C Disability and aged care interface

A large group of people with a disability get their support through the aged care system. While in the main, the clients of the aged care system are people who acquire a disability because of natural ageing, the system also currently funds and supports many older people who acquired a disability prior to the Age Pension age.

This appendix examines the conceptual and practical issues that are relevant to the interface between the aged care and disability sectors. It does so against the background that the terms of reference for the disability inquiry indicates that the proposed disability scheme is ‘intended to cover people with disability not acquired as part of the natural process of ageing.’

Drawing the exact boundaries between the responsibilities of the two systems is not straightforward, because there are significant similarities and differences. For instance, there are many shared goals — like preserving the dignity of the person, maintaining mobility, meeting peoples’ personal care needs, ensuring access to adequate aids and appliances, and exploiting any scope for rehabilitation.

That said, there are significant differences between the two sectors, such as in objectives, philosophy, the needs and aspirations of people in the two systems, appropriate funding sources, and the areas of greatest competence (such as management of dementia).

C.1 Differences in objectives, needs and funding

Objectives

In most instances, a key goal of the disability system is ‘enablement’ — widening the scope for the full participation of a person over their future lifetime. Where that is realistically possible, this involves the desirability of shifting from dependent support arrangements to independent ones (often involving weakening of the ties to familial in-home support), integration in the community, a job, and rich social relationships.

In a similar vein, historically others have made choices for people with disability over their whole lives, eliminating people's power and encouraging passivity. In many cases, people were assigned to institutions from birth to death, spanning 50 or more years of their lives. Furthermore, expectations were low — for independence, a job and marriage. This historical experience has produced a strong philosophical position of emancipation and choice in the disability sector. Notably, in the United Kingdom, where self-directed funding has been available for some time, the take-up rate of direct payments by people with physical and intellectual disabilities has been around four times greater than people aged 65 years and over (Health and Social Care Information Centre 2010a).

The contemporary orientation of the disability sector has been practically realised in the closure of institutions and the creation of options for independent living (housing, modified vehicles, communication devices) and genuine jobs, anti-discrimination laws, self-directed funding, and reducing specialist services in favour of mainstream ones (for example, schooling).

It is also increasingly recognised that it is inequitable and inappropriate for ageing parents to provide support for their middle-aged children in the disability sector. In this context, it is notable that the disability system involves greater levels of perceived unmet need than the aged care sector (figure C.1).

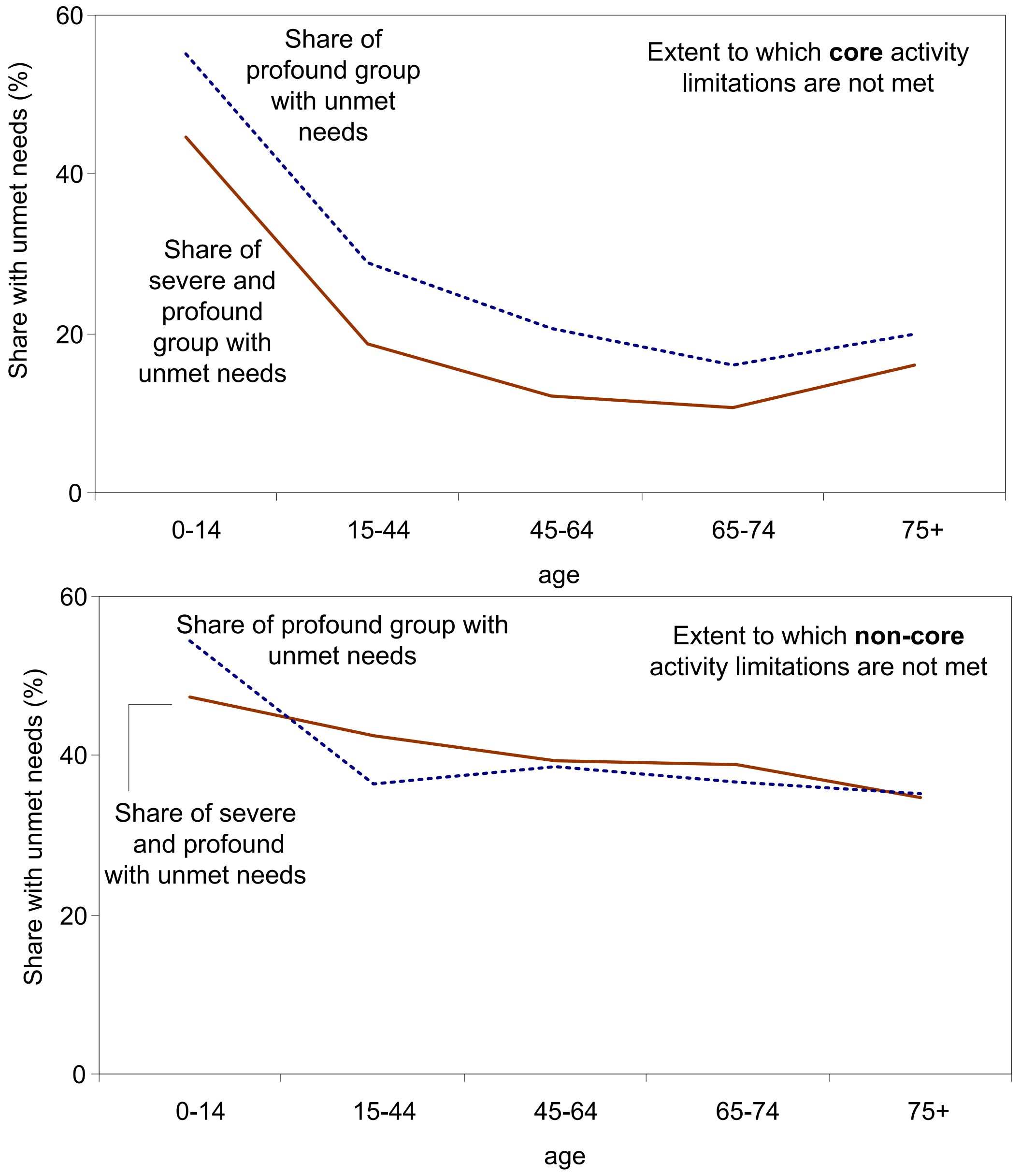
By contrast, in the aged care sector, a major goal is to minimise the rate of loss of autonomy of the person, and preserve people's links to their current home, familial supports and social networks. This recognises too that people have come from (at least the opportunity of) living a full life. Forward-looking aspects of life — like job opportunities, owning a house, and living independently from familial carers — are not targets for the aged care system. Institutionalisation in aged care remains common. For females aged 65 years, the likelihood of entering residential care in their remaining lifetime is estimated at 54 per cent and for males aged 65 years, 37 per cent (DoHA 2011). Overall, residential care facilities account for two thirds of the total government budget for aged care (PC 2011a, p. 28).

Nature of limitations and the level of need

Moreover, the kinds and persistence of disability presenting in the disability system are more varied than in the aged care system, requiring a greater diversity of responses. They involve a large mix of conditions (and co-morbidities), a wide span of intellectual capabilities, complex behaviours and support requirements. Accordingly, limitations in communication, cognitive and emotional tasks are much more prevalent in younger people with a disability (figure C.2). Self-care and mobility needs are much less age-related. Difficulty in performing routine daily tasks like transport, health care, household chores, meal preparation and property maintenance are much more prevalent among older people. Physical frailty will often be a major obstacle to performing such daily tasks.

Figure C.1 **Unmet need appears greater for younger people with a disability**

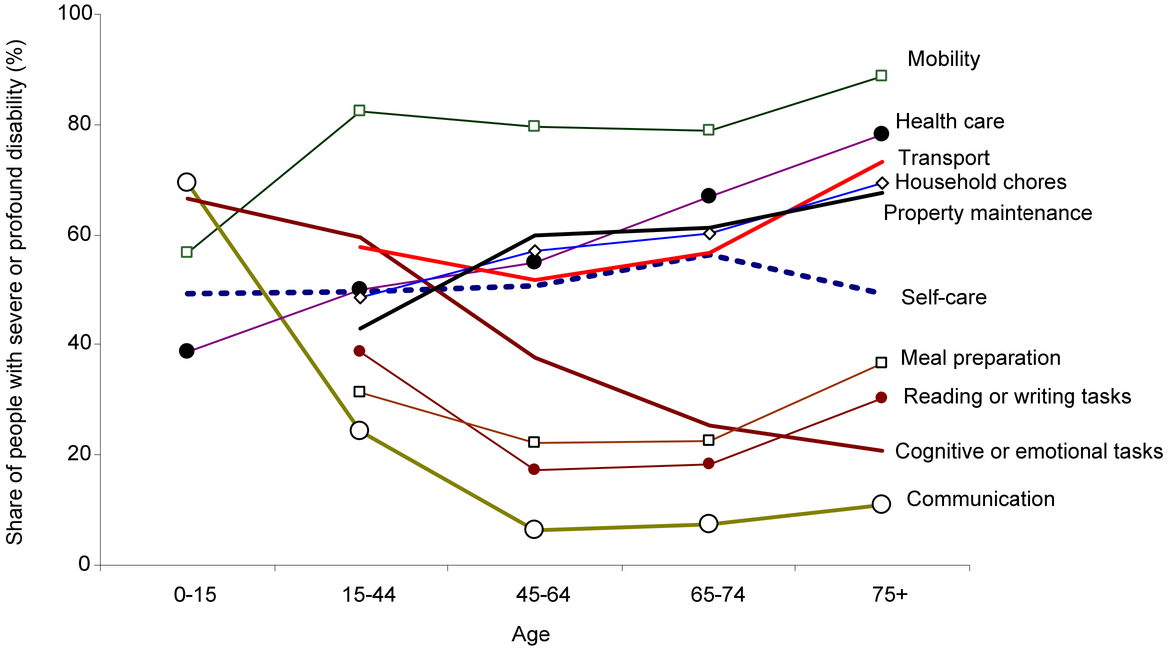
Share of groups with needs not met or only partly met



Data source: ABS SDAC 2009 survey (unpublished).

Even where the nature of the impairment is the same, the appropriate response is likely to be different. For example, it is unlikely that a person who becomes deaf at age 85 years will learn to sign, while that would be the norm for children born with deafness.

Figure C.2 **The nature of limitations varies with age**
2009



Data source: ABS Survey of Disability, Ageing and Carers, (Cat. No. 44300DO001_2009).

C.2 Financing the two different systems

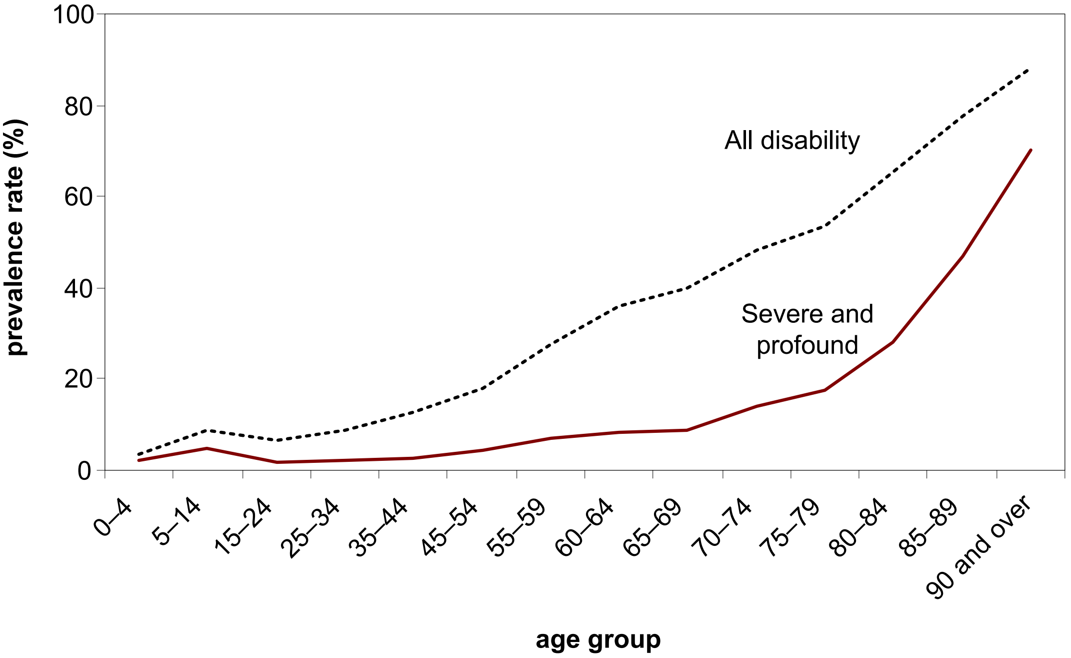
There are also differences in fair and efficient financing sources, which would be confused were the systems to be fully integrated. This reflects several factors.

Disability is a predictable outcome of old age. For example, 46 per cent of people aged 85-89 years have severe or profound disabilities and some 70 per cent of people aged 90 or more years (figure C.3). Moreover, 68 per cent of women and 48 per cent of men at 65 years of age will require some aged care services over the rest of their lifetime. As noted in the parallel Commission inquiry into aged care, 'if you live long enough, you will need some form of care and support because of frailty' (2011a, p. 147). This means that people can anticipate their likely need for support and could reasonably be asked to contribute to those costs (with government funding or some other approach used to cover the risks of higher costs if people use many more services).

Second, many older Australians have accumulated significant lifetime assets prior to the Age Pension age, which can help finance care (figure C.4).

Figure C.3 **Disability rates rise steeply with age**

2009



Data source: *Data source*: ABS Survey of Disability, Ageing and Carers, (Cat. No. 44300DO001_2009).

Moreover, the lifetime costs of that care will typically be small relative to people's lifetime income.[1] Given this, it is feasible and equitable for people to pay something towards their aged care if they have a financial capacity to do so. Moreover, co-contributions have the value that they create incentives for people to trade off less versus more expensive services and reduce the financial obligations of taxpayers (noting that taxes have adverse efficiency and other effects). Accordingly, there is a strong rationale for a co-contribution (also subject to income and assets tests) of the kind recommended by the Commission in the aged care inquiry (2011a).

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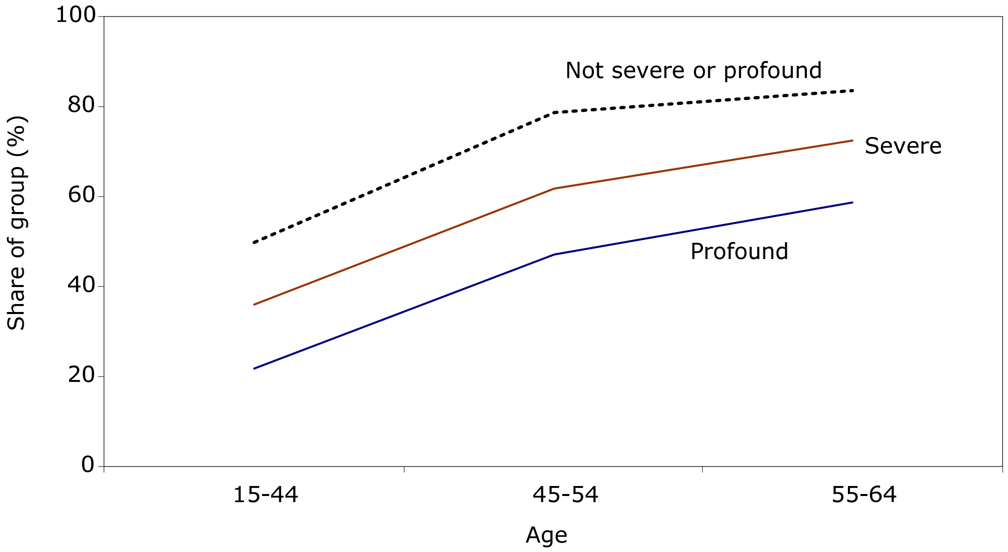
[1] The most costly part of aged care is residential care, with the highest cost of care in residential settings around $65 000 per year (PC 2011a, p. xxxiii). But such care is typically for a short duration only. For instance, around 50 per cent of men entering an aged care residence will be there for one year or less, while 75 per cent of men will be there for three years or less (PC 2011a, p. 149). The median length of time in permanent residential care for men is 1.2 years (PC 2011a, p. 24).

Figure C.4 **Share of people who own or are buying their own dwelling**[a]



[a] Note that these data are cross-sectional data, and fail to take account of cohort effects and of the potential impact of the duration of disability. It would be useful to know what share of the people who acquire a disability when young end up owning a dwelling when old. A particular concern is that at the oldest ages shown in cross-sectional data, some people classified as having a severe or profound disability would have acquired their disability later in life. As such, the dwelling ownership rate for this group would reflect the capacity to have purchased a dwelling in their earlier years when disability was absent. Nevertheless, this issue is unlikely to be present to any significant degree until after age 64 years. In that case, the difference between the ownership rates by severity of disability is probably a reasonable approximation of the capacity of different groups to accumulate assets.

Data source: ABS SDAC 2009 survey (unpublished).

In contrast, most people do not anticipate acquiring a significant disability when younger (with, for instance, 2.2 per cent of 0-4 year olds having a severe or profound disability), so the basis for self-insurance is weak. Moreover, given the younger age of onset and the considerable duration of disability, the lifetime costs of disability will often be very high. The high cost/low probability nature of (younger-age) disability provides a strong justification for risk pooling for disability costs experienced earlier in life.

That is accentuated by the fact that many people acquiring a disability when young will not have income or assets sufficient to make reasonable co-contributions. It is notable that the share of people with a profound disability aged 15-64 years who were employed was 14.6 per cent in 2009 compared with 78.6 per cent for people without a disability. Of those people with a profound disability who were employed, 62.6 per cent worked part time, whereas the part-time share of people without a disability was 30.7 per cent (based on the ABS 2009 SDAC survey).

In addition, means-tested co-contributions for supports by people with disabilities would create higher effective marginal tax rates on employment income (on top of those that occur as a result of taper rates and hourly limits applying to the Disability Support Pension — appendix K and chapter 6). That would be against a background of already large obstacles to employment for people with a disability. So income and assets tests would be likely to have the perverse effect of discouraging employment when that is a major goal of disability policy.

C.3 Implications of the differences

In theory, these differences could be managed in one system — simply taking into account the traits and goals of individuals, and social expectations about the appropriate level and nature of taxpayer-funded supports. However, people may be best served by different overarching arrangements. As an example, the effective realisation of choice and independence for people with disability requires a high degree of acceptance of this stance by those who run the system. It might be more difficult to gain that acceptance in a unified system in which many of the clients have few convictions in this area. The rights-based philosophy that is so prominent in the disability system is much less evident in the aged care sector at this time.

Accordingly, there are compelling arguments that the systems should be differentiated in terms of objectives, the role of co-contributions, the appropriate elements of funded support packages, and in funding sources. In particular:

- the NDIA and disability support organisations would have the social and economic participation, independence and power for people with disabilities as major goals. That would include funding of school-to-work transition programs certain employment supports, coordination with education services, and a strong emphasis on community engagement
- there is a stronger rationale for means and asset tested co-contributions in aged care.

There should be no artificial barriers to people accessing *eligible* services, even if those services are notionally identified as primarily serving the demands of the aged care or disability system. Rather, the critical concern is to ensure that people would be able to use the support system that best met their needs, regardless of the funding source. As an illustration, some people acquire dementia prior to the Age Pension age and may well find the best support from service providers that typically target older people. A key issue in encouraging the permeability at the service provider level between the two systems is how to address the needs for compatible standards, regulatory oversights and price controls (and not requirements to meet a complex amalgam of two sets of regulations and guidelines).

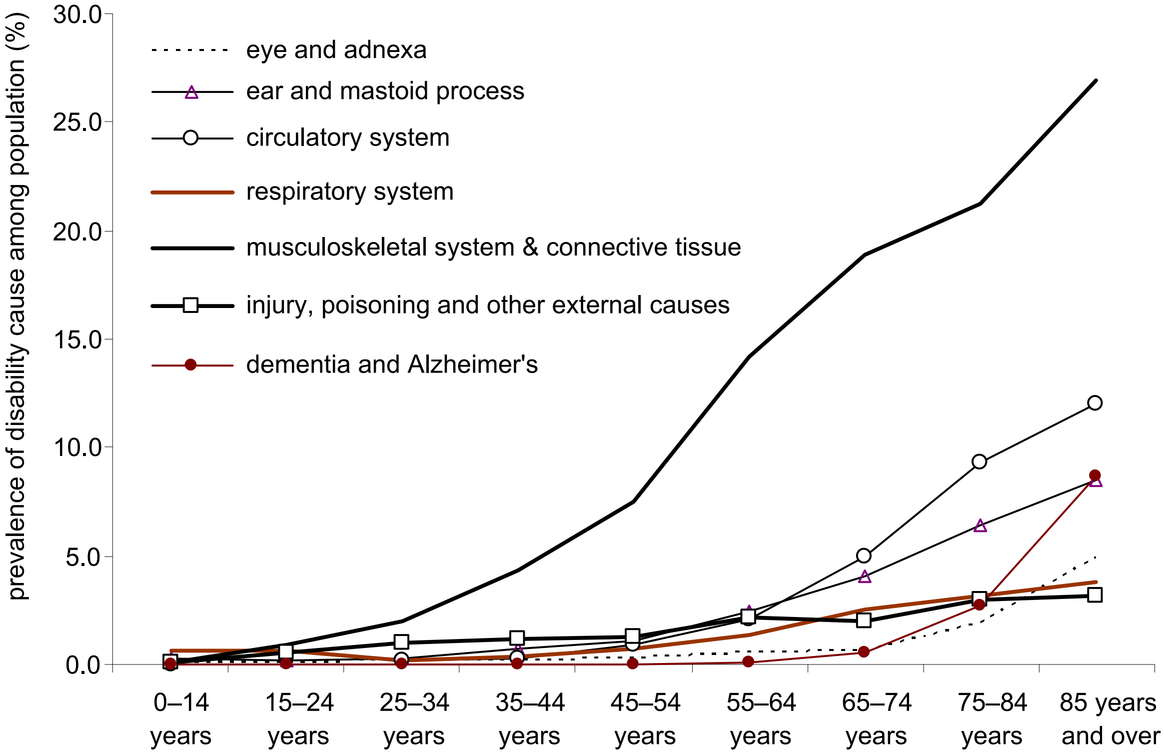
- There are strong grounds for the disability system to have an insurance framework akin to those used by the NSW Lifetime Care and Support Authority for managing costs, collecting data, having a focus on long-run costs for people rather than just costs for a given year, ensuring good longer-run outcomes (such as economic participation, social engagement, and independence) and achieving cost-effective early intervention. That governance model requires control over a ‘premium’ income source for the disability system.
- There is a particularly large burden of uncertainty that hangs over people with a disability and their carers about the adequacy of future funded support, a concern that does not appear to have the same intensity in the aged care system. (for instance, the uncertainty in the disability system could easily extend over a 60 year period.) For that reason, the Commission has recommended a funding model that guarantees ongoing access to supports to people with disabilities through legislated hypothecated funding arrangements.

Who goes where in the two systems?

There are four distinct groups using disability care and support services in Australia (*including* aged care):

- people who acquired a non-ageing related disability prior to the Age Pension age, but who continue to require disability support after that age
- people who acquire disability before the Age pension age through diseases most commonly associated with natural ageing, such as dementia and Alzheimer’s, diseases of the circulatory system (hypertension, heart disease, and stroke) and diseases of the musculoskeletal system and connective tissue (such as arthritis). Figure C.5 shows the diseases causing disability most closely correlated with ageing
- people who acquire a disability after the Age Pension age, but where the cause and impacts of the disability are not related to natural ageing. For example, this might be a catastrophic spinal cord injury suffered by a 70 year old as a result of a motor vehicle accident
- people who acquire a disability after the Age Pension age (not due to a catastrophic injury).

Figure C.5 **Main age-related conditions causing disability, 2009**



a It shows the prevalence of the conditions that are the main causes of disability (of any severity) by age. For example, around 27 per cent of people aged 85 years and over have a disability whose main causes are diseases of the musculoskeletal system and connective tissue.

Data source: ABS 2011, *Disability, Ageing and Carers, Australia: Summary of Findings, 2009*, Cat. No. 44300DO001_2009.

The Commission's proposal (chapter 3) is intended to ensure that all people with significant disabilities can access services and supports that best meet their needs, without disruption to any arrangements that are in place before the person reaches the Age Pension age. The Commission proposes that, upon reaching the pension age[2] (and at any time thereafter), a person with a disability could elect either to stay with the NDIS or move to the aged care system.

- If a person elected to move to the aged care system, they would be governed by all of the support arrangements of that system, including its processes (such as assessment and case management approaches).
- If a person elected to stay with the NDIS care arrangements, their previous support arrangements would continue, including any arrangements with disability support organisations, their group accommodation, their local area

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[2] A younger age threshold would apply to Indigenous people given their lower life expectancy, as is recognised under existing aged care arrangements.

coordinator, or their use of self-directed funding. The NDIS assessment tool would be used to determine their entitlements.

- If a person over the pension age required long-term residential aged care then they would move into the aged care system to receive that support, regardless of the age at which they acquired their disability.

The advantage of these flexible arrangements is that the NDIS would — from the perspective of any person — become a lifetime scheme if that was preferred.

Where the person lacks the capacity to make the choice between the two systems, and there was no responsible carer who could, the person would be directed to the system most likely to enhance their welfare. For instance, the aged care system has developed strong capabilities for the management of dementia because of its high prevalence among the aged, and their services might be used by those with early onset dementia.

The above arrangements would apply regardless of whether a person acquired their disability as a result of an ageing-related condition or from some other cause (such as a congenital birth defect). That recognises that even apparently ageing-related conditions can affect younger people and that given this, it would often be arbitrary to determine whether a *particular* person had an ageing-related disability or not. For instance, of the people with a severe/profound core activity limitation, around 31 000 people aged between 0 and 64 years report stroke as a health condition compared with 126 000 people aged 65 years and over (based on the SDAC 2003 data).

If a person entered residential aged care, they would, regardless of age, enter the aged care system, since the regulations and pricing of such high care services are determined by the aged care system. (Of course, in most instances it would be undesirable to have younger people in nursing homes. An exception might be someone with Down syndrome who has advanced dementia at age 60 years.)

People who acquired a disability after the Age Pension age would enter the aged care system, with the exception of the relatively few people experiencing catastrophic injury. The latter would be covered by the National Injury Insurance Scheme (NIIS) for their full lives, and so would generally lie outside both the aged care system and the NDIS, though potentially using some services common to both.

The role of co-contributions

As discussed above and at length in the parallel aged care inquiry, there are strong grounds for co-contributions to care and support services for older people where they have the capacity to pay. As discussed in chapter 3, after the Age Pension age, the person with a disability would be subject to the co-contribution arrangements set out by the Commission in its parallel inquiry into aged care (PC 2011a).

This reflects that some people who acquired a disability prior to the Age Pension age may have built up sizeable assets and pension income over their lifetime. Such a person could have reasonably predicted when younger that he or she would need care and support services when old (see above). It would be inequitable and discriminatory to require one group of higher income people with a disability to pay a contribution to their aged care, while *exempting* equally well off people of the same age and disability status because they acquired their disability in another context.

It should also be noted that an *exemption* for aged care co-contributions by people acquiring a disability before the Age Pension age would create an incentive for some people to have themselves classified as having a disability under the NDIS just prior to the Age Pension age to escape the co-contribution arrangements in the aged care system.

In most instances, people who acquired a disability early in their life would often not have accumulated sufficient wealth or retirement income to trigger a requirement for any co-contributions (chapter 6 and appendix D of PC 2011a). However, to provide an additional impetus for workforce participation, it may be appropriate for a *lower* aged care co-contribution to apply for people acquiring a disability early in their life. The Commission considers that the Australian Government should determine the appropriate aged care co-contribution level for those acquiring a disability earlier in life as part of the implementation arrangements for the NDIS.

Funding sources

In its draft report, the Commission outlined a number of approaches for determining appropriate funding sources. These approaches, particularly the 'apportionment' approach involve significant complexities. In any case, the Australian Government has already signaled its intention to fund the care and support needs of older Australians.

One of the objectives of the *National Health and Hospitals Network Agreement* was for the Australian Government to "..take full funding and program responsibility for a consistent and unified aged care system covering basic home care through to residential care …" (COAG 2010, p. 25).

In order to achieve a consistent and unified aged care system, the specific additional responsibilities that the Australian Government agreed to assume were:

> a. funding and program responsibility for basic community care services currently provided under HACC for people 65 years or over (50 years and over for Indigenous Australians); and
>
> b. funding responsibility for specialist disability services provided under the National Disability Agreement for people aged 65 years and over (50 years and over for Indigenous Australians). (COAG 2010, p. 26)

As such, a funding process has been already agreed (and has been incorporated into the forward estimates).