

SUBMISSION TO THE SENATE COMMUNITY AFFAIRS COMMITTEE

INQUIRY INTO PLANNING OPTIONS AND SERVICES FOR PEOPLE AGEING WITH A DISABILITY

Prepared by National Policy Office COTA Australia

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INTRODUCTION

COTA Australia - Council on the Ageing - is the national policy arm of the eight State and Territory Councils on the Ageing in NSW, Queensland, Tasmania, South Australia, Victoria, Western Australia, ACT and the Northern Territory. COTA Australia has a focus on national policy issues from the perspective of older people as citizens and consumers and seeks to promote, improve and protect the circumstances and wellbeing of older people in Australia.

COTA welcomes this Inquiry as the needs of people with a disability as they and their carers age has long been a concern for our members. There has been a reluctance on the part of policy makers to address the problem despite the fact that more people with a disability are ageing as is the rest of the population; so there is a greater likelihood that such people will have carers who are aged and so not able to continue to provide care, or that they will outlive their family carers. This latter prospect causes a great deal of stress for carers and they are looking for policies and services that will provide certainty of continuing care for their younger family members with disability..

COTA believes that all services should be focussed on meeting the needs and aspirations of people as individuals and allowing them to have greater control over what services they use, where they are delivered and who delivers them, in order to maximise independence.

COTA played a major role in developing and has formally endorsed the National Aged Care Alliance's (NACA) vision for support and care for older people which says that "Every older Australian is able to live with dignity and independence in a place of their choosing with a choice of appropriate and affordable support and care services as and when they need them"¹.(Copy attached for information)

This submission looks at three key issues that COTA Australia believes need to be addressed for that vision to become a reality for people with a disability as they age.

ISSUES

Housing and Accommodation

Housing and accommodation are critical issues, as the availability of appropriate housing is one of the key determinants of the type of support and care people are able to receive. Many people with disabilities are faced with the need to relocate as they and their carers age and this is a significant cause of stress for all concerned. Many carers raise the question of where the person they care for will live as the issue they most want to plan for in advance.

At the moment the options are limited and whilst there are a number of innovative projects around the country it is generally acknowledged that there is a shortage of appropriate housing and accommodation.

Currently a significant proportion of the residential housing stock is not suitable for people with disabilities and the supply of purpose built accommodation, public, social and private, is very limited.

¹ National Aged Care Alliance 2009, Leading the Way Our Vision for Support and Care of Older Australians September 2009

Often there is a very small number of 'disability' public housing options and so there are long waiting lists and people have to move out of their community when a place if offered.

COTA and Aged and Community Services Australia, working together as the Older Persons Affordable Housing Alliance, did some work on housing for older people and it clearly shows that one of the key ways to increase access to housing for older people is to move to implement universal design principles in residential housing. The Alliance called on all governments to implement universal housing design principles.²

This would mean all new public and social housing would be appropriate for people with disabilities and would give them a better chance of securing a place and being able to stay in it as they age. It is particularly important for public housing to be built in accordance with universal design principles as that would give people with disabilities and better choice of housing and hopefully allow them to stay within the community they have lived in rather than have to take a place in a 'disabled" specific house or unit that may be across town. It also levels the playing field in terms of people with a disability would then be able to compete for all the available public housing.

The Parliamentary Secretary for Disability Services established the National Dialogue on Universal Housing in 2009, bringing together all the key stakeholders including the building industry, consumers, services providers and governments and it is due to release its position paper in the near future.

Recommendation 1

COTA Australia calls on the Commonwealth, State and Territory Governments to:

- a. amend the Building Code of Australia to adopt the principles of adaptable housing in line with AS 4299;
- b. phase in Universal Design and sustainable living planning criteria; and
- c. further facilitate the development of concepts such as Aged Friendly Cities and Lifetime Neighbourhoods.

Support and care

The key issue for COTA is that support and care should be tailored to meet the needs of the individual and that the support and care changes as the person's needs change. One of the best and most efficient ways to achieve this flexibility is to have more consumer control over the type of services and who provides them as called for in the NACA Vision which is reflected in Recommendation 2 below.

There is a wide range of models for more consumer control, ranging from self held budgets and complete control over service type, provider etc to notional budgets held by a service provider with a negotiated range of services.

Implicit here is the idea of moving to an entitlement based model where once people have an assessed needs, with usually a financial amount assigned to it, they will receive it, not have to go on a waiting list for a package or wait until a service provider has enough funds or a vacancy to provide them with what they need. This would do much to allay carers' concerns about ongoing support and care and would give the individual more certainty and the capacity to plan for the future.

² Older Persons Affordable Housing Alliance (2009): A Fair Share for Older people- the need for a National Older Persons' Housing Strategy Discussion paper.

Recommendation 2

That Commonwealth and State and Territory governments move to linking funding for care and support services to each recipient, both people with disabilities and older people, so that the recipient and their family can determine how and where they receive their care and support, including the option to control how their funding entitlement is used. They would also remove the current regulatory restrictions on the quantity and type of services providers can offer removed so that they can be more responsive to older people's preferences.³

One barrier to people's changing needs being met as they age is the division of responsibility between levels of government that are based on age. The Commonwealth will, under the 2010 COAG agreement take full responsibility for aged care services (except in Victoria and possibly Western Australia) and the State and Territory governments will be responsible for accommodation and support for people under age 65. The COAG Agreement sets out the transfer of the aged care component of the Home and Community Care program to the Commonwealth with the State/Territories keeping the disability component.

COTA has for some time advocated the Commonwealth taking responsibility for all aged care services including the HACC program as it believes there needs to be an integrated aged care program so that funding and services can respond seamlessly to the changes in people's needs. However we acknowledge that this change has the potential to cause significant disruption for people with disabilities as they age, as it could mean they have to reapply for services, go to a different service provider and may receive a different level of service or funding. This needs to be addressed as the transfer of responsibility is negotiated.

Information from both consumers and service providers points to significant differences in types of services, level of service and accreditation and service agreements between disability and aged care services. This acts as a barrier to people to be able to age in place easily and is also something that needs to be addressed.

For consumer directed care to benefit people as they age there would need to be a guarantee that the funding provided as part of any State/Territory disability services program would be maintained after they transferred at age 65 to the Commonwealth funded aged care stream.

For other people not on consumer directed care arrangements there would need to be a mechanism to ensure that they kept the same level of funding and have access to a comparable level of service with, if they wanted it, the same service provider.

Recommendation 3

COTA Australia recommends the Commonwealth and State and Territory Governments, as part of the changes to the Home and Community Care program, guarantee continuity of services, in terms of type and quantum as well as continuity of service provider when people turn 65 years of age and move from the disability to the aged care sector.

The long term funding and financing of support and care for people with disabilities is a key issue.

³ National Aged Care Alliance 2009, Leading the Way Our Vision for Support and Care of Older Australians September 2009: p 6

There has been a strong push from people with disabilities, service providers and most recently the Parliamentary Secretary for Disabilities to move towards a National Disability Insurance Scheme that would ensure the long term care needs of people are met. COTA supports the idea of such a scheme in principle and, like others, is keenly awaiting the outcomes of the Productivity Commission Inquiry into this issue.

Transition as people age

In our society we pay a great deal of attention to planning for some of the key transitions in life. For example when a child first starts school, the family often spend time looking for the right school, then the child will have orientation visits to school and in many cases shorter days at school initially to ease them into the new environment and routine. In Australia we have started to appreciate that the transitions for people with disabilities need more planning and some intensive services as they move from early childhood to school and most importantly out of school.

One of the key transitions for everyone as they age is the move from paid employment to retirement. Increasingly there has been an emphasis on encouraging people to plan for this move with phased retirement through moving to part time work, retirement seminars, workshops on retirement incomes, housing options etc. However there is a lack of such services for people with disabilities or their carers.

More effort need to be put into phasing people out of paid work, if they are in it, into retirement through shorter hours etc. Some thought needs also to be given to assisting with the provision of meaningful activity post work as healthy ageing is more likely if people have meaningful activity and provision made for people to start accessing such activities prior to finishing work completely. Mainstream activities could be encouraged to be more accessible for people with disabilities but there still may need to be additional support provided to make participation possible.

Recommendation 4

COTA recommends that the Commonwealth and State and Territory governments fund specific initiatives to provide for transition services from work to retirement for people with a disability.

The additional costs incurred by people with a disability do not disappear when they turn 65 and move from the disability pension to the age pension. In particular if they have mobility problems and have needed support in the past they will continue to do so. If they are to continue to participate in society it is essential that they continue to receive support for mobility and the mobility allowance should continue when they move onto the age pension.

Recommendation 5

COTA recommends that the Commonwealth Government review income support payments to ensure that when people move from the disability pension to the age pension they do not automatically lose access to additional financial allowances such as the mobility allowance.

A key issue is that as informal carers age they may not be able to provide as much support and care as they had in the past. One of the issues that comes up often in discussions with carers is the difficulty they have in accessing services when this happens. They often report feeling penalized for having provided support for many years as it appears that people who 'get in early use up most of the funding' and there is little left for later entrants into the care pool. They often only get any services when the situation has deteriorated to a crisis and then the solutions are less than optimal with no preparation possible to ease the person with a disability into a new environment with different carers.

Funding for support and care for people with disabilities is generally acknowledged to be inadequate and to have not kept pace with growth in demand or increased costs. Because the disability is for a lifetime once somebody starts receiving care there is little chance their needs will diminish and so funds are not freed up for later entrants.

The proposed National Disability Insurance scheme should address this issue. However if it is not implemented, there still needs to be adjustments to the current arrangements to give later entrants to the support and care pool access to reasonable levels of funding. One possible model is to encourage everybody with a disability to have their needs assessed and a level of funding to be notionally allocated. This could be activated when required, in a gradual way so the carers can ease themselves out of their caring duties as the need arises. There would also need to be an ongoing link between these disability services and the people and their carers so that services could be activated in a timely way. It is important that the activation is initiated by the person with a disability or their carer rather than the disability service so that the individual remain in control of the services they choose to use. This would give carers a greater sense of certainty and allow for a more planned transition for both the carers and the people with disabilities.

Recommendation 6

COTA recommends that the Commonwealth and State and Territory Governments ensure that people with disabilities who have not previously accessed government funded services are assisted to obtain formal support as they and their family carers get older.

CONCLUSION

As people with disabilities and their carers age it is important that they can access additional support and care as and when they need it. COTA has put forward a number of recommendations to try to assist with the transition for people as they age and to give everybody with an interest a better chance to plan and put in place a support system that will continue to assist people to maximize their quality of life.