs.

This is reflected in the Australian Government's paper on 'Working Together: Policy on Ageing and Disability, July 2005, which stated that 'people with a disability who are ageing will be adequately supported by both disability and aged care services working within a seamless interface'.

"There is a strong focus on developing an integrated service planning approach focussing on the ***needs of this population rather than developing a specific service model*** *or responding to the requirements of the existing funding programs."*

Key points

The State and the Commonwealth Governments have yet to implement policies to guide their funding and planning response to the reality of ageing adults who have a lifelong disability.

Neither the disability nor aged care nor health systems currently take responsibility for effective, planned responses to this population. The absence of clear policy relating to the intersection of formal and informal support systems usually means that responses can be crisis driven and inconsistent and usually based on available funding and/or resources.

A person with a disability is a citizen who experiences the various life transitions as experienced by others and, with real person centred planning through their life journey should be confident about access to supports for a good life.

Australian disability policy needs a transformational shift of structural reform that **sees need determine resource allocation**. A shift to real person centred planning which includes life course planning and preparation for life transitions.

Ageing in Place

This concept is widely seen as giving all people the opportunity and support to choose where they live as they age. For a person with a disability, as with people who are frail and ageing, it is recognized that this choice can only be real when underpinned by a comprehensive range of supports. Too often, for a person with a disability, their 'ageing in place' is based on availability of resources and decisions made by the service provider. 'Ageing in place' for people who have a disability is not recognized in policy or funding programs, so, as one service provider said, it is policy 'by default' or action in the absence of policy. Also, there are no protocols relating to people who are ageing with a lifelong disability accessing Aged Care services.

As with the general ageing population, service and support responses will need to be individualised.

The definitions of “older” and “ageing” are subject to debate but ‘in line with most published Australian research on ageing and disability, the age of 55 years was chosen to define an “older person with a disability.”[2]

- the Aged Care system should take a lead role in ensuring that services for people who are frail & aged are accessible and responsive for people with disabilities who have additional age related disabilities and frailty; and

- Professionals within the Aged Care system should have basic training in current values, attitudes and strategies for providing support to and communicating with ageing adults with a lifelong disability.

Functional abilities, not age, should be the factor in determining the suitability of services and supports for ageing adults with a lifelong disability.

The following is a strategy proposed through the National and NSW Councils for Intellectual Disability & Australian Association of Developmental Disability Medicine.[3]

“This proposal advocates the funding of a network of specialised services focused on the health care of people with intellectual disabilities. These services would comprise multidisciplinary teams and a network of clinical nurse consultants. This would not be a parallel health system for people with intellectual disabilities. The proposed services would rather be a consultancy and training resource to the mainstream health system, facilitate the development of local networks and undertake research.”

There is a strong focus on developing an *integrated-service planning approach* focusing on the needs of this population rather than developing a specific service model or responding to the requirements of the existing funding programs.

While the complexities surrounding service provision, particularly in relation to the interface between the aged care system and the disability services system cannot be minimized, it will be critical to develop effective collaboration and cooperation within and between the disability, aged care and generic service systems to effectively and appropriately meet the needs of ageing adults with a lifelong disability.

FUNDING MODEL AND BUSINESS CASE FOR CHANGE

The annual recurrent cost of providing care for people aging with intellectual disabilities at Allambe is approximately $65,000 per resident. This compares very favourably with the cost of alternative accommodation and care options, especially in the acute care sector. Our research shows the (cash) cost of alternative accommodation in the acute care sector can be well in excess of $110,000 per resident per year. However, the real economic cost to the acute care sector is higher. By occupying beds, pressures on the acute care system are increased. The State Government largely carries the financial burden, the community suffers the systemic inefficiencies and patient care is not optimal as acute care facilities are

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[2] Bigby, C., Fyffe, C., Balandin, S., McCubberry, J., Gordon, M. (2000) ‘*Ensuring Successful Ageing: Report of a National Study of Day Support Service Options for Older Adults with a Disability.’* Executive Summary, LaTrobe University, School of Social Work and Social Policy.

[3] National and NSW Councils for Intellectual Disability & Australian Association of Developmental Disability Medicine (November 2008), *‘Proposal for specialised services to enhance the capacity of the mainstream health system to provide equitable and cost effective health care to people with intellectual disabilities.*

stretched and unable to provide the specialist care needed for these vulnerable patients.

There is an opportunity for efficient aged care service providers to ease the daily strains placed on the acute care sector by expanding capacity and accommodating for people aging with intellectual disability presently occupying acute care and other beds. The need for specialist care and accommodation services for this group is clear and compelling.

The Commonwealth Government meets the recurrent cost of providing care for this group under its aged care program. However, a significant deficit exists in the provision of capital funding.

The majority of those aging with intellectual disability do not have the financial capacity to pay the accommodation bonds and the capital subsidies provided by the Commonwealth for those with few assets only cover part of the capital development costs.

The first stage of the development of the Allambe facility, costing $4.5m was funded by the Sisters of Mercy, Brisbane Congregation.

There is a need for State and Commonwealth Governments to bridge the capital funding gap. The Government capital contribution would be quickly recovered through a reduction in the number of older people with an intellectual disability occupying acute care beds and improving outcomes in the acute care sector.