

1. Introduction: Developing the National Disability Insurance Scheme

The Australian Government is in the process of developing a National Disability Insurance Scheme (NDIS) for Australia. The NDIS will help to cover the costs of support for people with significant and permanent disabilities. The NDIS commenced in mid 2013 in a limited number of launch sites in order to test the operation of the scheme and to allow for its design to be informed by feedback from people with a disability, their families and carers, service providers and community organisations.¹ As this monograph was written before the initial launch of NDIS, it contains no discussion of the launch sites or their evaluation.

The best available data suggests that the Indigenous population experiences profound or severe core activity limitations at more than double the rate of non-Indigenous Australians. These higher rates of disability mean that the NDIS is likely to be of significant benefit to Indigenous Australians.

Not only are rates of disability higher for Indigenous Australians, but many Indigenous people also face significant barriers to accessing disability planning and support services. In part this is due to the substantially higher proportion of the Indigenous population living in remote and very remote areas which generally lack disability services; services not always being responsive to or compatible with the cultural values of some Indigenous people; and Indigenous Australians disproportionately experiencing barriers associated with socioeconomic factors such as low income and low levels of literacy and numeracy.

Addressing these barriers—and indeed the whole question of addressing Indigenous disability—are further complicated by the fact that while across ‘mainstream Australia’ there has been a developing understanding of the notion of ‘disability’ and its impact on people’s lives, there are a number of differences in the way in which Indigenous Australians view disability. The differences across Australia in how Indigenous Australians view disability complicate any attempt to address these barriers, and indeed to address Indigenous disability more generally. This reflects both questions of how Indigenous people and communities generally view disability and the extent to which they have been participants, or more frequently non-participants, in wider community change. That there is no simple conception or cultural view of disability is an important starting point, and one which is recognised in the preamble to the United Nations Convention on the Rights of Persons with Disabilities which

¹ The launch sites are South Australia (for children 0–14 years), Tasmania (young people aged 15–24 years), Australian Capital Territory (all age groups), Barwon region of New South Wales (all age groups) and the Hunter region of New South Wales (all age groups).

notes 'that disability is an evolving concept' (United Nations (UN) 2006). Over recent years this evolution has been impacted by many factors, including the work of advocacy groups, events such as the 1981 International Year of Disabled Persons and the introduction of the *Disability Discrimination Act 1992*, as well as evolving community attitudes.

According to the First Peoples Disability Network (FPDN: 2011), many Indigenous people with disabilities do not identify as having a disability. This may be due in part to a reluctance to adopt additional labels of disadvantage, as well as a markedly different cultural perception of disability.

The terms of reference for the project upon which this monograph is based outline two distinct but related pieces of work. Accordingly, the first part of this monograph aims to identify and assess the range of disability service delivery models available in order to overcome the barriers to accessing disability support services experienced by Indigenous Australians. The second part analyses existing quantitative data sets to ascertain the extent and nature of disability in the Indigenous population, and how this varies according to geographic remoteness and key population groups. The work is intended to inform future policy development of a national scheme, and thereby assist Indigenous Australians in accessing support services appropriate to their cultural and geographic needs; sharing in opportunities available to the general Australian population; and participating fully in the economic and social life of their community.

This monograph is in three parts. Chapters 2–3 provide background and contextual information which is relevant to the disability service needs of the Indigenous population and how the NDIS can best meet the needs of Indigenous Australians. Chapter 4 considers the existing statistical evidence regarding the extent and nature of disability in the Indigenous population, the data gaps and how these gaps can best be filled. Chapters 5–8 focus on issues concerning the delivery of disability services to Indigenous Australians as part of the NDIS. Some possible models and approaches to service delivery are discussed and, drawing upon the available evidence base, the advantages and disadvantages of different models are outlined. The final chapter integrates the conclusions and offers recommendations.

Overview of the NDIS

In April 2008, the then Parliamentary Secretary for Disabilities and Children's Services, the Hon. Bill Shorten, established the Disability Investment Group (DIG). The Group's role was to explore innovative funding ideas from the private sector that would help people with disabilities and their families to

access increased current support and life-long security. The possible model proposed by DIG was a National Disability Insurance Scheme (NDIS) that would fund individuals based on their needs, replacing the current system of capped programs and services. It was proposed that the scheme be funded from general revenue or a levy similar to the funding arrangements for Medicare. The first recommendation from DIG (2009: 6) was that ‘the Commonwealth Government, in consultation with States and Territories, immediately commission a comprehensive feasibility study into a National Disability Insurance Scheme’.

In early 2010, the Productivity Commission was asked by the Australian Government to inquire into the feasibility and structure of a cost-effective ‘National Disability Long-term Care and Support Scheme.’ The Terms of Reference for the Productivity Commission inquiry ask that the Productivity Commission consider an approach that:

- provides long-term essential care and support for eligible people with a severe or profound disability, on an entitlement basis and taking into account the desired outcomes for each person over a lifetime
- is intended to cover people with disability not acquired as part of the natural process of ageing
- calculates and manages the costs of long-term care and support for people with severe and profound disability
- replaces the existing system of funding for the eligible population
- ensures a range of support options is available, including individualised approaches
- comprises a coordinated package of care services which could include accommodation support, aids and equipment, respite, transport, and a range of community participation and day programs available for a person’s lifetime
- assists the person with disability to make decisions about their support
- offers support for people to participate in employment where possible.

The Productivity Commission (2011) identified four key issues with regards to the system of disability services operating in Australia at the time of its report.

- First, it argued that the disability system is significantly underfunded and that as a consequence individuals with a disability who are in need of a particular service or support (e.g. wheelchairs) are either unable to obtain the service they need or are subject to excessive waiting periods due to what is termed the rationing of services.

- Second, there is uncertainty in how services are allocated, which can make it very difficult for people with a disability or their carers to effect long-term planning decisions. Part of this uncertainty is due to a lack of integration across agencies and jurisdictions.
- Third, differences between States and Territories in the nature, timing and coverage of services provided mean that when individuals cross State/Territory borders the services they are entitled to receive may change.
- Fourth, people with a disability and their carers lack choice or control over the services they receive.

It is argued by the Productivity Commission that although a significant injection of funds would alleviate rationing and supply issues, the three factors of uncertainty, lack of consistency across States, and lack of choice would cause significant limitations to persist.

For this reason the Productivity Commission proposed a new NDIS which would not only substantially increase the level of funding for disability services, but would also combine the funding under a single, national framework. While this framework would be consistent across jurisdictions, the aim would be to provide much greater choice and control at the individual level. The scheme would be established alongside a new, no-fault National Injury Insurance Scheme, which would cover individuals who acquire a disability through catastrophic injury.

In the 2012–13 federal budget \$1 billion was set aside for the development of the first stage of an NDIS. The NDIS launch took place in mid 2013, with services provided to around 10 000 people with significant and permanent disabilities in select locations across the country. There have been further developments for the NDIS since the work for this monograph was undertaken. Most importantly, the way in which the scheme is intended to operate in the NDIS launch sites is described in the draft National Disability Insurance Scheme (NDIS) Bill introduced into Parliament on Thursday 29 November 2012.

As noted above, the Terms of Reference for the report which forms the basis of this monograph were that the Productivity Commission-proposed design of the NDIS be used as the starting point. This necessitates the following summary of key aspects of the Productivity Commission's proposed design.

Key characteristics of the NDIS

Eligibility and assessment

The Productivity Commission proposal is for a system comprising three tiers of beneficiaries. The first tier of beneficiaries covers all Australians, including those without a disability or who are not carers. The NDIS is designed to provide reassurance for all Australians that in the event of themselves or someone they care for acquiring a significant or permanent disability they will be able to obtain assistance under the NDIS if they are not covered by another scheme such as workers compensation or motor vehicle accident compensation.

The second tier of beneficiaries are all those with a disability or who are carers, but who do not receive financial support under the NDIS. The Productivity Commission (2011: 15) estimates that this includes approximately 4 million Australians and, in addition, 800 000 carers. This second tier of recipients would receive information and referral services, and general information regarding the most effective care and support services for their particular needs.

The third tier of beneficiaries consists of people with significant care and support needs due to a permanent disability who would receive financial support from the NDIS. Permanent disabilities include episodic and chronic disabilities. Also covered would be those with significant and enduring psychiatric disability. This tier would not include people covered by other schemes, but may include those acquiring new catastrophic injuries who are covered by the National Injury Insurance Scheme; those with certain health conditions for which the publicly funded healthcare system is better suited; and a limited number acquiring a disability after commencement of the age pension.

The two main groups within the Tier 3 group are people with 'significantly reduced functioning in self-care, communication, mobility or self-management' who 'require significant ongoing support', and people who fall within an 'early intervention group' (Productivity Commission 2011: 14). It is estimated that the former comprises roughly 330 000 individuals, whereas the latter totals 80 000 people, for whom 'intervention would be safe, significantly improve outcomes and would be cost-effective.' It is also pointed out by the Productivity Commission that 'eligibility would be determined by functional limitations, not conditions'.

This focus on need as opposed to disabling conditions adds a significant degree of complexity to assessing eligibility. The proposed screening mechanism is that at the first stage when individuals approach the newly created agency responsible for the scheme they will be administered a short assessment module

designed to identify whether they are likely to be eligible for a funded package. Those assessed as ineligible will then fall into Tier 2 of the scheme and, if necessary, be directed towards appropriate services not funded by the NDIS.

For those who are assessed as likely to be eligible a more detailed assessment process will then be triggered. As summarised (Productivity Commission 2011: 336), this includes the completion of a more detailed self-reported questionnaire; review by a trained assessor, including review of medical certificates; a meeting between this assessor and a local area coordinator; and a review and costing of the assessment by the National Disability Insurance Agency. While the assessment process is expected to be resource intensive, it is necessary in order to implement targeted and limited eligibility criteria.

This strict distinction between Tier 2 individuals—who receive minimal funding—and Tier 3 individuals—who receive an extensive range of support as documented below—places pressure on the operation of the assessment mechanism, a crucial aspect of the scheme.

Once assessed as being in Tier 3, a draft support package will be developed that is either accepted by the relevant person or their carer/family member, or sent for further review.

Type of support provided

The Productivity Commission Report (2011: Box 2: 23) proposes that the following types of support be provided to people with a significant and permanent disability who are covered by the NDIS.

- Aids and appliances, as well as home and vehicle modifications.
- Personal care that supports an individual to take care of themselves in their home and community.
- Community access supports. These are designed to provide opportunities for people to enjoy their full potential for social independence, and include facility and home-based activities, as well as supervision and physical care.
- Respite to provide a short-term and time-limited break for people with disabilities, families and other voluntary carers of people with a disability.
- Specialist accommodation support, such as group homes and alternative family placement.

- Domestic assistance to enable individuals to live in the community and live on their own, such as meal preparation and other domestic tasks; banking and shopping; assistance with selecting and planning activities, and attending appointments.
- Transport assistance to provide or coordinate individual or group transport services.
- Supported employment services and specialist transition to work programs that prepare people for jobs.
- Therapies such as occupational and physiotherapy, counselling, and specialist behavioural interventions.
- Local area coordination and development. These are broad services, including individual or family-focused case management and brokerage.
- Crisis/emergency support.
- Guide dogs and assistance dogs.

Methods of providing support

The Productivity Commission proposed two broad approaches to how the package of support is to be provided. The first is self-directed funding, where individuals or their carers ‘cash out their individualised package of supports and manage their own budget’ (Productivity Commission 2011: 346). The second is through choice of provider, where individuals are given an individualised package of support items, rather than a budget, with the ability to choose the service provider from whom the items will be sourced. There is also considerable scope in the proposed model for individuals to opt for self-directed funding for some types of services, but choice of provider for other aspects.

The self-directed funding model places a greater degree of risk onto the individual. However, this comes with the potential benefit of being able to make savings in one area which will lead to scope for additional expenditure in another area. There are likely to be differences in the extent to which people are able to realise the potential efficiency gains from a self-directed funding model. For example, individuals or carers with a high level of education are more likely to be able to negotiate or obtain low-cost services. People living in highly urbanised and more socioeconomically advantaged areas are likely to have a broad range of services available to them, and will therefore benefit from the self-directed funding model. The Productivity Commission Report notes that for those in regional—and to a lesser extent, remote—areas with

practical, everyday needs, it will not be difficult to find the required services. However, this is less likely to be true for those with complex needs, a group into which Indigenous Australians disproportionately fall.

There are a number of eligibility restrictions for self-directed funding proposed by the Productivity Commission. Chief among these is an assessment that the individual is able to make the complex decisions required for such an approach. Where this is not possible, there is the option of guardians, including parents or partners, acting as the individual's agent. However, this not only places an additional burden on these carers—hence the voluntary nature of the self-directed funding—but also opens up the possibility of financial and other abuse. The Productivity Commission proposes a number of safeguards to mitigate these risks.

One of these safeguards or restrictions is that money from self-directed funding cannot be used to hire close family members. While it is important to minimise the risk that a close family member who is being paid to care for a person with a disability does not provide adequate care, the risk of this occurring needs to be weighed against the potential negative consequences of the restriction. In many regional and remote areas there may be few other available options than family members. Problems resulting from such a restriction are likely to be exacerbated in an Indigenous context in which kinship networks do not fit the standard western model of the nuclear family. The Productivity Commission Report (2011: 382) proposes a trial for employment of family members: if undertaken such a trial is likely to provide important data. However, it proposes a number of restrictions—including a decrease of the individual budget and a six-month limitation on paying family members—that may need to be reconsidered in regional and remote areas.

Recommendations of the Productivity Commission Report

The Productivity Commission Report identifies a number of issues related to Indigenous Australians that need to be considered in designing and implementing the NDIS. Specifically, Chapter 11 of the Productivity Commission Report focuses on the prevalence of disability within the Indigenous community, and how a future NDIS might address a number of other issues specific to Indigenous disability.

One of the issues identified by the Productivity Commission as requiring further consideration is whether in certain circumstances Indigenous people with a disability should be able to pay family members to provide disability support

services. According to the Productivity Commission Report, the Australian Government spends 30 per cent more per capita on Indigenous Australians with disabilities than non-Indigenous Australians. However, considering the considerably higher costs of providing services in remote areas as well as the underreporting of Indigenous disability, it is likely that disadvantage in terms of access to services still exists.

A number of socioeconomic factors are relevant to the high rate of disability observed among Indigenous Australians, and a large gap in disability rates persists between Indigenous and non-Indigenous Australians. The Productivity Commission (2011) describes this relationship in which poor socioeconomic outcomes greatly increase rates of disability, which further compound socioeconomic disadvantage. Greater exposure to certain risk factors such as smoking and obesity contributed almost half of the difference in disability-adjusted years of life between Indigenous and non-Indigenous Australians (Productivity Commission 2011: 539).

Compounding these higher rates of disability are barriers that may prevent Indigenous Australians from accessing necessary disability services. Mistrust of—and lack of information about—government services is one of the primary barriers identified in the report. This mistrust might stem from negative past experiences, or simply from a feeling that government services are not applicable to a given individual's circumstances or cannot meet their needs. We will expand on these issues in a later section of this volume. However, the important point to note is that these cultural differences might be preventing some Indigenous Australians in seeking assistance from government service providers.

A further barrier to service use among Indigenous Australians with a disability is geographic; in 2006 around one-quarter of Indigenous Australians were living in remote or very remote areas, while only 1 per cent of non-Indigenous Australians did so. Geographical remoteness not only reduces the scope of services available to Indigenous communities, but also greatly increases the cost. Scarcity and proximity were found to be a bigger problem than cultural barriers, with half of Indigenous Australians seeking health services reporting having no available service in their area, and 45 per cent reporting distance and lack of transport as a barrier to accessing services (Productivity Commission 2011: 548).

A complicating factor is the age distribution of the Indigenous population. According to the Australian Bureau of Statistics (ABS) (2012a), 97 per cent of Indigenous Australians are aged 64 years and under, compared to 86 per cent of non-Indigenous Australians. This means that if the threshold was applied universally, Indigenous Australians would be more reliant on the NDIS as opposed to the aged care system. However, in Recommendation 3.6 of Productivity Commission (2011: 200) it is stated that 'a younger age threshold

than the Age Pension age should apply to Indigenous people given their lower life expectancy, as is recognised under existing aged care arrangements'. However, this creates equity issues if the NDIS provides a higher level of support than the aged care system. It is important, therefore, that Indigenous Australians under the age of 65 be allowed to opt in or opt out of the NDIS (as opposed to the aged care system) based on their individual circumstances and assessment of needs.

The Productivity Commission Report recommends a lower level of NDIS funding for those aged less than 15 years compared to those aged 15 years or over. The recommendation for the lower level of funding for children is based on the assumption that 'that families provide most care to children between the ages of 0–14 years, regardless of disability, and that care should be provided predominantly to support parents in their role of caring for a child with a disability' and also on the assumption that the education system is responsible for providing some supports to children with a disability (Productivity Commission 2011: 767) and/or the child's family. However, this assumption may be problematic in an Indigenous context in which: (a) many Indigenous Australians do not participate as intensively in formal schooling, in part because of their disabilities; (b) many regional and remote schools may not be able to provide the same degree of support to students with a disability as can be provided by larger urban schools and an associated network of special schools; (c) the level of income and wealth of the households in which Indigenous Australians live is substantially lower; and (d) Indigenous children are more likely to be cared for by non-family members. The validity of the assumptions about the need for NDIS funding for children for the Indigenous population is particularly important given that 36 per cent of the Indigenous population is aged less than 15 years compared to 18 per cent of the non-Indigenous population.

While the NDIS for the most part will be based on a self-directed funding model, the feasibility of this in rural and remote communities is something that cannot be assumed. In some cases it is possible that a different approach is likely to be needed in these locations, with this having particular implications for providing disability services for Indigenous Australians who disproportionately live in these locations. Block-funding services constitute one way to overcome the problem of incomplete markets for disability services in remote communities. The Productivity Commission (2011) proposes a number of forms that this block-funding could take, including funding new or existing community organisations to provide services. Where such organisations are lacking, however, it might be necessary to fund larger organisations to provide managerial oversight and mentoring to build capacity over the longer term.

In order to ensure services are meeting the needs of Indigenous communities, the Productivity Commission (2011) proposes a number of strategies, including

embedding these services within the community, employing Indigenous staff, and providing cultural awareness training to staff. The strategies clearly pose challenges of their own, including lack of existing expertise within the community, the difficulty of recruiting Indigenous staff, and the reservations individuals might have in accepting care from outsiders when this is necessary. These problems can be mitigated by adequate language and cultural awareness training, and by allowing for increased flexibility in working conditions in order to attract Indigenous employees.

The demographic and geographic context

This section summarises key demographic and geographic features of the Indigenous population that are of particular relevance to the design and implementation of the NDIS.

Indigenous age structure and projected growth of the Indigenous population

According to the preliminary 2011 Census population estimates, the median age of the Indigenous population is about 21 years for males and about 23 years for females. This is compared to 37 years and 39 years for non-Indigenous males and females respectively. The Indigenous population has a much younger age structure than that of the non-Indigenous population, as demonstrated in Fig. 1.1, which overlays the age distribution of the Indigenous and non-Indigenous populations, according to the percentage present in each age group. In comparing the two populations, it is clear that a much higher proportion of the Indigenous population is aged 24 years or less. Across males and females, these age groups represent 56 per cent of the total Indigenous population, compared to 32 per cent of the total non-Indigenous population. At the other end of the age distribution, 14 per cent of the total non-Indigenous population is aged 65 years and over, compared to 3 per cent of the Indigenous population.

The Indigenous population has been increasing at a faster rate than the non-Indigenous population. The preliminary population estimate for the Indigenous population in 2011 (ABS 2012a) was 30 per cent higher than the 2006 population estimate. By comparison, the non-Indigenous population estimate grew by only 7.3 per cent over the period. There are two main reasons why the Indigenous population has and will continue to grow at a faster rate than the non-Indigenous population. First, Indigenous women have a higher fertility rate than their non-Indigenous counterparts, with an Indigenous female expected to have 2.7 children over her reproductive life compared to the total female population

expected to have 1.9 children (ABS 2012b). The second reason for higher growth rates is that, in addition to those children born to an Indigenous mother, a substantial number of Indigenous children have non-Indigenous mothers and Indigenous fathers. Nationally, 31 per cent of Indigenous children born in 2011 had two Indigenous parents and a further 42 per cent had an Indigenous mother and a non-Indigenous father. These births will have been captured by the Indigenous fertility rate mentioned in the previous paragraph. However, a further 27 per cent of Indigenous children had a non-Indigenous mother and an Indigenous father. These births represent an additional contribution to the Indigenous population.

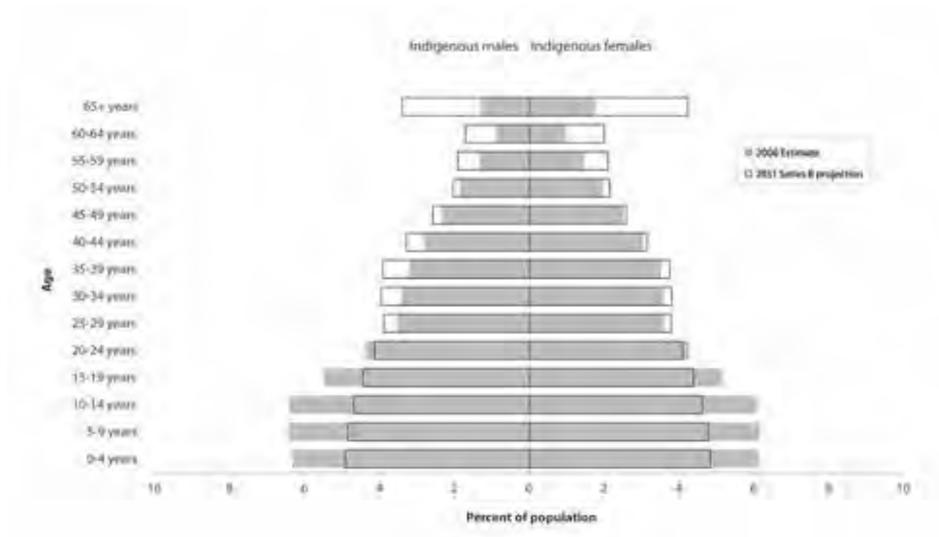


Fig. 1.1 Age distribution of the Indigenous and non-Indigenous population, Australia, 2011

Source: ABS 2012a

While it is clear that the Indigenous population will grow at a faster rate than the non-Indigenous population, it is very difficult to predict this growth accurately. For example, in using the 2006 Census, Biddle and Taylor (2009) projected that the Indigenous population would grow from just over 517 000 in 2006 to 848 000 in 2031 and that this trajectory would result in the Indigenous population being around 575 000 in 2011. However, the preliminary 2011 estimate (ABS 2012a) is that in 2011 the Indigenous population was around 670 000, approximately 17 per cent higher than the projections of Biddle and Taylor (2009). Although the current Indigenous population is relatively young, in part due to increasing longevity, it is likely that it will age noticeably in the future. While there is

still a large gap in life expectancy between Indigenous and non-Indigenous Australians, age-specific mortality rates of the Indigenous population appear to be falling.

The projected age distribution of the Indigenous population in 2006 and 2031 indicated in Fig. 1.2, assumes convergence between Indigenous and non-Indigenous fertility and mortality rates over the period. The proportion of the Indigenous population aged 0–24 years is projected to fall from 57 per cent in 2006 to 46 per cent in 2031. Correspondingly, the proportion of the population aged 50 years and over is projected to increase from 12 per cent to 20 per cent between 2006 and 2031.

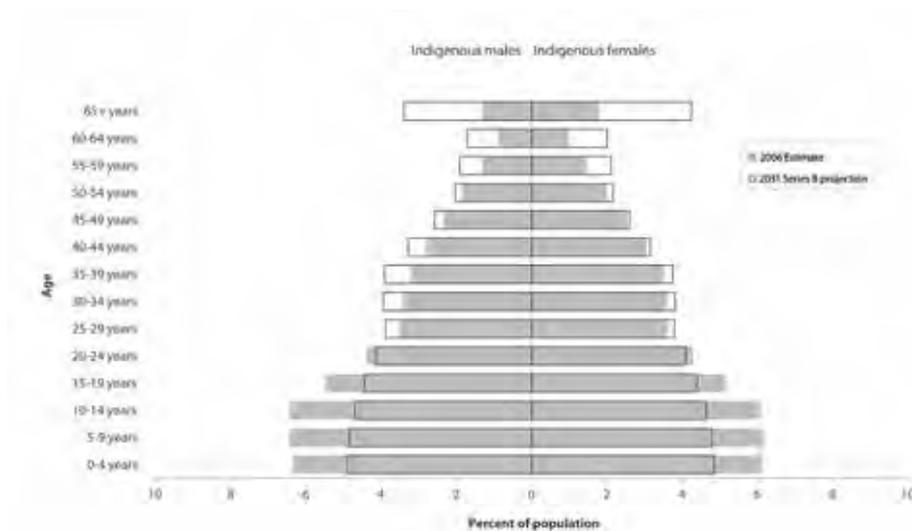


Fig. 1.2 Indigenous age distribution, Australia, 2006 (estimates) and 2031 (projections)

Source: Biddle and Taylor 2009

While we do not yet have official projections based on the 2011 Census, it should be noted that the fastest rate of growth in the Indigenous population between 2006 and 2011 was among those aged 50 years and over. Specifically, in comparison with 2006 estimates there were 47.6 per cent more Indigenous Australians aged 50 years and over in 2011. The projected increase in the number of Indigenous people aged 50–64 years, the upper end of the age distribution covered by the NDIS, combined with increasing rate of disability with age (see Chapter 2 of this volume) means that the number of Indigenous Australians within scope of the scheme will increase in coming decades.

The geographic distribution of the Indigenous population

While the majority of the Indigenous population lives in major cities (32%), inner regional (21%) and outer regional (22%) areas, a substantial proportion live in remote (10%) and very remote areas (16%). Overall, Indigenous Australians are much more likely to live in remote parts of the country relative to the non-Indigenous population. For example, while in 2006 (the most recent year for which we have remoteness estimates) 2.5 per cent of the total Australian population was estimated to be Indigenous, in major cities 1.2 per cent of the population are Indigenous. In remote areas 15 per cent of the population are Indigenous and in very remote areas 47.5 per cent of the population are Indigenous.

Using a region-based geography, Fig. 1.3 shows the proportion of the total Indigenous population estimated to live in each Indigenous Region (IREG) in 2011.² The differences between IREGs can be highlighted by comparing the remote 'region' of Apatula in central Australia with the city of Sydney. Apatula has an area of around 548 000 square kilometres and, in 2011, a total estimated population of 10 174 of whom 81 per cent were Indigenous, the highest percentage outside of the Torres Strait IREG. The Sydney-Wollongong IREG has an area of around 11 500 square kilometres and an estimated population in 2011 of 4 555 865, of whom just 1.1 per cent were Indigenous. Clearly, Apatula is much more Indigenous in its population makeup than Sydney. However, at the time of the 2011 Census, there were estimated to be 6.2 times as many Indigenous Australians living in Sydney as there were in Apatula. Indeed, 29 per cent of the total Indigenous population was estimated to live on the eastern seaboard between Sydney and Brisbane. This is 2.8 times as many as the whole of the Northern Territory (10% of the Indigenous population) and more than the combined Indigenous populations of Western Australia, South Australia and Tasmania.

What the results summarised in Fig. 1.3 make clear is that, even if rates of Indigenous disability were much lower in major cities and regional centres compared to remote parts of the country, the sheer weight of population means that the majority of the disability services provided to the Indigenous population as part of the NDIS will need to be provided in urban centres. On the other hand, however, most of the disability services in remote parts of the country will be used by Indigenous Australians. This geographic distribution also has clear service delivery and workforce implications, as discussed in Chapter 7.

² Official Indigenous Region population estimates will not be available until late 2013. The results in Fig. 1.3 apply the state-specific undercount (from ABS 2012a) to Indigenous Region-specific census counts.

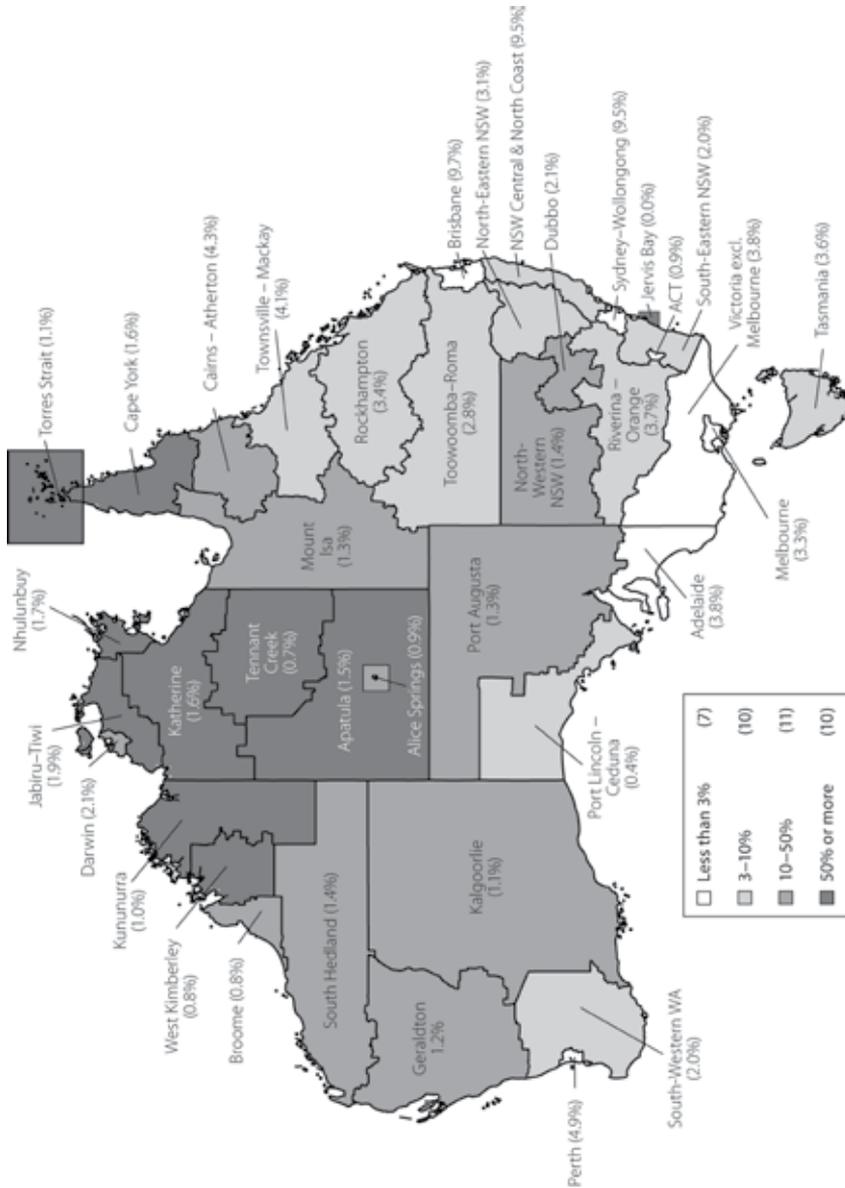


Fig. 1.3 Geographic distribution of the Indigenous population, Australia, 2011

Source: Customised calculations using ABS 2012a

It is anticipated that the Indigenous population will become more urbanised over the next few decades. This is driven by two factors. First, there has been a steady out-migration of the Indigenous population from remote areas to regional centres and major cities that shows no sign of abating in the future (Biddle 2009). Secondly, while Indigenous female fertility rates tend to be evenly spread across the country, most of the births of Indigenous children to non-Indigenous mothers occur in urban parts of the country. This is mainly due to the relatively high rates of intermarriage in these areas (Heard, Birrell and Khoo 2009).

Using data from the 2006 Census, Biddle and Taylor (2009) estimate that the Indigenous population in major cities will grow by 34 per cent between 2006 and 2016, compared to 9 per cent in very remote areas. While it is projected that the Indigenous population will increase in remote and very remote areas at a slower rate than in major cities and regional areas, the non-Indigenous population is projected to decline in remote and very remote Australia over the period 2006–2016, meaning that the proportion of the Indigenous population in these parts of the country will be higher in 2016 than it was in 2006. Early results from the 2011 Census suggest that, if anything, these trends are intensifying. A feature of the Indigenous population in remote and very remote areas is that it is spread throughout a very large number of small, discrete, largely Indigenous communities. This means that the absolute number of people in most discrete Indigenous communities that will be covered by the NDIS is quite low.

Analysis of the ABS Housing and Infrastructure in Aboriginal and Torres Strait Islander Communities Survey 2006 by the Australian National Audit Office (ANAO 2012) provides useful information on the number of discrete Indigenous communities, the population in these communities, and the average population of the communities according to geographic remoteness. Overall, 20 per cent of the 2006 Indigenous population lived in these identifiable discrete communities, mostly in non-urban locations, as shown in Table 1.1.

Table 1.1 Number of discrete Indigenous communities and population by remoteness area, Australia, 2006

Remoteness category	Number of communities	Population	Average population
Major city	4	346	87
Inner regional	19	1 870	98
Outer regional	52	10 254	197
Remote	104	11 237	108
Communities of less than 50	71	1 436	20
Communities of more than 50	33	9 801	297
Very remote	1 008	69 253	69
Communities of less than 50	767	8 723	11
Communities of more than 50	241	60 530	251
Total	1 187	92 960	78

Source: Derived from ANAO 2012: Table 1.3

The data shown in Table 1.1 highlights the large number of small Indigenous communities which exist in remote and very remote Australia. There were 1 187 discrete Indigenous communities in 2006 in which 92 960 Indigenous people were counted (20% of the Indigenous population). The average population of these communities was 78. The vast majority of the discrete communities are in very remote areas (1 008), with an additional 104 such communities in remote areas. Of the 1 008 discrete communities in very remote areas, 767 have less than 50 people living in them, and 241 have a population of 50 or more. The communities in very remote areas with a population of less than 50 people, have a total population of 8 723 and an average population of just 11. The communities with a population of greater than 50 have a total population of 60 530 and an average population of 251.

Indigenous notions of and approaches to disability

Disability, health and community participation

As with non-Indigenous Australians, the lived experience of Indigenous people with disabilities is complex and personal. Further, as discussed previously, the cultural concept of disability is one that continues to evolve. This complexity is further nuanced by the diversity of cultures and traditions among Indigenous Australian communities. However, there are particular cultural and historical factors that play an important role in how Indigenous Australians approach disability as a concept, and how it is experienced by the individual and by the community.

It has often been observed that there is no word for disability in many Indigenous languages. Ariotti (1999: 218) notes that the Pitjantjatjara language has no single word that captures the idea of disability; instead, specific words are used for particular ailments, such as *kuru pati* (blind), *pina pati* (deaf), *witapitjara* (to have back pain) or *lurpani* (to hobble around). The lack of an abstract concept of disability goes beyond language, as found by King (2010) in her interviews with Indigenous users of a respite centre in Brisbane. Despite being regular users of disability services, and requiring assistance with a range of day-to-day tasks, the women she interviewed simply did not identify themselves or the people around them as having a disability. When asked if they could remember people from their communities with a disability, few could recall any such individuals. Furthermore, even when disability is recognised, it is mostly not considered a salient issue when compared with problems such as

unemployment, poverty, discrimination and chronic disease. A further factor is that the higher rate of disability in the Indigenous population may 'normalise' perceptions of disability.

In order to understand how disability is conceptualised by Indigenous Australians today, it is important to understand both the history of disability in Indigenous Australia, and more generally the history of Indigenous people in their interface with other elements of Australian society and in particular their relationship with government and welfare services, including the extent to which the Indigenous community has had voice in the wider conceptualisation of disability within Australian society. One attempt to do this has been by Ariotti (1999) who describes three broad phases in this history: impairment, oppression, and empowerment. In the impairment phase, '[d]isability did not exist' (Ariotti 1999: 217). This is not to say that no members of the Indigenous population had physical or mental impairments; rather, there was no concept of disability that separated those individuals from the rest of their community. In the oppression phase, the concept of disability was first constructed for Indigenous Australians by non-Indigenous Australians; the introduction of this concept had cognitive, behavioural and social impacts for Indigenous Australians. As well adapting to the new concept of disability, its introduction also had behavioural consequences. Unlike the impairment phase, in which individuals are treated no differently by the group, the labelling of a person as having a disability has the potential to separate them from their community. This may lead to an individual's internalisation of helplessness, and the realisation that they require assistance and are thus potentially a burden. Labelling an individual as having a disability might not only cause shame but also may threaten their place in the community, with many Indigenous Australians having experienced family members being removed because of physical or mental impairment. Ariotti's final stage, the empowerment stage, reflects recent desires within the Indigenous community to reconstruct the idea of disability in a way that is culturally appropriate, a goal that is reflected in the work of organisations like the FPDN.

While there is very little research into how contemporary groups of Indigenous people view the concept of disability, the limited evidence that is available suggests that Indigenous Australians are less likely to identify as having a disability compared to non-Indigenous people with a similar level of impairment and that, where it is used, the concept of disability is more closely linked to notions of community participation and belonging (King 2010). While there are a range of views and experiences within the Indigenous population, the connection between disability, health and community participation suggests that for the Indigenous population assisting individuals with a disability to participate as fully as possible in community life is likely to be particularly

important. The FPDN (2011: 14) criticises many disability services for ignoring the importance of participation, suggesting that the services are ‘...dealing only with the health aspects through the provision of a technical aid without addressing the systemic barriers that impact the person’s life, such as an inaccessible community’.

If a disability makes it hard for a person to travel then it is likely that Indigenous Australians with a disability will not be able to participate fully in expected cultural activities (e.g. funerals). While this is an issue in both remote and non-remote areas, it is likely to be a bigger issue in remote areas where, for example, an individual’s disability might prevent them from travelling by light plane if it is not properly fitted for wheelchairs. Furthermore, the individual might require special care that is not available when visiting other communities (Senior 2000: 8). As well as the inability to travel long distances, a disability might prevent an individual from participating in cultural activities closer to home, such as going into the bush to fish or camp (Senior 2000: 20). Accessible transport was one of the key issues identified in the FPDN submission to the Productivity Commission Inquiry into Disability Care and Support.

The care of Indigenous people with a disability

A unifying theme in much of the research into disability in the Indigenous community is the importance of caring for people with impairments within the family and wider community. Senior (2000) reports that within Indigenous society, responsibility for caring for those with disabilities as well as the elderly traditionally rests with the immediate and extended family. Senior (2000: 19) notes that ‘[i]t was commonly stated that it was families’ responsibility to look after people with disabilities, and that caring for people and helping one another was a very important part of life and also as how people viewed themselves’.

The experience of Indigenous Australians with disabilities is thus highly dependent on the ability of their family members to provide the necessary care. While this might not pose a problem for individuals with straightforward needs, many individuals with disabilities have complex requirements, often compounded by the co-prevalence of multiple diseases or disabilities.

The ability to care for family members with disabilities is further complicated when families must care for multiple individuals, experience poverty or where family breakdown occurs. The high incidence of chronic disease and poverty related problems in Indigenous communities makes it more likely that families will struggle with caring for individuals with a disability, especially when the carers often suffer health problems of their own. This magnified burden of care has been identified by health workers, carers and people with disabilities as a serious issue in Indigenous communities (Senior 2000: 22).

While the family is traditionally the primary source of care for Indigenous people with disabilities, the extended kinship group and wider community also plays an important role in providing care and assistance. This care can take a range of forms, from informal assistance provided by one person to another, to more formal arrangements in which the community arranges professional care for an individual. Ariotti (1999: 221) describes the role of the Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council, which has introduced an employment service and mental health program, as well as employing a physiotherapist, two traditional healers, and a social worker.

Demand for disability services

Barriers to increased use of disability services by Indigenous Australians can generally be considered in terms of supply side and demand side issues. The supply side will be discussed in detail in a later section of this volume. While not always framed in these terms, on the demand side the perceptions of disability discussed above are often cited as the reason disability services are underused in Indigenous communities (e.g. FPDN 2011). One potential problem identified in the literature is that of the shame felt by individuals who believe they are a burden on their community, and also by carers who feel that they cannot provide adequate assistance (King 2010: 196).

Lack of knowledge about access to services is a related issue, as shame may prevent Indigenous Australians from seeking out information concerning services available to them. Senior identifies reluctance among many Indigenous Australians with disabilities to seek assistance when issues of disability and poor health are often seen as something out of their control (Senior 2000: 22). Another common reason given for the limited use of services is negative past experiences with government services, notably where these involve outsiders entering an individual's home. The concern was often raised that care workers who came into an Indigenous person's home, for respite care for example, would be disparaging of the person regarding the cleanliness of their home (King 2010: 205). Further to these barriers are issues surrounding the cultural appropriateness of disability services being offered, including the gender and cultural background of carers.

Frameworks for disability and other service delivery models

The Productivity Commission Report (2011) proposes a move towards a model of service delivery that places much greater focus on choice and competition.

This model should be seen in the context of increasing reliance on such approaches across a range of social and community services. To provide an overview of the advantages and disadvantages of different models for delivering government services, we turn to *The Other Invisible Hand* by Le Grand (2007). According to Le Grand, services can be delivered under four different models: trust, targets and performance management, voice, and choice and competition.

Trust

According to Le Grand (2007: 16), under the trust model, 'government sets the overall budget for the service; those who provide the service spend it as they wish.' The underlying assumption of this model is that the public servants who are providing the service (e.g. doctors, nurses, teachers, social workers) do so under mainly altruistic motivations. Any interference by government in terms of how services are to be allocated will be inefficient, either because it does not have the level of expertise or local insight that professionals possess, or because doing so will lead to an erosion of the intrinsic motivation held by the professionals.

The main benefit of this model, therefore, is that the knowledge of public service professionals working in a complex environment has the potential of being implemented in the most efficient and effective way possible. A potential limitation of the trust model, however, is that the incentives of service providers in the public service do not always overlap with the best interests of either the patient or the system. Where there is a conflict in such incentives there is a strong possibility that resources will be allocated inefficiently.

Targets and performance management

In many ways the opposite to trust, the system of targets and performance management assumes that service providers are motivated less by public (or patient/student/client) interest and more by their self-interest. Various labels command-and-control, or mistrust, 'workers are instructed or in other ways directed to deliver a good service by a higher authority' (Le Grand 2007: 1). This direction generally takes the form of numerical targets. Meeting or exceeding these targets will result in rewards, including financial bonuses or greater autonomy for staff and/or the organisation. Failure to meet targets, on the other hand, results in various penalties including greater outside intervention, demotion or dismissal of senior staff, or public censure.

The obvious benefit of a system of targets is that it does not rely on the altruism of professionals in the system. In addition, it allows decisions to be made by a central authority that is able to shape priorities for the system as a whole. However, this

central authority is unlikely to be aware of mitigating factors at the local level. Furthermore, if workers are motivated by their self-interest, they are as likely to favour decisions benefiting themselves regardless of systemic disadvantage as they are to work with it, and are less likely to seek continuous improvement once threshold targets have been set. Using targets as a means to allocate resources can lead to serious negative consequences for motivation and morale, especially among those workers who are used to a high degree of autonomy.

In addition the practical design of targets and performance management systems often present some difficulties. These systems frequently face a conflict between simple outcome measurement designed to focus the system on the desired goals, and the extent to which specifying these targets can be difficult and the system is open to abuse through processes such as 'creaming', or, where the targets are of necessity only an approximation of the outcome sought, the extent to which providers will seek to achieve the target, rather than the broader outcome it is meant to represent.

Voice

A limitation of both trust and targets as a system of delivering services is that the priorities within the system are set by service providers (in the case of the former) or funding agencies (in the case of the latter). The only way in which the interests of users of the service are taken into account is indirectly, through the ballot box, or on an ad hoc basis, through informal discussions with service providers. An alternative way to allocate services is by providing a direct avenue for users to shape the priorities within the system. One way to do this is through voice, a catch-all description by which 'users of public services communicate their views directly to service providers' (Le Grand 2007: 1). This can be done individually or collectively.

Collective voice mechanisms have the benefit of conveying the needs and interests of the community at the local level. This can provide very useful information to service providers. However, in order for systems of voice to exert a beneficial effect on the quality of service provision, those providing the service need to be sufficiently motivated to act in the user's interest, as opposed to their own. Another limitation of using such mechanisms to allocate services is that not everyone within the community has the same capacity for their voice to be heard. Those who are relatively disadvantaged based on their age, sex, income, geography or ethnicity are less likely to have their interests taken into account than dominant groups within the society.

Choice and competition

The final system for allocating services discussed in Le Grand (2007), and the one which occupies the majority of the discussion, is choice and competition. Here, 'users choose the service they want from those offered by competing providers' (Le Grand 2007: 1). In this system, choice can manifest in a number of ways, including 'choice of provider (where)...choice of professional (who)...choice of service (what)...choice of time (when)...[and] choice of access channel or method of communication (how)' (Le Grand 2007: 39–40). On the supply side, competition is the 'presence in the public service of a number of providers, each of which, for one reason or another, are motivated to attract users of the particular service' (Le Grand 2007: 41).

There are four main arguments for a system of choice and competition as a model for public service delivery. First, by providing a greater level of autonomy to service users, choice can be seen as a beneficial outcome in and of itself. Second, it can encourage providers to be more responsive to user needs, thereby leading to services which are of greater quality. This higher quality can be achieved regardless of whether the service providers are completely altruistic or completely self-interested. The former, it is argued, are likely to provide a better service because they are motivated by maximising client satisfaction. The latter provide a better service because it is in their economic interest to do so. Third, choice and competition can lead to services being delivered more efficiently by creating incentives for providers to offer the same level of services at a lower cost.

The final benefit of choice and competition, its proponents claim, is that services are provided more equitably by reducing the opportunity for those with greater political clout to demand preferable service. However, this comes at the cost of providing scope for those with greater financial resources to obtain a superior service. This can be mitigated to a certain extent by the use of quasi-markets in which individuals do not use their own resources to purchase goods and services, but rather use money provided by the government in the form of a voucher or a specially formulated budget. Equity criteria are still not met, however, unless individuals are restricted from purchasing additional services.

In order for a choice and competition model to result in the above benefits, three criteria need to be met—'competition must be real; users must be properly informed, especially ones who are less well off; and opportunities and incentives for selection or cream-skimming must be eliminated' (Le Grand 2007: 76–7). The latter refers to the situation where providers maximise profits by excluding those clients who are more difficult to service and are hence more costly. Examples of this include private schools which receive government funds excluding students with learning or behavioural difficulties, or health

providers excluding those patients with more serious conditions and/or multiple conditions. The potential for cream-skimming can be minimised by removing the ability of service providers to choose the clients that they administer to, or by adding a disadvantage premium, whereby the service providers receive additional payments for those clients deemed to be disadvantaged.

A further limitation of the choice and competition model is the necessity for a large number of users to ensure a well-functioning market. This is unlikely to be met for relatively rare conditions or, more generally, in rural and remote parts of a country. In these circumstances, governments will be required to underwrite a certain level of services. Le Grand (2007) argues that this problem can be mitigated to an extent by franchising— a system whereby a local monopoly service is offered to a single provider under a fixed-term contract that is renewed on a competitive semi-regular basis. However, even then, in a country like Australia (as opposed to the United Kingdom) there are likely to be many areas where that option is not profitable for service providers.

Direct payments and disability service provision

While there are a number of examples where direct payments for social services have been used in Australia, such a framework is much more widespread and has a longer history in the United Kingdom. Glasby and Littlechild (2009) examine the recent changes to the British social care system, including the expansion of direct payments and the introduction of personal budgets as means of financing community care. Glasby and Littlechild (2009) describe the evolution of the British social care system from one based on a paternalistic Professional Gift philosophy (where support is defined and controlled by professionals and given as a unilateral gift to the needy), to one based on the principles of independent living. After the Second World War the *1948 National Assistance Act* distinguished between the financial and non-financial welfare needs of social service users, allocating responsibility for these two separate bodies. The authors argue that this purely artificial distinction could not meet the complex needs of service users, and restricted the scope of social work in the period after the war. The emphasis during this period was on directly providing services which, echoing the discussion in Le Grand (2007), has been criticised as inflexible, unreliable, and giving the service user little control or choice in the kind of assistance they require.

In response to these criticisms and the growing strength of the Independent Living Movement, the Independent Living Fund was introduced in 1988, introducing direct payments as an option for local authorities in funding

social care. Applications for the Independent Living Fund were not expected to number more than around 300 per year, but by 1993, 22 000 people were receiving payments through the fund (Glasby and Littlechild 2009: 14). Its popularity, according to Glasby and Littlechild (2009), was due to the freedom it gave in choice of service provider, increased continuous care without disruption, flexibility and a greater breadth of care arrangements, but most importantly the feeling of self-respect that many of the fund's users reported. Due to financial limitations, eligibility for the Independent Living Fund was progressively tightened, and eventually the fund was discontinued in anticipation of replacement by a new system.

As the Independent Living Fund was wound back, local authorities were still able to make indirect payments, whether to third parties or trusts, in order to fund social care, and in 1994 just under 60 per cent of authorities surveyed reported doing so (Glasby and Littlechild 2009: 27). Legal issues surrounding these indirect payments, as well as increasing vocal lobbying from disability advocacy groups, finally lead to the 1996 *Community Care (Direct Payments) Act*, which gave authorities the power (but not the duty) to provide direct payments for community care services. Direct payments were only to be authorised if it could be shown that the service user was both willing to receive the payments and able to manage them. Furthermore, authorities were directed to make direct payments only if they were more cost effective than providing the services directly.

Because of the voluntary nature of this system, as well as the guidelines described above, it is unsurprising that uptake of direct payments has been uneven across the country and between different user groups. In 2006–07 only 3.2 per cent of adults receiving community based services were recipients of direct payments (Glasby and Littlechild 2009: 42). The authors identify a number of factors that appear to impact the uptake of this scheme: local concerns about the privatisation of social care, the flexibility of existing purchasing arrangements, and the influence of the disability movement. This last factor was found to be especially significant, with a high correlation recorded between the uptake of direct payments and the prevalence of user-led advocacy and support schemes in a given area.

In the 2006 National Centre for Independent Living report on direct payments discussed in Glasby and Littlechild (2009), the conditions most conducive to increased uptake of direct payments are summarised as follows: sufficient levels of support provided to users; good knowledge of direct payments among local authorities and community/voluntary groups; local authorities taking a strategic lead on direct payments; users who are involved in all areas of the payments; and a sound understanding of the principles of independent living (Glasby and Littlechild 2009: 38).

A further evolution of direct payments, namely personal budgets, were first introduced in 2003 on a small scale, allowing individuals even more input into how they allocated their resources, with guidance from social workers as needed. The authors describe personal budgets as an important progression from direct payments in terms of the principles of Independent Living. Under the direct payment scheme, users were still constrained to purchasing certain services and were allocated fixed sums with which to do so. Personal budgets, on the other hand, allow flexibility and creativity in how users decide to meet their needs, which the authors argue leads to efficiency gains as well as an increased sense of independence and control.

Preliminary findings from pilot programs suggest that personal budgets have led to important welfare improvements for the majority of users, as well as cost savings of around 10 per cent, and in some instances significantly greater savings (Glasby and Littlechild 2009: 92). One group for which personal budgets did not appear to have such a positive result was elderly service users, who might have found managing their own support a burden compared with other groups.

The authors argue that both the direct payment scheme and the small number of personal budget programs have had a significant impact on the wellbeing of service users, and contribute greatly to the goal of independent living. Direct payment recipients are found to be happier than direct service recipients, citing choice and control as the two most important factors in their wellbeing (Glasby and Littlechild 2009: 113). One of the most important aspects of the direct payment system identified by the authors was the ability of service users to take their custom elsewhere when not satisfied with the service provided—that is, ‘empowerment by exit’ (Glasby and Littlechild 2009: 133). Improved mental and physical health have also been attributed to direct payments, as users are able to tailor services to their personal needs, thus increasing the effectiveness of the services (Glasby and Littlechild 2009: 118). Furthermore, the authors argue that direct payments and personal budgets have the potential to result in significant cost savings due to increased efficiency, thus alleviating the burden on public spending.

Like Le Grand (2007), however, Glasby and Littlechild (2009) identify a number of barriers to the successful expansion of both the direct payment and personal budget programs. First, for empowerment by exit to be a realistic goal of these systems, acceptable alternatives have to exist, information about these alternatives must be available, and switching service providers must be easy (Glasby and Littlechild 2009: 133). This might not be possible in rural areas, especially in terms of recruiting personal assistance staff. While employing close relatives is not permitted under the direct payment system in the United Kingdom, the authors argue that this rule might need to be relaxed in order to overcome the problem of recruitment in rural areas.

Minority ethnic groups are also likely to face additional barriers in accessing direct payments if assessment processes do not adequately take into account cultural background and requirements in terms of care, especially if there is a lack of advocacy or support services. This is not guaranteed, though; Glasby and Littlechild (2009: 154) cite the example of one region in which minority ethnic groups comprised 20 per cent of the population but only 1 per cent of those accessing traditional social services. However, after the introduction of personal budgets, this proportion had risen to 10 per cent. Another potential barrier the authors foresee in the expansion of the direct payments system is financial; the very cost effective nature of this system might lead to less resources being devoted to community care overall if governments perceive direct payments as a cost cutting mechanism.

The authors identify a number of risks that must be addressed if direct payments and personal budgets are to become the norm in social care. Some commentators have expressed concern that direct budgets will lead to a two-tier system of social care, in which wealthier, educated individuals gain access to better services. The authors disagree with this assessment, arguing that, if anything, direct payments will place service users on a more equal footing, as they will be less subject to the inbuilt inequalities of the current care system. Another risk identified is that of exploitation of social carers, most notably underpayment, being forced to work antisocial hours, or not possessing paid insurance. The authors agree that direct payments are likely to result in more cash-in-hand work, and that this can lead to the above problems, but that this issue is not unique to the social care sector. Child benefits paid to parents are often spent on unofficial work such as babysitting and cleaning, they argue; direct payments to individuals with a disability should not be seen as a new problem. Furthermore, they argue that these issues are to some extent due to financial restrictions, and that social care users often express a desire to pay higher wages, including insurance and holiday pay to their personal assistants, if their payments were more generous. Despite these issues, the authors report that 95 per cent of personal assistants who were employed using direct payments were satisfied with their role (Glasby and Littlechild 2009: 150).

The authors also discuss potential risks to the service users themselves, notably from rogue operators who have not acquired sufficient experience in social care, or who potentially pose a threat to the user. The authors see a role for the government in regulating the sector to mitigate these risks, including training and inspections, but they stress that ultimately people with a disability should accept the same risks as everyone else with regards to hiring personal assistants. The authors suggest that these risks can be managed by putting in place adequate support for service users, including peer support networks. Overall, the authors believe that these risks are manageable, and should not prevent the successful uptake of direct payments and personal budgets for more social care users.

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