

# Individualised budgeting for social care services for people with a disability:

International approaches and evidence on financial sustainability



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# Executive summary

## Introduction

This evidence review addresses two key questions:

1. What models or approaches to individualised or personalised budgeting in response to needs assessment for social care services for people with a disability are used in other jurisdictions?
2. What is the evidence on the financial sustainability of different approaches?

In posing these questions, the Department of Health has a particular interest in the criteria for determining eligibility for a needs assessment and the entitlements following a needs assessment, and also on financial limits set on service provision and the relationship between individualised or personalised budgets and other income supports.

Six countries were chosen for this evidence review: Australia, Canada (eight provinces), England, the Netherlands, New Zealand and Scotland.

## Methods

As Question 1 sought a description of the legislative provisions with regard to individualised budgets, it was decided that the most appropriate way to answer the question was to identify official government sources within the chosen jurisdictions with a view to identifying the relevant legislation, statutory instruments, implementation guidelines and factsheets, any related strategy and policy documents, and associated research and evaluation reports. With regard to Question 2, preliminary scoping searches were undertaken; these yielded a number of reviews that provided useful summaries of the evidence with regard to the evaluations of the financial sustainability of different approaches. The reviews were supplemented and updated by a search of bibliographic databases, reference lists of articles and reviews, and relevant government and organisation websites.

## Legislative framework

Three different approaches to legislating for individualised budgets have been discerned – legislative frameworks enabling a brand-new and ideologically driven policy approach in Australia, England and Scotland; a consolidation of different pieces of relevant legislation in the Netherlands; and an incremental approach within broad legislative parameters found in New Zealand and different provinces of Canada.

In Australia, England and Scotland, very recent legislation has grounded disability policy and services on principles of personalisation and self-direction. In each case, this new legislation has shifted the focus from determining the eligibility of the person for routine supports to correct perceived deficits due to an individual disability, to determining 'eligible need', i.e. desired outcomes defined by the disabled individual (with or without others interested parties) and methods to achieve these outcomes. As a result, specific lists of entitlements are not provided; rather, parameters are set including:

- *Underpinning principles* such as personal choice and control, participation, respect and dignity – in England's legislation, local authorities are required to ensure the well-being of the participant.
- *Co-production* – professionals and participants work together to identify ways of achieving the desired outcomes.
- *Innovation* – in other words, supports provided not just through purchasing of services but through natural (non-monetary) supports and mainstream infrastructure, e.g. information provision, referral, web services, building individual and family capacity and community engagement.
- *Market development*, regulation and maintenance, including reconfiguring resources invested in older traditional service models and investing in service provider capacity building, particularly in the area of 'individualisation of services'.
- *Monitoring, reporting and review* of the implementation of the scheme by participants and by professional personnel.

The legislation establishes processes of assessment and planning, in which the person with the disability is at the centre of the process, and formal plans are developed. (Self-assessment is being trialled in some jurisdictions.) The

legislation devolves responsibility for financial management to the participant, if competent; to a party nominated by the participant, or with the participant's consent; or to the local authority or the National Disability Insurance Agency, which disburses the funding.

In the Netherlands, legislation governing personal budgets is part of the legislative framework governing long-term care, i.e. care for people with physical and developmental disabilities, chronic illness and the frail elderly. At the time of writing, reform of long-term care is a live issue in the Netherlands, with the most recent legislative changes coming into effect in January 2015.

The Dutch government, the municipalities and the health insurer are jointly responsible for long-term care, including personal budgets, and the vast majority of personal budget payments (for personal care and domestic care) are made under the Social Support Act 2015. Personal budgets for elements of long-term care and for nursing care are also covered under the Long-term Care Act and the amended Healthcare Insurance Act, respectively.

In New Zealand, since 2000, legislation development has been incremental and in response to emerging challenges and policy shifts. In 2002, an 'individualised funding' programme was piloted to provide funding for home care services for people with a disability; in 2010, the government adopted a new 'model for supporting disabled people', in which people with disabilities were to have improved access to information and advice, be allocated funding rather than services (called 'enhanced individualised funding'), and have more choice and control over the support that they could purchase. As part of this new approach, new programmes continue to be piloted and evaluated.

Historically, in Canada there has been a focus on direct payments for purchasing services costed by the hour, but since 2006 or thereabouts, disability policy has been evolving and gradually shifting towards a more self-directed care approach. The incremental nature of this development has led to a complicated pattern of different solutions in different provinces:

- Type of disability – the three most populous provinces (Alberta, Manitoba and Ontario) organise their disability services by type of disability – home care service for people with a physical disability, and individualised funding for people with a developmental disability.
- Type of need – three small provinces on the eastern seaboard (New Brunswick, Nova Scotia, Prince Edward Island) organise their disability services by need – a single Disability Support Program for people with all types of disability.
- Type of service – British Columbia, on the west coast, organises services by type of service: home care services for people with physical disability and people with a physical disability plus a developmental disability, and community living and participation support and services for people with developmental disabilities. The province of Saskatchewan is in the process of providing individualised funding for people with a physical disability.

The review identified four key factors considered in determining eligibility for individualised budgets – age, the nature of the disability, the severity of the disability and the likely trajectory and long-term effects of the disability. The process for determining eligibility varies between jurisdictions and some examples are presented here:

- *Age restrictions* may include an upper and/or a lower age limit for making applications, or may involve targeting particular age groups. Age restrictions may reflect the existence of other schemes which address the needs of the excluded age groups; for example, children up to the age of 18 years or those over the age of 65 years. The existence of these complementary schemes has not been considered in this review.
- *Nature of the disability* – the recent planned models adopted in Australia, England and Scotland cover a wide range of disabilities – 'intellectual, cognitive, neurological, sensory and/or physical impairments and attributable to a psychiatric condition' in Australia, whereas Scotland seeks to address needs arising out of 'infirmary, youth or age, illness, mental disorder or disability'. In Canada, as we noted in discussing the legislative framework, several provincial governments provide separate schemes for different categories of disability – distinguishing between provision for people with a physical disability and people with a developmental disability.
- *The severity of a disability*, i.e. its impact on the life of the person who has it, is also taken into account in determining eligibility. Schemes providing care and support for living at home tend to assess the impact by means of calculating the resulting 'deficit', which translates into the 'amount of care hours required'. The recent Australian, English and Scottish legislation assesses the impact as follows:



- Australia: reduced functional capacity and impact on ability for social and economic participation
- England: well-being significantly impacted upon
- Scotland: level of risk – from critical to low
- *Likely trajectory and effect over time can lead to the justification for an ‘early intervention’*

Personal care and home support services are the approach funded through direct payments made in the individualised funding scheme in New Zealand, introduced in 2003, and the various home care programmes in Canada. The guidelines tend to provide specific lists of what may be provided and what should not be provided. For example:

- Personal care includes assistance with personal hygiene, dressing, toileting, mobilisation and transferring, eating, oral care and medications.
- Home support services include services that meet the therapeutic and socialisation needs of clients. They may also support activities needed to live independently in the community, such as assistance with preparing meals, homemaking, and recreation activities.
- Respite includes respite care, such as a break from caring duties, for primary caregivers.

The new legislative frameworks that focus on personalisation and self-direction shift from lists of specific services that are included or excluded to requiring that ‘eligible needs’ be met (England) or that ‘reasonable and necessary supports’ be provided (Australia). These broad terms are hedged around by specification of outcomes and underpinning principles and values, the requirement for planning and co-production, regular monitoring and reviewing, in order to ensure that appropriate services are provided. Support for day-to-day living costs not related to the participant’s disability support needs (such as rent, groceries or utility fees) are excluded.

Information and advice and prevention are provided for under these new legislative frameworks, even where a person may not be eligible, as they are regarded as a means of reducing demand, or of delaying the emergence of needs that have to be met. Early intervention similarly is a means of reducing the person’s future needs for supports in relation to disability, and mitigating or alleviating the impact of the person’s impairment on the functional capacity of the person.

## Limits on expenditure on individualised budgets

This chapter outlines upper and lower expenditure limits in relation to individual funding schemes in the provinces of British Columbia and Prince Edward Island in Canada, and in relation to personal budgets and direct payments in England. Information was not found with regard to possible expenditure limits in other jurisdictions.

In England, from April 2016, it was intended that adults up to the age of 25 would have a zero cap on care costs for life, and everyone else would have a cap of £72,000. However, in 2015, the government announced that it was deferring the introduction of the cap until April 2020. An additional note relating to the tax treatment of individualised funding in New Zealand reports that when funding for carer support was transferred into the ‘enhanced individualised funding’ (EIF) scheme, it was treated as taxable income, rather than a subsidy, which disadvantaged the person with the disability in terms of the support that they could access.

## Relationship between individualised budgets and other income supports

This chapter explores the relationship between individualised budgets and other income supports. On the relevant Australian and Scottish websites, it is clearly stated that funding provided as part of self-directed care or self-directed support programmes for people with disabilities is viewed as a quite separate and distinct funding stream, supporting needs associated with the disability, and not other needs such as day-to-day living costs. The same distinction is made with regard to the administration of the Prince Edward Island Disability Support Program in Canada. The distinction or otherwise is not clearly made in relation to the other programmes described in this evidence review – England, New Zealand and the other provinces of Canada reported on in this review.

Regarding the combining of income supports, a pilot has been completed and evaluated in England, and another pooled funding pilot is under way in New Zealand. The pilot in England, ‘The Right to Control’, combined funding different streams supporting access to work, housing-related support, independent living, disabled facilities and social care. Given that the evaluation did not result in any measurable impact on outcomes, and given that the Care Act 2014 enabled greater choice and control for individuals, the government decided not to roll out the Right to Control programme nationally. In New Zealand, a pilot, Enabling Good Lives, which blends funding from the ministries of

education, health and social development to provide people with disabilities with the freedom and support to plan their own good life and fund it from one personal budget, is still being evaluated.

Provision is also made for pooled budgets for healthcare and social care in the recent Scottish and English legislation on individualised budgets and self-directed support.

Research was recently undertaken in Canada with regard to the equity of service levels for people with developmental disabilities who are served by the Community Living British Columbia (CLBC), and people who have similar levels of disability-related needs but who are not eligible for CLBC services because their disability is not a developmental one. It found that there are significant inequities in the amount of funding that is available between the different groups and that those with developmental disabilities feel relatively more well served than those in other disability groups.

## Evidence of financial sustainability

Personal budgets are an international trend, with many countries experimenting with some form of individualised funding for people with disabilities. A number of schemes have been revised since 2014 in light of evaluations and concern about expanding eligibility. In the Canadian province of British Columbia, a series of legal decisions led to the broadening of eligibility criteria for personal or individualised budgets. A similar situation occurred in the Netherlands due to 'creep' in the interpretation of who was eligible. A limited amount of economic evaluation has been done in the form of converting observed improvements in life quality to monetary values; however, transaction costs are almost never fully accounted for. In some countries, there is a clear distinction between health and social services; in others, the position is more blurred. The term 'personalisation' assumed many different meanings when put into practice. In some cases, it referred to a means to privatising supports; in others, it referred to a new model of social citizenship. Eligibility criteria have been altered over the lifetime of schemes. In some instances, this has come about as a result of a court challenge; in others, it was the result of not having sufficiently rigorous rules in the first place.

Almost all schemes in the EU have underestimated the costs of implementation, including start-up costs, unpaid care provided by families and out-of-pocket expenses. Financial risks in introducing individualised budgets for health include double running costs, existing unmet need, infrastructure and working with the provider market. Research has shown that better outcomes, such as an enhanced feeling of well-being, are achieved, but at a higher cost. Individualised budgets were found to be cost-effective overall, but with a great variation between people with physical disability, learning difficulty, mental health and older people. Most of the benefit was derived by young people with physical disability, and virtually no benefit was derived by older people.

To be economically sustainable into the future, and to fulfil the expectation that care in the future will be honoured and that the taxpayer will be happy to subscribe, governments need to coordinate care resources and set eligibility criteria to deliver the appropriate level of service to a variety of different categories of people. Increasing choice to people with disabilities seems to improve their sense of well-being, but, for some, the additional burden of decisions and administration can lead to apprehension and worry. There is also the danger that attempts at cost saving may lead to unregulated, unskilled workers replacing qualified and protected workers.

Australia's National Disability Insurance Agency has a built-in sustainability plan, which has been modelled from the agreed time it will be fully operational i.e. from 2019 to 2045. This will be achieved by a continuous monitoring and adjusting the scheme over time. In British Columbia, individualised funding (IF) has been in place since 2005, with costs similar to traditional delivery methods, but with variation over types of services and age groups. Here, younger people derived greater benefit from the scheme than did older people. In New Zealand, the IF scheme proved more expensive at the beginning, but this was explained by the fact that people with the greatest needs were early adopters of the new scheme. In a review of what helps and hinders the move to individualisation, research shows that lack of information and legal clarity can work against implementation, but are facilitators when they are positive. Scottish authorities suggested 'light touch' regulation in their pilot projects, in order to reduce bureaucracy, but research concludes that such an approach gives rise to risks on a number of levels, including administration burden and cost overruns.

# Chapter 1. Introduction

## 1.0 Introduction

This evidence review was undertaken by Brigid Pike, Gerald O’Nolan and Louise Farragher of the Evidence Centre in the Health Research Board (HRB). The evidence review was requested by the Department of Health (DoH) in Ireland. Evidence reviews are undertaken as part of a knowledge brokering service offered to policy makers in the DoH by the Research Utilisation Team in the DoH in collaboration with the Evidence Centre in the HRB. The questions were set by the DoH through an iterative process with the Research Utilisation Team and the Evidence Centre.

The DoH asked the following questions.

- 1. What models or approaches to individualised or personalised budgeting in response to needs assessment for social care services for people with a disability are used in other jurisdictions? (Social care includes respite care, residential supports, personal assistance, day supports, etc.)**
  - a. Describe the legislative framework in other jurisdictions for needs assessment and individualised or personalised budgeting for social care services for people with a disability. In particular, outline the legislation in relation to:**
    - i. the criteria for determining eligibility for a needs assessment, and
    - ii. the entitlements following a needs assessment.
  - b. Describe expenditure or financial limits set on service provision. In particular, is there an upper limit on the cost or quantum of services provided to eligible people? Are social care services free at the point of delivery or is there cost sharing (e.g. co-payments) or a lower limit (i.e. is the first €x amount of costs excluded, or the first x amount of home help hours)?**
  - c. Describe the relationship between individualised or personalised budgets and other income supports (expenditure or financial limits set on service provision. In particular:**
    - i. Is there a requirement on the person with disability to cover the costs of certain items/services from support payments/personalised budgets?
    - ii. Is the level of income supports (e.g. social welfare) higher for individuals with disabilities?
    - iii. Is a person with a disability provided with income supports in one payment, or are there separate income supports?
- 2. What is the evidence on the financial sustainability of different approaches in other jurisdictions and, in particular, the effects of eligibility and entitlement requirements on the financial sustainability of the approach at national level?**

## 1.1 Context setting

The *Future Health*<sup>1</sup> report recommended the move to individualised budgeting in social care, and individualised budgeting is also a fundamental element of the *Value for Money and Policy Review of Disability Services in Ireland*<sup>2</sup> report, which is the Government’s key policy document on disability services. This evidence review will describe models or approaches to individualised or personalised budgeting in response to needs assessment for social care services for people with a disability, and review evidence on the financial sustainability of different approaches in other jurisdictions and, in particular, the effects of eligibility and entitlement requirements on the financial sustainability of the approach at national level.

## 1.2 Choice of countries and jurisdictions

Following a reading of the 2012 National Disability Authority’s review of practice with regard to personal budgets in other jurisdictions<sup>3</sup> by Anand *et al.*, the following countries, which were considered in that review, were chosen for inclusion in the current review: Australia, Canada, England, the Netherlands and Scotland. Due to a lack of adequate information in English in respect of continental European countries, and also due to the wide variety of eligibility criteria and entitlements applied in different states in the USA, these jurisdictions were not examined in detail.

When it became apparent that disability policy and service provision in Canada is determined at provincial level, Spalding and colleagues' survey of self-managed care in Canada,<sup>4</sup> which was cited in the National Disability Authority's 2010 study,<sup>3,p13</sup> was examined with a view to selecting a representative sample of provincial governments. Spalding and colleagues' 'first major finding' was that for the 10 provincial and territorial jurisdictions they surveyed, it was difficult to access relevant information about self-managed care programmes either online or in person. Notwithstanding this lack of readily available comprehensive information, they found one or two examples of 'self-managed care programs' in each province or territory. In 2012, the authors of a report outlining a framework for effective implementation of 'individualised funding' in Canada noted that six provinces had now adopted individualised funding for people with a disability – Alberta, British Columbia, Manitoba, New Brunswick, Ontario and Prince Edward Island.<sup>5</sup> These provinces had all been described in the earlier 2006 report. It was decided that the six provinces covered in the Dozar report should be selected for investigation. The information provided in this and the earlier Spalding report was supplemented by looking for up-to-date information on the websites of the various provincial governments. The review of websites indicated that Nova Scotia and Saskatchewan have also adopted an individualised funding approach; therefore, they were also included among the Canadian provinces examined in this evidence review.

New Zealand was not in the original list of countries, as it had not figured in the evidence review by Anand and colleagues. However, New Zealand was included during the search of selected government websites for information on disability policy and services (described below), and as relevant information was located, New Zealand was included in the final list of countries to be investigated. Those countries were:

- Australia
- Canada
  - Alberta
  - British Columbia
  - Manitoba
  - New Brunswick
  - Nova Scotia
  - Ontario
  - Prince Edward Island
  - Saskatchewan
- England
- The Netherlands
- New Zealand
- Scotland

It became clear during the review that each country has its own language and terminology for the various mechanisms that describe individualised funding or budgets to individuals receiving health or social care supports. Table 1 summarises the main terms by country and provides an explanation of the terms. A more detailed explanation of the terms and their use is provided in the various chapters of the report.

**Table 1: Terminology used for person-centred or individualised care and support policies and programmes in different countries**

Country	Term	Definition
Australia	Self-directed care	Under the National Disability Insurance Scheme, each person has their own plan that is built around what they want out of life and the supports they need to achieve that; this plan is flexible and can change as people's needs change. <sup>6</sup>
Canada	Individualised funding	Individualised funding (IF) is a method of delivering services by providing funds directly to individuals or their families, so that they can purchase individualised services which support their own vision of how they want to live and how they want to participate in their community. With appropriate planning and management supports, individualised funding can be made available to anyone who wants it, regardless of their perceived 'capacity'.
	Self-directed funding	Saskatchewan's recently published disability strategy indicates a shift towards person-centred planning for people with developmental disabilities.
England	Personal budget	A personal budget for an adult is a statement which specifies the cost to the local authority of meeting whichever of the adult's needs it is required to meet or it decides to meet; the amount which, on the basis of the financial assessment, the adult must pay towards that cost; and if on that basis the local authority must pay towards this cost, the amount that it must pay. A personal budget for an adult may also specify other amounts of public money that are available in the adult's case including, for example, amounts available for spending on matters relating to housing, healthcare or welfare. Care Act 2014, s. 26
	Direct payment	Payments made directly to someone in need of care and support by their local authority to allow the person greater choice and flexibility about how their care is delivered. Care Act 2014, ss. 31–32
The Netherlands	Personal budget (Persoonsgebonden budget)	A personal budget allows clients to buy and organise their own care instead of receiving care in kind. Personal budgets are available for health and social care, and are regulated under various pieces of legislation.
New Zealand	Individualised funding	Individualised funding (IF) is a way of paying for disability support services. IF enables disabled people to directly manage the hours they are allocated for home and community support services. This can range from simply choosing support workers and planning how best to use the hours of support, to employing support workers and managing all aspects of the service delivery. <sup>7</sup>
Scotland	Self-directed support	Self-directed support (SDS) is a term that describes the ways in which individuals and families can have informed choice about how their support is provided to them. It is most commonly used in the delivery of social care and support, but it can cover a much wider range of services. <sup>8</sup>

## Chapter 2. Method

### 2.1 Question 1 – Searching

The three sub-sections of Question 1 all begin with the verb ‘describe’ and are concerned with aspects of legislation and service provision in other jurisdictions with regard to ‘personalised/individualised budgets’. As a result, it was decided that the most appropriate way to approach the task was to identify official government sources within the chosen jurisdictions, with a view to identifying the relevant legislation, statutory instruments, implementation guidelines and factsheets, any related strategy and policy documents, and associated research and evaluation reports.

The search was conducted in Google using two approaches:

1. Searching by the relevant keywords listed in Anand et al.<sup>3</sup> (p. 12-13) both with and without the names of the selected countries: consumer directed, direct payment, individual budget, individualised funding, personal budget, self-directed, self-managed. This yielded results for the following countries:
  - a. Australia + individualised funding;
  - b. England + direct payment/individual budget/personal budget;
  - c. New Zealand + individualised funding;
  - d. Netherlands + personal budget;
  - e. Scotland + self-directed.
2. Links from the initial Google search led to a range of official sites and sites of professional organisations, which contained the relevant statutory, policy and other reports. For a list of the most useful websites, see Table 2.
3. For Canada, the Spalding report,<sup>4</sup> which described the self-managed care programmes provided in each of the 14 Canadian provinces, was used as the starting point. Although this report was published in 2006, it provided sufficient leads to be able to locate and update the information on the programmes available on official government websites, and also to identify new programmes.

The inclusion criteria applied to the retrieved literature were:

- Relevance (in terms of describing aspects of individualised budgets in relation to the country in question);
- Published or written by an authoritative source.

Appendices 1–6 include details accounts of the information found in relation to each of the countries covered. At the end of the appendix for each country, a full list of the legislation, statutory instruments, guidelines and factsheets, relevant strategy and policy documents, and related research and evaluation reports, is provided, together with hyperlinks.

**Table 2: Websites of official and professional bodies relevant to individualised budgets**

Country/Jurisdiction	Website
Australia	<a href="http://www.ndis.gov.au">www.ndis.gov.au</a>
Canada – Alberta	<a href="http://humanservices.alberta.ca/pdd-online/index.aspx">http://humanservices.alberta.ca/pdd-online/index.aspx</a> Home page of the Persons with Developmental Disabilities (PDD) Policy Manual
Canada – British Columbia	<a href="http://www.sdsi.gov.bc.ca/pwd/isst.html">www.sdsi.gov.bc.ca/pwd/isst.html</a>
Canada – Ontario	<a href="http://www.communitylivingbc.ca/individuals-families/support-for-adults/individualized-funding">www.communitylivingbc.ca/individuals-families/support-for-adults/individualized-funding</a> <a href="http://blog.individualizedfunding.ca">http://blog.individualizedfunding.ca</a>
Canada – Prince Edward Island	<a href="http://www.communitylivingontario.ca/issues/policy-issues/individualization">www.communitylivingontario.ca/issues/policy-issues/individualization</a> <a href="http://www.gov.pe.ca/ssd/disabilitysupport">www.gov.pe.ca/ssd/disabilitysupport</a>
England	<a href="http://www.gov.uk/government/publications/the-care-bill-factsheets">www.gov.uk/government/publications/the-care-bill-factsheets</a>  <a href="http://www.nhs.uk/choiceintheNHS/Yourchoices/personal-health-budgets/Pages/about-personal-health-budgets.aspx">www.nhs.uk/choiceintheNHS/Yourchoices/personal-health-budgets/Pages/about-personal-health-budgets.aspx</a> Contains information on ‘personal health budgets’ and how they and ‘personal budgets’ may be combined.  <a href="http://www.scie.org.uk/care-act-2014/index">www.scie.org.uk/care-act-2014/index</a> The Social Care Institute for Excellence (SCIE) provides advice and guidance, and resources including videos, for local authorities and care providers involved in implementing the Care Act 2014.  <a href="http://disabilityrightsuk.org/how-we-can-help/independent-living">http://disabilityrightsuk.org/how-we-can-help/independent-living</a> Disability Rights UK is a charity run by and for people with lived experience of disability or health conditions. It seeks to influence national policy on independent living, benefits, education, employment, transport, human rights and other issues — shaping policy through direct experience and expertise. The charity also works with local individual and organisation members to empower and to influence local policy and services.
The Netherlands	<a href="http://www.hspm.org/countries/netherlands25062012/countrypage.aspx">www.hspm.org/countries/netherlands25062012/countrypage.aspx</a> The Health Systems and Policy Monitor – Netherlands  <a href="http://www.government.nl/topics/care-for-older-people/contents/living-independently-for-longer">www.government.nl/topics/care-for-older-people/contents/living-independently-for-longer</a> Dutch Ministry of Health website
New Zealand	<a href="http://www.health.govt.nz/your-health/services-and-support/disability-services">www.health.govt.nz/your-health/services-and-support/disability-services</a> Sections on Individualised Funding and New Model for Support, which includes enhanced individualised funding  <a href="http://www.enablinggoodlives.co.nz/about-egl/a-new-approach/1-how-enabling-good-lives-started-the-august-2011-report/">www.enablinggoodlives.co.nz/about-egl/a-new-approach/1-how-enabling-good-lives-started-the-august-2011-report/</a> Website dedicated to Enabling Good Lives demonstration project
Scotland	<a href="http://www.selfdirectedsupportscotland.org.uk/">http://www.selfdirectedsupportscotland.org.uk/</a>
European Platform for Rehabilitation (EPR)	<a href="http://www.epr.eu/index.php/thematic-expertise/independent-living/429">www.epr.eu/index.php/thematic-expertise/independent-living/429</a> EPR is a network of leading European providers of rehabilitation services to people with disabilities and other disadvantaged groups. It receives structural funding under the EU’s Lifelong Learning Programme, has a seat on EU’s High Level Group on Disability and has participatory status with the Council of Europe.
Academic Network of European Disability Experts (ANED)	<a href="http://www.disability-europe.net/theme/independent-living">www.disability-europe.net/theme/independent-living</a> ANED was created by the European Commission in December 2007. ANED established and maintains a pan-European academic network in the disability field to support policy development in collaboration with the Commission's Disability Unit.

## 2.2 Question 2 – Searching

In preliminary scoping searches for this review we retrieved a number of reviews, evaluations and reports that provided useful summaries of the evidence with regard to evaluations of the financial sustainability of approaches to individualised budgets across various jurisdictions. The following papers were used to inform the review:

Fleming P, Furlong M, McGilloway S, Keogh F and Hernon M (2015) *Personal Budgeting Interventions to Improve Health and Social Care Outcomes for People with a Disability: A Systematic Review* [Protocol]. Campbell Collaboration.<sup>9</sup>

Knapp M, Andrew A, McDaid D, Iemmi V, McCrone P, Park A-L *et al.* (2014) *Investing in recovery: making the business case for effective interventions for people with schizophrenia and psychosis*. London: London School of Economics and Political Science, and Centre for Mental Health.<sup>10</sup>

Wirrman Gadsby E (2013) *Personal budgets and health: a review of the evidence*. Policy Research Unit in Commissioning and the Healthcare System. University of Kent.<sup>11</sup>

Gadsby EW, Segar J, Allen P, Checkland K, Coleman A, Mcdermott I *et al.* (2013) Personal Budgets, Choice and Health – a review of international evidence from 11 OECD countries: A Review of International Evidence from 11 OECD Countries. *International Journal of Public and Private Health care Management and Economics*, 3(3): 15-28.<sup>12</sup>

Forder J, Jones K, Glendinning C, Caiels J, Welch E, Baxter K *et al.* (2012) *Evaluation of the personal health budget pilot programme. Discussion Paper 2840\_2*. London: Department of Health.<sup>13</sup>

Hilary A and Kemp PA (2008) *Dimensions of Choice: A narrative review of cash-for-care schemes. Working Paper No DHP 2250*. York: Social Policy Research Unit, University of York.<sup>14</sup>

These papers were used to summarise the evidence on costs and financial sustainability of approaches to individualised budgets across various jurisdictions up until 2013. To supplement and update these papers, two additional approaches were taken. A search was made of bibliographic databases in order to ensure inclusion of peer-reviewed, published evidence. The databases included MEDLINE, Embase, EconLit and Social Policy & Practice, all on the OVID platform. All databases were searched for papers published from January 2013 to August 2015 using a combination of terms listed in Table 3. A total of 615 records were retrieved and screened for inclusion by Gerald O’Nolan (GON).

**Table 3: Databases and search terms for the review**

Database	Search String	Results
Econlit (Ovid Platform)	((individual* adj budget*) or (personal adj health adj budget*) or (personal* adj budget*) or (individual adj budget*) or (individual?ed adj budget*) or (individual?ed adj funding) or (cash adj1 care) or (cash adj1 counselling) or (cash adj1 counseling) or (consumer-directed adj care) or (direct payment*)).mp	309
MEDLINE, Embase and Social Policy & Practice (Ovid Platform)	((Intellectual Disability/) OR (Disabled Persons/) OR (Developmental Disabilities/) OR (disab*).ab,ti OR (physical ADJ1 disab*).ab,ti OR (intellectual ADJ3 disab*).ab,ti OR (development* ADJ3 disab*).ab,ti ) AND ((budget* ADJ3 personali*).ab,ti OR (budget* ADJ3 individual*).ab,ti OR (finance* ADJ3 sustainab*).ab,ti OR (Cash ADJ3 Counse?ling).ab,ti OR (Direct ADJ1 payment*).ab,ti OR (Recovery ADJ3 Budget*).ab,ti OR (resource* ADJ1 allocation*).ab,ti)	307
<b>Total results</b>		<b>615</b>



In addition, reference lists of identified papers were searched for relevant documents, and the results of the search process for Question 1 were also screened for relevant documents. The results of these three approaches informed the basis for answering Question 2.

### ***Inclusion/exclusion criteria***

Many of the retrieved documents provided a good outline of how schemes worked or would work in different parts of the world; they also provided other valuable insights into this area. However, the criteria for inclusion or exclusion regarding economic evaluation and financial sustainability was limited to those sources that had real and verifiable figures (in cash), and against which some comparisons could be made between these schemes and the position that existed before their introduction. This reduced the number of sources considerably.

Some documents mentioned issues such as 'economic evaluation', but closer examination revealed that is merely a heading to state that there has been no economic evaluation, and figures are not readily available for the expenditure and financial impact of these schemes. Because many of these schemes are relatively new or considerably reformed, the quality and consistency of the information varied. Moreover, because studies often came up with opposite conclusions, we can conclude that information on costs is difficult to establish, and not all costs are captured in the available documents.

## **2.3 Reviewing the evidence**

With regard to Question 1, Brigid Pike reviewed the evidence in relation to Australia, Canada, England, New Zealand and Scotland. Louise Farragher reviewed the evidence in relation to the Netherlands. Gerald O'Nolan reviewed the evidence with regard to Question 2 concerning financial sustainability.

## **2.4 Limitations**

Approaches to the provision of individualised budgets in continental European countries other than the Netherlands were not covered in this evidence review, due to a lack of adequate authoritative sources in English. In addition, due to the wide variety of eligibility criteria and entitlements used in the different states in the United States, the approach taken to individualised budgets in the US was not investigated in this evidence review.

Given that the information needed to answer Question 1 was of a purely descriptive and factual nature, no quality assessment as such was undertaken. However, the validity of the information was ensured by only using official government sources.

Given that the approaches to introducing individualised budgets for social care for people with disabilities in all the countries and jurisdictions investigated were still in the process of development and roll-out, it has not always been possible to give a definitive account of how the system works. Moreover, it has been difficult to compare findings across jurisdictions, given the differences in programmes, contexts and deeper historical and cultural differences.

## Chapter 3. Legislative framework

### 3.0 Introduction

This chapter addresses the following question: ‘Describe the legislative framework in other jurisdictions for needs assessment and individualised or personalised budgeting for social care services for people with a disability. In particular, outline the legislation in relation to the criteria for determining eligibility for a needs assessment, and the entitlements following a needs assessment.’

Six countries were studied in detail for this evidence review – Australia, Canada, England, the Netherlands, New Zealand and Scotland. Due to a lack of adequate information in English in respect of continental European countries, and the wide variety of eligibility criteria and entitlements applied in different states in the USA, these jurisdictions were not examined.

This chapter outlines the key features of individual budget/individualised funding schemes in the six countries that were examined. As follows:

- legislative and governance frameworks;
- primary motivation;
- eligibility criteria, and
- entitlements.

Primary motivation has been added to reflect the findings of a recent review of the international evidence from 11 OECD countries which have implemented personal budgets for health (and social) care.<sup>11, 12</sup> The authors of this review identified primary motivation as inextricably linked with eligibility requirements and entitlements in shaping personal budget schemes.

Detailed information on each of the countries is provided in separate appendices at the end of the report. The information in these appendices is organised under the same four headings.

### 3.1 Legislative and governance frameworks

#### Australia

As early as the 1990s it was apparent that in Australia there was significant unmet need and potential latent demand for supported accommodation and other services among people with a disability. Moreover, the forward projections made as part of a modelling exercise commissioned by the New South Wales government ‘virtually guaranteed continued cost escalation in the disability system for many years to come, with little positive outcomes’.<sup>15(p. 333)</sup> It was in this context that the federal government invited the Productivity Commission to make a feasibility study of a national disability insurance scheme. Published in 2011, the Productivity Commission’s report found that ‘current disability support arrangements are inequitable, underfunded, fragmented and inefficient, and give people with a disability little choice’.<sup>16(p. 5)</sup> It recommended ‘a new national scheme – the National Disability Insurance Scheme (NDIS) – that provides insurance cover for all Australians in the event of significant disability. Funding of the scheme should be a core function of government (just like Medicare)’ (p. 2). Recognising the issue of latent demand, the Productivity Commission proposed a three-tiered funding model (see Table 4).

**Table 4: Three tiers of the National Disability Insurance Scheme (2009 population estimates)**

Tier	Population Group	Demand and Cost Implications
Tier 1	Total Australian population of 22.5 million	Full social participation in NDIS, minimising the impact of disability insurance
Tier 2	People with a disability and their primary carers – 4 million and 800,000, respectively	Given the nature and severity of disability for this group, it should be possible to meet many of their needs through natural supports and mainstream infrastructure, e.g. information provision, referral, web services and community engagement.
Tier 3	People aged 0 to the pension age with sufficient needs for disability support and early intervention – around 410,000 (2% of total population), comprising: People with intellectual, physical, sensory, or psychiatric disabilities who have significantly reduced functioning – 333,000; Early intervention group – 80,000; Other optimally supported – number unknown but modest; Funded support for some carers.	The group of people who will be supported with an individual resource allocation and package of support.

The Productivity Commission anticipated economic benefits arising from ‘wellbeing gains to people with disabilities and informal carers; efficiency gains in the disability sector; savings to other government services; increased participation, and the resulting fiscal gains’.<sup>16(p. 941)</sup> Moreover, the economic net costs were expected to be exceeded by the estimated economic benefits arising from reductions in Disability Support Pension beneficiaries, the welfare impacts for people with a disability and their carers, an improvement in employment ratios both for people with a disability and among carers.

In March 2013 the National Disability Insurance Scheme Act 2013 (NDIS Act) came into force. In introducing the Bill for its second reading in 2012, the Prime Minister stated:

*The risk of disability is universal, so our response must be universal. The only solution is therefore a nation-wide, demand-driven system of care tailored to the needs of each individual and established on a durable, long-term basis. ... The current funding model based on historical budget allocations will be replaced by an insurance approach, based on actuarial analysis of need and future costs. ... The National Disability Insurance Agency (NDIA) will work with people to plan, and to take account of their individual circumstances and needs. The scheme will give people the care and support that is objectively assessed as being reasonable and necessary over the course of their lifetime. It will give people real choice and control over these supports, including the ability to manage their own funding, if they wish.*<sup>17</sup>

The NDIA is established under the Commonwealth Authorities and Companies Act 1997. This gives the agency a high degree of autonomy and legitimacy, placing it beyond the vagaries of politics, or electoral and budget cycles. The NDIA holds all funds contributed by the Commonwealth, States and Territories in a single pool, manages scheme funds, administers access to the scheme and approves the payment of individualised support packages. The Board of the NDIA is responsible for the performance of these functions as well as the strategic direction of the NDIA. The Commonwealth Minister is responsible for administering the NDIS Act, and exercises statutory powers with the agreement of States and Territories, including a power to make the NDIS Rules and direct the National Disability Insurance Agency.

The Australian system is established on insurance principles, i.e. an extra 1% is contributed by every citizen (22 million) to fund services for the predicted 2% who will require disability services from Medicare.

## Canada

Provision of services for people with disabilities, including individualised funding, in Canada has evolved in a piecemeal fashion, with different solutions being developed by different provincial governments. The two organising principles are type of disability and type of need, which are separated or combined in a variety of ways.

### Separate provision for different needs

Table 5 lists five provinces (Alberta, British Columbia, Manitoba, Ontario and Saskatchewan) where the governments have developed separate self-managed programmes for adults with long-term physical disabilities and for adults with developmental disabilities. The programmes targeting those with long-term physical disabilities focus on the participants' immediate goals for daily living, and the services and supports they need to perform daily activities (e.g. bathing and meal preparation). No evidence has been found of specific legislation or statements of the desired outcomes, guiding principles etc. for these 'self-managed care/support services' programmes. By contrast, the programmes targeting the developmental disability (DD) population focus on identifying participants' major life goals and making decisions regarding living arrangements and locations, companions, education, and employment. These programmes, which make explicit provision for 'individualised funding', typically adopt a person-centred planning approach, using a structured system of tools, checklists, and protocols. They are specifically provided for in legislation, and the desired outcome is, broadly speaking, that people living with a developmental disability should be able to lead satisfying, productive lives in their communities, to make their own decisions and direct their own lives. Underpinning values include recognition of the worth and dignity of every individual, choice and control, fairness and equity.

British Columbia, on the west coast, takes a slightly different approach from the three neighbouring provinces. While it provides community living and participation support and services just for people with developmental disabilities, it provides its home care service not only for people with a physical disability but also for people with a physical disability as well as a developmental disability.

In Saskatchewan, a distinction appears to be made between individualised funding for home care services and self-directed funding for more aspirational suites of services. Home care supportive services are available for people with a physical and/or a developmental disability to purchase personal care, home management and other supportive services with individualised funding. In the province's disability strategy, *People before systems: transforming the experience of disability in Saskatchewan*, published in 2015, the concept of 'self-directed funding' is mentioned in relation to ensuring that in the future services for people with an intellectual disability are person centred:

*Expand opportunities for people experiencing disability to manage and direct the programs and services they receive, such as individualized funding for home care and self-directed funding programs for people experiencing intellectual disabilities.*<sup>18 (p. 14)</sup>

**Table 5: Canada – self-care programmes for people with a physical disability, and programmes including individualised funding for people with a developmental disability**

Province	Programme	Target group
Alberta	Home Care Self-Managed Care Program	Adults with a long-term physical and/or developmental disability and/or are frail/elderly
	Persons with Developmental Disabilities Program	Adults aged 18 or over with developmental disability
British Columbia	Choice in Supports for Independent Living (CSIL)	Adult with a physical disability or a developmental disability combined with a physical disability
	Community Living British Columbia (CLBC)	People with a developmental disability
Manitoba	Self- and Family-Managed Home Care Program	Adults over age of 16 with a physical disability
	In the Company of Friends (ICOF)	People with a developmental disability
Ontario	Self-Managed Attendant Service Direct Funding Program	Adults over age of 16 with a physical disability
	Passport Program	Adults aged 18 and over with a developmental disability
Saskatchewan	Home Care Program includes an individualised funding option	People with physical and/or developmental disability
	Self-directed funding programme proposed in Saskatchewan disability strategy published in 2015	People experiencing intellectual difficulties

### Single comprehensive provision

Table 6 lists three provinces (New Brunswick, Nova Scotia and Prince Edward Island) that have just one programme supporting the needs of both people with a physical disability and people with a developmental disability. These

‘disability support programmes’ all emphasise the importance of recognising the dignity and worth of the individual, of independence, choice and control, and the need for a person-centred and needs-based approach.

- The New Brunswick disability support programme (DSP) targets people aged between 19 and 64 years who require disability-related supports in order to address unmet needs and to establish or maintain their living arrangement in the community; to assist or enhance the capacity of their natural support networks to provide support in the community; or to help them participate in the community, thereby helping to avoid long-term inactivity and stress on themselves or their caregivers.
- The Prince Edward Island DSP targets people under the age of 65 when they apply for the programme. The DSP provides supports in three main areas – child disability supports, adult disability supports, and employment and vocational supports. The services and supports are for the purpose of meeting an unmet need that is directly related to the eligible person’s disability. The DSP was the first programme in Canada to distinguish between disability-specific support and income support.
- The Nova Scotia DSP is offered through three main channels – community-based, residential and vocational/day programmes. Among the community-based programmes, the Independent Living Support Program, which provides up to 21 hours a week of supports and service for people who require minimum support in their own home, and the Alternative Family Support Program, which supports people with disabilities in an approved, private family home, include direct payments to the person with a disability or their family. The participant is required to be over 19 years of age.

**Table 6: Canada – Disability support programmes – meeting all the needs of people with a physical and/or a developmental disability**

Province	Programme	Target group
New Brunswick	Disability Support Program	People with significant functional limitations
Nova Scotia	Disability Support Program	People with physical and/or developmental disability
Prince Edward Island	Disability Support Program	People with physical and/or developmental disability

## England

Direct payments were first introduced in England in 1997, under the Community Care (Direct Payments) Act 1996, for working-age adults. In subsequent years, eligibility was extended to older people, the parents of children with disabilities and carers; provision was then extended to people appointed to receive direct payments on behalf of individuals lacking mental capacity and those subject to mental health legislation. In time, direct payments became a duty, rather than a power, of local authorities, i.e. it became mandatory for councils to make direct payments to individuals who consented to, and were able to manage, them.<sup>19, 20</sup>

In 2007, the government made a commitment to introduce personal budgets as part of its new approach to adult social care, which has been increasingly set within the context of personalisation.<sup>21</sup> The idea behind personalisation is to enable citizens to shape their own lives and the services they receive. The goal of personal budgets is to give individuals greater control over how they receive support, operating under a self-directed, State-approved budget of individual social care needs.

The Care Act 2014, which came into force in April 2015, creates a single, consistent route to establishing an entitlement to public care and support for all adults with needs for care and support. It creates a legal entitlement to:

- *a personal budget*, which is defined as ‘the mechanism that, in conjunction with the care and support plan, or support plan, enables the person, and their advocate if they have one, to exercise greater choice and control over how their care and support needs are met’<sup>22</sup> (paras. 11.2–11.3); and
- *a direct payment*, which is defined as ‘a payment of money from the local authority to either the person needing care and support, or to someone else acting on their behalf, to pay for the cost of arranging all or part of their own support’.<sup>23</sup>

A direct payment is one of four ways in which a personal budget can be managed; the other ways include a managed account held by the local authority, with support provided in line with the person’s wishes; a managed account held by a third party, with support provided in line with the person’s wishes; or a ‘mixed package’ that includes elements of the three means already identified.<sup>20</sup>

While the Department of Health has responsibility for policy and legislation in the area of social care and support, local authorities have responsibility for implementing the provisions of the Care Act 2014 in their areas. The English legislation continues to fund services through central taxation, which is distributed to local authorities. The legislation establishes a national eligibility threshold with which all local authorities have to comply, but the local authorities are responsible for setting the level of funding that is provided to meet the eligible need.

### **The Netherlands**

Following active promotion and campaigning by the patients' rights movement and the disability movement throughout the 1980s and 1990s, personal budgets (persoonsgebonden budget, or pgb) were first introduced into the Dutch healthcare system in 1996 as a 'major innovation' of the Dutch welfare state, supported by both left-wing and right-wing parties.<sup>24</sup> Personal budgets were introduced as an alternative to care in kind. Access to personal budgets was controlled and regulated under long-term care legislation, specifically the 1968 Exceptional Medical Expenses Act (AWBZ). Following the creation of the 2007 Social Support Act (the WMO), the responsibility for providing domestic care (and a personal budget to fund domestic care) to eligible individuals was transferred and decentralised to the municipalities, and removed from the AWBZ. While the AWBZ is primarily focused on intramural care (hospital/institution-based care), the WMO is administered by the 441 municipalities and is mainly focused on providing extramural (community-based) support.

In 2012, following political pressure to reduce a consistent overspend in the national long-term care budget, and as a response to allegations of fraudulent use of personal budgets, eligibility for personal budgets for AWBZ care was restricted to those whose impairments were severe enough to require residential care. This curtailment of eligibility pre-empted additional reform, much of which has been enacted since January 2015.

As of 2015, under the reformed system, many entitlements that were that part of the AWBZ have been transferred to the following four Acts, depending on the nature of the entitlement. Together, they aim to provide a coherent legal framework within which healthcare can be delivered 'according to the desires, capabilities and needs of individual people.'<sup>25</sup> A personal budget is available for care under all the following Acts:

#### ***The Long-term Care Act (WLZ 2015)***

The new Act covers all forms of care for people with serious, long-term care needs who require intensive care or supervision at close hand 24 hours a day, including vulnerable old people and people with severe disabilities. The Act governs care in institutions and at home. Benefits may be in kind, on the basis of a personal budget, or be made up of a combination of the two. Care is granted on the basis of a care needs assessment. Just like the AWBZ, the Long-term Care Act (the WLZ) provides a right to long-term care for individuals who qualify following a needs assessment. In other words, the WLZ remains a rights-based programme.

#### ***The Social Support Act (WMO 2015)***

The primary objective of WMO 2015 is to enable individuals to live independently for as long as possible in their own homes and to participate in society. The Dutch municipalities have responsibility for the implementation and policy making for this Act and have significant latitude in how social support is offered and delivered.<sup>25</sup>

#### ***The Youth Act (Jeugdwet 2015)***

All care provided for people with a mental disorder, including mental health care, parenting support and social support provided to children under the age of 18 years has been decentralised under the Youth Act (Jeugdwet 2015). The Jeugdwet is also implemented by the municipalities and has similar aims – that children should be enabled to grow up in a healthy and safe way towards independency, self-reliance and participation in society; all dependent on their age and level of development.<sup>25</sup>

#### ***The Health Insurance Act (ZVW)***

As well as the regular 'basket of services', several additional benefits in kind have been transferred to the Health Insurance Act (the ZVW) as a result of the repeal of the AWBZ:

- Care related to sensory disabilities;
- District nursing services (and a personal budget for district nursing services);
- The second and third year of treatment-focused intramural mental health care.<sup>25</sup>

Personal budgets are funded in a number of ways. The WLZ personal budget is paid out of the WLZ fund. The WLZ is funded from the income-dependent contributions collected by the Tax Office from Dutch residents. In addition, those individuals who receive long-term care are required to share in the costs. The total amount of cost-sharing depends on the individual's income and is levied by the Central Administration Office (the CAK). Both sources of funding are pooled in the WLZ general fund (the AFBZ), which is administered by the Health Care Insurance Board (the CVZ). The CAK then acts on the payment order of the care offices and pays the long-term care providers from this fund, based on the intensity of care that is needed for their clients as assessed by the Centre for Needs Assessment (the CIZ).

The WMO personal budget, to fund domestic care, is paid from the WMO scheme. The WMO is a tax-funded scheme which is operated by the municipalities. Municipalities receive a state grant to implement the WMO and have discretionary power in its implementation. Since 2007, additional funds have been provided to the municipalities to cover the costs of new services outlined in the reformed WMO (i.e. a personal budget for domestic assistance.) This so-called 'integration payment' is adjusted each year, based on advice by the SCP (Netherlands Institute for Social Research) about the macro budget. The remainder of the budget is increased annually according to a standard growth rate (Putters *et al.* 2010). When the macro budget is determined, the division of funds for domestic assistance within the WMO is based on a newly developed 'objective model'. This model ended a situation in which historical figures determined the funding a community received; the division is now based on objective measures of the composition of the population of each respective community.<sup>26(p.96-97)</sup>

The new objective model divides approximately €1.5 billion annually across the 413 municipalities. The budget is strictly limited and expenses that exceed the budget are not compensated, which means that the budget is fixed even when the exact demand is determined at a different level, i.e. at the municipalities' WMO offices, making the new objective model quite a typical risk-adjustment system. If individual municipalities either exceed or manage to stay within their budgets, there is no legitimate ground for compensation and/or other reclaims. The responsibility whether or not to exceed the budget therefore lies with the municipality.<sup>26</sup>

The personal budget available under the Jeugdwet 2015 is also be funded and administered by the municipalities, who receive increased funding from central government to cover the cost of administering the scheme.<sup>27</sup> Personal budgets available under the Health Insurance Act are funded through individuals' mandatory health insurance premiums, and these personal budgets are administered by the health insurers themselves.

## New Zealand

Under the New Zealand Public Health and Disability Services Act 2000, disability support services include goods, services and facilities that are provided to people with disabilities for their care or support, or to promote their inclusion and participation in society and independence, or for related or incidental purposes. In 2003, in order to create national consistency and to reduce the risk of funding abuse, both of which had been problems with the previous incremental arrangements for 'discretionary funding' for goods and services for individuals with disabilities, the Ministry of Health piloted an IF programme. Over the next few years this scheme was evaluated and the eligibility criteria were expanded to include all individuals, rather than limiting it to high-cost/high-need packages.<sup>28</sup>

In 2010, following extensive consultations and deliberations, the government adopted a new way of providing support so that disabled people could have the life they aspired to, like other New Zealanders.<sup>29</sup> This 'new model for supporting disabled people' has four underpinning principles:

- improved access to information and personal assistance;
- allocation of funding, not services;
- more choice and control;
- greater accountability.

Since 2011, the Ministry of Health has been rolling out projects demonstrating the various elements of this 'new model', and evaluating them on a rolling three-year cycle. Two of these projects provide further opportunities for self-directed support:

- *Choice in Community Living* (CiCL), an alternative to existing residential services, was established as a demonstration project in 2012, and a developmental evaluation was undertaken in 2013.<sup>30</sup>
- *Enhanced Individualised Funding* (EIF), to enable more choice and control over funding, was established as a pilot in 2013.



Another demonstration project, launched in 2011 as part of the ‘new model’, and relevant to the administration of self-directed support, are Local Area Coordinators (LACs), whose role is to assist disabled people to plan for a good life.<sup>31,32</sup>

In August 2015, towards the end of the three-year demonstration period of the ‘new model for supporting disabled people’, a report was published assessing the extent to which the components of the ‘new model’ had contributed to increasing choice and control for disabled people over the way they live and the support they receive.<sup>33</sup> This evaluation covered CiCL and EIF, and also considered whether CiCL and LAC can be implemented in a fiscally neutral way. The findings of this evaluation are discussed in Chapter 5.

The Ministry of Health has overall policy responsibility for disability support services, including IF, EIF and CiCL, whereas three contracted non-governmental entities – Needs Assessment and Service Coordination (NASC) organisations, IF host providers, and LACs – have responsibility for administration and service provision.

### Scotland

Published in 2010, the 10-year strategy *Self-directed support: a national strategy for Scotland* marked the start of the transformation of Scotland’s approach to the delivery of care and support for all categories of people in need of social assistance, including people with disabilities, and for carers.<sup>34</sup> The strategy document explains the background to the change. There had been a growing focus on the ‘personalisation’ of social care services in Scotland, as in England, following the emergence of the Independent Living Movement in the US, and subsequently in the UK, and the coming into force of the United Nations Convention of the Rights of Persons with Disabilities in 2008. The government had responded by introducing ‘direct payments’ for social care under the Community Care and Health (Scotland) Act 2002. This had resulted in greater independence for the people who used them.<sup>35</sup> However, ongoing research and consultations pointed to the need to:

- extend the options for individuals to exercise choice, through new approaches to agreeing individual outcomes and assessing and allocating individual budgets;
- legislate specifically for self-directed support, as distinct from legislation for direct payments;
- move away from strict definitions of what can and cannot be funded to achieve social care objectives; and
- build synergies with the preventive agenda and enjoying the economic and social benefits that can be derived from a joint outcomes-based approach.

These new directions were included in the 10-year strategy for self-directed support (SDS). This new approach is founded on the concept of ‘choice and control’, and is strongly linked to the goals of recovery, rehabilitation and reablement. It seeks to do things *with* rather than *to* people, within the framework of personalised and co-produced assessment, outcome planning, service design and care management and review. Four years later, in April 2014, the Social Care (Self-Directed Support) Scotland Act 2013 (SDS Act) came into force, providing for individual choice over care and support and a range of payment options, including direct payments. Work is continuing on extending and integrating the concept of self-directed support across a range of health and social policy sectors, ‘applying the approach to other funding streams that collectively support people to live independently’.

The Scottish government’s Health and Social Care Directorates are responsible for the legal framework and the strategies and policies surrounding the implementation of SDS. Scotland’s 32 local authorities have the statutory duty to assess people’s need for social care and to make provision for community care services in their area. The Scottish government continues to fund services through central taxation, which is distributed to local authorities.

## 3.2 Primary motivation

Gadsby<sup>11</sup> identifies four ‘primary’ motivations for introducing a self-directed care scheme: giving individuals more choice, expanding the options for care, improving outcomes, and/or reducing expenditure.

Most jurisdictions are aiming both to increase the independence and freedom of choice for individuals by expanding the options for long-term care outside institutions, and to reduce overall care costs. As Gadsby comments, behind these primary motivations, or expectations ‘lies an assumption that more choice will lead to greater autonomy, which will in turn improve outcomes at a lower cost’.<sup>11(p.18)</sup>



In addition to these twin basic aims, different countries may have other priorities. Gadsby and colleagues reviewed reports that reducing the demand for places in care homes has underpinned the schemes adopted in Belgium, France, Germany and the United States, whereas in Austria and the Netherlands the schemes have been designed explicitly to stimulate private sector provision of care services. This has also been an outcome of the recent developments in support for people with disabilities in New Zealand. The schemes introduced very recently in England, Scotland and Australia (after Gadsby and colleagues had completed their review) have all broadly focused on increasing ‘choice and control’ for participants. The articulation of the underpinning principles and values is a distinctive feature of these three new schemes (see Table 7). The Australian initiative also arose out of a need to stop the continuing cost escalation of the national disability system. The two different approaches adopted across Canadian provinces (summarised in Tables 5 and 6) have been shaped by different objectives – the home care schemes predominantly for people with physical disabilities to reduce costs by keeping participants out of institutional care, and the individualised funding schemes to provide choice and control for people with developmental disabilities.

**Table 7: Statutory principles and values underpinning recent individualised funding schemes**

**Australia – the NDIS Act 2013**

Sections 4 and 5 of the NDIS Act set out the principles and values underpinning and guiding actions under the NDIS, and specifically, the rights, types of support available and the legitimate expectations of people with disability, their families and carers.

**England – the Care Act 2014**

Part 1 (1–3) of the Care Act sets out the principles that are to underpin the implementation of the Care Act by local authorities in ‘promoting individual well-being’. Nine different aspects of a person’s life are listed in the legislation as contributing to a person’s well-being. In exercising a function with regard to an individual, in order to promote well-being, a local authority must have regard to eight specific elements of their service provision, which are also listed in the legislation.

**Scotland – the SDS Act 2013**

The SDS Act 2013 specifies four statutory principles to help achieve the underlying aims or ‘spirit’ of the legislation: participation and dignity, involvement, informed choice and collaboration. The intention is that these four statutory principles will ensure a human-rights-based approach to the assessment, determining eligibility and entitlement, support planning and support provision process, which in turn will improve outcomes and lead to person-centred and outcome-centred service delivery.<sup>36 p17–19</sup> They are also expected to shift the systems and processes surrounding assessment from a focus on deficits towards a focus on strengths and capacities.<sup>36 (p. 32)</sup>

**‘Open’ versus ‘planned/budgeted’ models**

Drawing on the work of Alakeson,<sup>37</sup> Gadsby goes on to show how the primary motivations and expectations in introducing a scheme of self-directed care help shape the model that is adopted, in essence by determining the degree of patient choice and control. Gadsby describes two different models – open, and planned or budgeted.

- Typically, the ‘open’ model is a cash payment for care provided to those eligible for long-term care, with few strings attached. The cash for care schemes introduced in Austria and Germany, and the voucher scheme introduced in Finland, in the 1990s are cited as examples. Canada’s self-managed care/support services programmes primarily for people with physical disabilities and New Zealand’s individualised funding scheme (as opposed to its subsequent ‘enhanced individualised funding’ scheme) are further examples. The recipient can choose how to spend the money, and the money does not need to be accounted for. The only proviso is that the individual must obtain adequate care and this is checked at regular intervals. Gadsby comments that while autonomy may be high in the open model, the degree of choice may be limited by the budget and the availability of services. Moreover, where programmes are very simple and include little or no support for budget holders, eligibility may be restricted to those able to manage their own budgets.
- The ‘planned or budgeted’ model maintains a closer link between a recipient’s needs and the goods and services purchased to meet those needs. Alakeson maps a three-step process used to develop a planned model:

1. An individual budget is calculated for an eligible person, by calculating (i) the costs that would be spent on delivery of the same services by a home care agency, (ii) historical costs for the previous year, or (iii) a predictive model.
2. Consumers identify their needs and goals for care through a person-centred planning process, on the basis of which an annual spending plan is developed in line with the budget allocation.
3. The spending plan must be approved either by the government agency running the programme or by a designated agent.<sup>37</sup>

Examples of planned models are to be found in Australia, Canada, England, The Netherlands, New Zealand, Scotland and the United States.

### Moving towards self-direction?

Table 8 lists the main terms used in each of the six jurisdictions examined in this evidence review in referring to their policies and programmes with regard to providing people with disabilities with greater choice and control over the services and support they receive. Each term emphasises a particular characteristic of the policy and/or programmes, be it 'personal budgets and direct payments', emphasising personalisation; 'individualised funding', highlighting the fact that services for individuals are bespoke; and, most recently, 'self-direction', reflecting recent thinking in relation to person-centred practice in human service delivery systems.

**Table 8: Terminology used for person-centred or individualised care and support policies and programmes in different jurisdictions**

Country	Terminology	Definition
Australia	Self-directed care	Under the National Disability Insurance Scheme, each person has their own plan that is built around what they want out of life and the supports they need to achieve that; the plan is flexible and can change as people's needs change. <sup>6</sup>
Canada	Individualised funding	Individualised funding (IF) is a method of delivering services by providing funds directly to individuals or their families, so that they can purchase individualised services that support their own vision of how they want to live and how they want to participate in their community. With appropriate planning and management supports, IF can be made available to anyone who wants it, regardless of their perceived 'capacity'.
	Self-directed funding	Saskatchewan's recently published disability strategy indicates a shift towards person-centred planning for people with developmental disabilities.
England	Personal budget	A personal budget for an adult is a statement which specifies the cost to the local authority of meeting those of the adult's needs which it is required or decides to meet; the amount which, on the basis of the financial assessment, the adult must pay towards this cost, and if on that basis the local authority must itself pay towards this cost, the amount that it must pay. A personal budget for an adult may also specify other amounts of public money that are available in the adult's case, including, for example, amounts available for spending on matters relating to housing, healthcare or welfare. Care Act 2014, s. 26
	Direct payment	Payments made directly to someone in need of care and support by their local authority to allow the person greater choice and flexibility about how their care is delivered. Care Act 2014, ss. 31–32
The Netherlands	Personal budget (Persoonsgebonden budget)	A personal budget allows clients to buy and organise their own care instead of receiving care in kind. Personal budgets are available for health and social care, and are regulated under various pieces of legislation.
New Zealand	Individualised funding	Individualised funding (IF) is a way of paying for disability support services. IF enables disabled people to directly manage the hours they are allocated for home and community support services. This can range from simply choosing support workers and planning how best to use the hours of support, to employing support workers and managing all aspects of the service delivery. <sup>7</sup>
Scotland	Self-directed	Self-directed support (SDS) is a term that describes the ways in which

Country	Terminology	Definition
	support	individuals and families can have informed choice about how their support is provided to them. It is most commonly used in the delivery of social care and support, but it can cover a much wider range of services. <sup>8</sup>

Crozier and colleagues describe self-direction as follows: ‘... the next step in the implementation of personalised approaches, enabling individuals’ better choice, control and empowerment than ever before. The self-direction movement advances these critical personalisation concepts and actively promotes a person’s ultimate control over most if not all aspects of their care and support, including financial management’.<sup>38(p.5)</sup>

### 3.3 Eligibility

There are four eligibility criteria – citizenship, residency, age and disability – common to all self-managed social care programmes examined as part of this review. Without exception, all schemes and programmes require applicants to be legally entitled to live in the country – either through citizenship or some other means of legal authorisation – and to be residing permanently in the local area or region in which they are applying for self-managed care. Each jurisdiction has detailed provisions concerning how to handle contingencies such as a temporary absence from home, and other exceptions to the rules. These requirements are not discussed further in this review.

Age restrictions tend to vary according to policy and programme type and will be explored in more detail below. In two jurisdictions – England and Scotland – carers are eligible for support in their own right. Aspects of disability that are assessed in determining eligibility include the nature and duration of the disability, the likely trajectory and impact of the disability over time, and its impact on the life of the person. The procedure for determining eligibility, and the nature of the eligibility thus determined, varies by jurisdiction.

#### Age

Age restrictions may include an upper and/or a lower age limit for making applications, or may involve targeting particular age groups. Age restrictions may in some cases relate to the policy aims and the scope of the programme, or they may reflect the existence of other schemes which address the needs of the excluded age groups, for example children up to the age of 18 or those over the age of 65 years. The existence of these complementary schemes has not been considered in this review.

#### *Minimum age*

In Scotland, children and their families are eligible to apply for self-directed support. Similarly, in Australia, no lower age limit is specified in the legislation, although some states have imposed age restrictions during the transition to the new insurance-based national scheme. In Austria, the cash payments scheme for home and institutional care for people with physical disabilities or mental illness is open to anyone over the age of three years. In New Zealand, no lower age limit is mentioned in the literature that has been reviewed. However, in other jurisdictions, applicants have to be classed as ‘adults’ in order to be eligible: for example, in England, people have to be 18 years or older in order to be eligible for care; in Canada the home care programmes for people with a physical disability and the support programmes for persons with physical and/or developmental disabilities are all targeted at adults, with the minimum age ranging between 16 and 19 years.

#### *Maximum age*

Applicants are required to be under 65 years of age for some programmes, notably those that have aspirations to enhance choice, control and independence among participants; for example, in Australia, for the National Disability Insurance Scheme, and in Canada for the combined disability support programmes for people with a physical and/or developmental disability. In New Zealand, it is stated on the Disability Support Services DSSS website that those eligible for disability support services (which include an IF option) ‘are mainly younger people under the age of 65 years’, implying that older people may qualify. However, the website also states: ‘In most cases, district health boards fund disability support services for older people, including people with disability aged 65 and over assessed as requiring aged residential care, and those with mental health needs.’ The new Scottish scheme leaves it to the discretion of individual local authorities to decide whether applicants aged over 65 years are eligible for personal care or for nursing care.

### ***Changes in situation/circumstances***

Recipients cease to be eligible for certain schemes on reaching certain ages or stages in life: thus, in Australia, a person ceases to be eligible for the NDIS when they permanently enter a residential care service, or when they start being provided with home care on a permanent basis after the age of 65; in Scotland, direct payments are not permitted for people receiving long-term residential or nursing care. In Canada, IF through programmes to support both those with physical disability (home care support) and developmental disabilities (disability programmes) are generally only available for those living in the community. On the other hand, in England, where local authorities have statutory responsibility for the eligible care and support needs of all individuals, a personal budget may be used to pay for individuals residing in care homes.

In New Zealand the Choice in Community Living (CiCL) programme has a two-stage eligibility assessment – first, an applicant must meet the criteria for disability support services funded by the Ministry of Health (relating to age and disability), and then must also meet one of the following criteria: be in residential care; have disability support needs similar to those of someone living in residential care; live with family members; or be in a living situation that is unsustainable.

### ***No age restrictions***

In Germany, Sweden and the USA, according to Gadsby and colleagues, age limits are not specified in relation to either making an application or continuing to be eligible for individualised funding programmes for care and support. Gadsby and colleagues note that these countries' schemes were introduced with objectives other than enhancing the individual's degree of choice, control and independence: Germany introduced its schemes in order to reduce nursing home admissions and costs; in the USA, the cash and counselling scheme was introduced in order to expand options for home and community-based long-term care.<sup>12</sup>

### ***Targeting specific age groups***

According to Gadsby and colleagues, specific age groups have been targeted by two countries: the schemes in France and Finland have targeted older people (age not specified). They also note that in Finland the scheme is to be extended to younger age groups. In the Netherlands, most entitlements to care for disabled children and young people previously part of the AWBZ have been transferred to the new Youth Act, the Jeugdwet 2015. In Australia, young people with disabilities have been targeted for the initial years of the roll-out of the National Disability Insurance Scheme in several locations.<sup>39</sup> The intention has been to ease the transition:<sup>40</sup>

- Tasmania: the trial stage of the NDIS covered young people aged between 15 and 24 years. The objective was to improve supports to transition these participants from school to further education, vocational training, employment, or to more involvement in the community.
- South Australia: the first year of the trial focused on children aged under six years with significant and permanent disability, or who would benefit from early intervention. In the second year, the NDIS was to become accessible to persons aged under 14 years, and from the third year, to persons aged under 15 years.

When the NDIS was launched in the Nepean Blue Mountains area of New South Wales, starting on 1 July 2015, applicants had to be aged 17 years or less.

### ***Carers***

Carers are eligible for assistance in the newly introduced Scottish and English schemes. In England, carers aged over 18 years caring for another adult may be assessed: the assessment will consider the impact of caring on the carer, including its impact on the things that a carer wants to achieve in their own life, whether the carer is in paid work or wants paid work, wants to study, or do more socially. In Scotland, the assessment of eligibility will consider characteristics of the carer including their health, other responsibilities and personal goals and aspirations. In the Netherlands, informal carers can receive support under the WMO, including offering assistance with finding effective solutions if they are temporarily unable to carry out their tasks.

### ***Disability***

While citizenship, residency and age criteria are binary criteria, assessments of the nature and severity of disability are a matter of degree and are central to determining the level of support that an applicant is entitled to. Aspects of disability that are assessed in determining eligibility include the nature and duration of the disability, the likely trajectory and impact of the disability over time, and its impact on the life of the person.

### ***Nature of disability***

In Canada, several provincial governments provide separate schemes for different categories of disability: home care programmes, which tend to adopt the open model, target people with a physical disability, whereas disability support programmes, which are closer to the planned or budgeted model, target people with developmental disabilities. Three Canadian provinces offer combined programmes, catering for both people with a physical disability and people with a developmental disability.

The more recent planned models adopted in Australia, England and Scotland cover a wide range of disabilities – ‘intellectual, cognitive, neurological, sensory and/or physical impairments and attributable to a psychiatric condition’ in Australia, whereas Scotland seeks to address needs arising out of ‘infirmity, youth or age, illness, mental disorder or disability’. According to Gadsby and colleagues, a similar range is encompassed by schemes in Austria, France and Germany. Mental illness, however, is not always included in schemes; for example, New Zealand’s IF scheme excludes those with a mental illness. Chronic illnesses and conditions commonly associated with ageing are also excluded from the New Zealand scheme.

### ***Duration of disability***

Generally speaking, all schemes have a requirement that the disability be permanent or that it has lasted for a minimum length of time, usually six months to one year. Under the Australian NDIS, an impairment that varies in intensity, perhaps because it is of a chronic episodic nature, may still be permanent, and qualify for support, despite the variation. For developmental disabilities, there is a requirement that onset should have occurred before the applicant reached the age of 18 years. An exception to this is Community Living British Columbia, the disability support programme for people with developmental disabilities in British Columbia, under which a person over the age of 19 years with a diagnosis of foetal alcohol syndrome or autism, who is having ‘a hard time doing things on their own like shopping or managing money’ may be deemed eligible for support.

### ***Impact of a disability***

The severity of a disability, i.e. its impact on the life of the person who has it, is taken into account in determining eligibility. Schemes providing care and support for living at home tend to assess the impact by means of calculating the resulting ‘deficit’, which translates into the ‘amount of care hours required’, e.g. in Germany, all people ‘frequently or to a considerable extent in need of care’, whereas in Sweden those needing more than 20 hours of assistance per week. In Canada, under the Alberta Home Care scheme for example, people with a physical disability must have unmet healthcare needs, stable health and predictable care needs, and ongoing needs for personal care and home support services. Under the New Brunswick Disability Support Program Canada, the applicant must require disability-related supports in order to address unmet needs in two areas:

- his or her living arrangement in the community, including assisting or enhancing the capacity of his or her natural support networks to provide support in the community, or helping him or her to participate in the community, thereby helping to avoid long-term inactivity and stress on the individual and their caregivers; or
- the capacity of his or her natural support networks to help him/her personally, or to help him/her participate in the community.

The recent Australian, English and Scottish legislation shifts the focus from determining the eligibility of the person for support to make up any deficits due to disability, to determining ‘eligible need’, i.e. desired outcomes for the achievement of which extra supports are needed. Thus:

- *Functional capacity reduced* to the extent that a person cannot participate effectively in activities, or perform tasks or actions, without assistance from other people, or through the use of assistive technology, in relation to one or more of the following: communication, social and economic participation, learning, mobility, self-care and/or self-management (Australia).
- *Well-being significantly impacted* on as a result of needs arising from a physical or mental impairment or illness which, if unmet, would result in the person being unable to achieve two or more of a list of 11 specified outcomes. The Care and Support (Eligibility Criteria) Regulations 2015 outline the national minimum threshold for eligibility that applies across all local authorities in England, under which three interlinked conditions all have to be present:<sup>41</sup>
  - the adult’s needs arise from, or are related to, physical or mental impairment or illness;
  - as a result of these needs, the adult is unable to achieve two or more of a list of 10 specified outcomes, and

- as a consequence, there is, or is likely to be, a significant impact on the adult's well-being.
- *Level of risk* to a person's independent living, health or well-being is gauged as critical, substantial, moderate and low, and this results in different levels of response as well as prioritisation of need (Scotland). The statutory guidance for the Self-Directed Support (Scotland) Act 2014 gives an example of an eligibility framework for adults based on assessment of risk:
  - *critical risk*: major risks to the person's independent living or health and well-being likely to require immediate or imminent provision of social care services (high priority);
  - *substantial risk*: significant risks to the person's independence or health and well-being likely to require immediate or imminent provision of social care services (high priority);
  - *moderate risk*: some risks to the person's independence or health and well-being, which may require some social care services to be managed and prioritised on an ongoing basis; and
  - *low risk*: some quality of life issues, but a low risk to the person's independence or health and well-being with very limited, if any, requirement for the provision of social care services. There may be some need for alternative support or advice and appropriate arrangements.

Similarly, in Canada, under Saskatchewan's Home Care Program, 'acceptance priorities' are based on assessed need and level of risk if the service is not provided.

In Australia, individuals may be eligible for support even if they do not currently have a disability that is reducing their functional capacity or their ability to live independently, i.e. people may be eligible for an 'early intervention' if it will benefit them by reducing their future needs for supports in relation to disability, or mitigate the impact of their impairment on their functional capacity. Even if a person is not deemed eligible for early intervention support, preventive or universal services available through some other channel may be identified to assist the person. In Scotland, a person may be eligible for individual funding to cover 'reablement' services, i.e. a short-term package of support, for example following a fall, or discharge from hospital. Local authorities are encouraged to regard this as an 'early intervention', which helps to reduce the need for ongoing support.

### **Process for determining eligibility**

Different jurisdictions have different ways of determining 'eligibility for a needs assessment'.

#### **Australia**

According to the NDIS Act 2013:

1. A person makes an 'access request' to the NDIA to become a participant in the NDIS, and is then referred to as a 'prospective participant'. The access request must include all the information required by the NDIA and all the necessary documents.
2. The NDIA will assess whether the prospective participant meets the 'access requirements' specified in the legislation, which relate to residence (including citizenship), age, disability and early intervention, as outlined in Sections 4.2 and 4.3 above.
3. A person becomes a 'participant' in the NDIS if they are deemed to meet the access requirements. Once a person becomes a participant, the NDIA must facilitate the preparation of the person's plan.

#### **England**

According to the Care Act 2014:

1. Where it appears to a local authority that an adult may have needs for care and support, the local authority must assess whether the adult does have needs for care and support, and if so, what they are. This 'needs assessment' must be carried out regardless of the local authority's view of the level of the adult's needs for care and support, or their financial resources.
2. The needs assessment must include an assessment of the impact of the disability on the person's well-being (as outlined in Section 4.2 above), the outcomes that the adult wishes to achieve in day-to-day life, and whether, and if so to what extent, the provision of care and support could contribute to the achievement of those outcomes.
3. The adult, any carer that the adult has, and any person whom the adult asks the local authority to involve or, where the adult lacks capacity to ask the local authority to do that, any person who appears to the local authority to be interested in the adult's welfare.
4. The local authority must also consider whether, and if so to what extent, matters other than the provision of care and support could contribute to the achievement of the outcomes that the adult wishes to achieve in



day-to-day life, and whether the adult would benefit from the provision of anything under sections 2 or 4, or of anything that might be available in the community.

The Care and Support (Eligibility Criteria) Regulations 2015 state that when an adult is found to have care and support needs following a 'needs assessment' under section 9 of the Act (or in the case of a carer, support needs following a carer's assessment under section 10), the local authority must determine whether those needs are at a level sufficient to meet the 'eligibility criteria' under section 13 of the Act, i.e. they are (a) of a description specified in regulations, or (b) they form part of a combination of needs of a description so specified. Sections 18 and 20 of the Act set out the duty of local authorities to meet those of an adult's needs for care and support and those of a carer's needs for support that meets the eligibility criteria.<sup>41</sup>

### ***New Zealand***

For individualised funding (IF), the process is as follows (Ministry of Health 2012):

1. the NASC undertakes a needs assessment and discusses IF as an option;
2. the applicant chooses an IF Host and the NASC makes the referral; and
3. the person and the IF Host discuss the options, agree the level of support needed, and work together to develop an individual service plan.

For enhanced individualised funding (EIF), the process is as follows (Ministry of Health 2013):

1. The Local Area Coordinator (LAC) or Support Net (NASC) advises the person whether EIF is a relevant option. If it is, the person is encouraged to talk to their family and people such as their LAC about the life he/she wants and the dreams he/she has. Together, the person and the various stakeholders create a document that outlines these goals, agrees on a plan on what needs to happen in order for the person to achieve his or her dreams.
2. The NASC helps the person through an assessment process to establish the amount of funding.
3. The person is then referred to a host organisation that will work with him or her to manage the budget.

### ***The Netherlands***

To determine eligibility for WLZ care and a WLZ personal budget, clients must request an indication or needs assessment from the CIZ. It is important to note that there are no eligibility requirements for the needs assessment itself. The CIZ carries out an objective, standardised investigation into personal circumstances and environment, which is checked against the following mandatory criteria:

- Is there continuous need for client monitoring or supervision?
- Is 24-hour care available in the neighbourhood?

An application for needs assessment can be made by a client, or on their behalf by a carer or companion. Consultation can also be arranged with a free, independent client supporter. The CIZ, in principle, provides an outcome to the needs assessment within six weeks. The CIZ may invite clients to its offices, or may visit clients in their home, and may request additional information if necessary.<sup>42</sup>

For care under the WMO, municipalities have discretionary power with regard to conducting a needs assessment and providing for assessed needs. They can formulate their own criteria to determine who qualifies for publicly funded services (including personal budgets). Individuals who wish to obtain WMO care must apply to their municipality, usually to a specific 'WMO Help Desk.' A care assessment is undertaken (by the municipality or the CIZ) taking into account:

- personal and family situation;
- client preferences;
- availability of additional care under different legislation.

Applicants have the right to be assisted by an independent client supporter during the assessment process, and the municipality must arrange this. There is no charge for this service. Municipalities are required to conduct the assessment within six weeks of application. If the assessment shows that an individual is not sufficiently self-reliant to participate in society, and cannot receive such support from their social network, then the municipality is obliged to offer support through customised services and general services.<sup>43</sup>

## Scotland

Underpinning the process of determining eligibility and entitlement to self-directed supports is a statutory requirement for local authorities to apply the principles outlined in Section 3.0 above – participation and dignity, involvement, informed choice and collaboration. The steps for assessing eligibility and determining entitlement are as follows:

- **Step 1: Inform** The supported person decides that they need additional support. The supported person makes contact with social care services or community health services. There is an initial screening to determine if the person should progress to a formal decision on their eligibility for support. At this stage, the supported person should be provided with the relevant information and advice in relation to eligibility, assessment and support options.
- **Step 2: Assess** Initial decisions are made about the person's eligibility for support under the various legal obligations. Following the initial determination of the person's eligibility, the person's needs are explored in detail, and these needs are translated into a more detailed exploration of the individual's personal outcomes.
- **Step 3: Plan Support** planning covers a wide range of issues, but will tend to include a discussion of the choices available to the supported person, the main risks, and how the supported person and others can manage those risks, as well as the resources that will help to deliver the person's support plan.
- **Step 4: Choose** This is the stage where the supported person and the professional agree the support plan.
- **Step 5: Support/Speak out** This describes the provision of support to the person and the day-to-day decisions that will be made.
- **Step 6: Review** This marks the update of the original assessment, a review of the person's needs and consideration of any adjustments to reflect the changing needs or any changes in circumstances etc.

## 3.4 Entitlements

The range of services and supports to which people are entitled varies according to the purpose of the scheme and the target group. The means of determining entitlement – through assessing need and planning supports – also varies. As a result, this section is organised by country, rather than through presenting a pattern.

### Australia

#### Scale

The National Disability Insurance Scheme (NDIS) in Australia is a nation-wide, demand-driven system of care tailored to the needs of each individual. The NDIS is managed by the National Disability Insurance Agency (NDIA), which holds all funds contributed by the Commonwealth, States and Territories in a single pool, manages scheme funds, administers access to the scheme and approves the payment of individualised support packages.

#### Scope

The Statement of Participant Supports specifies both the 'general' supports and 'reasonable and necessary' supports that a participant receives. General supports are defined in the legislation as being in the nature of a coordination, strategic or referral service or activity, and are described by reference to a specified purpose or otherwise; with regard to general supports, the participant has a high degree of flexibility over provision and implementation. By contrast, reasonable and necessary supports are more closely defined, including specifying the funding and the way in which they are to be provided, in order to help ensure that the expected outcomes are attained.

Under Section 4 (11) of the NDIS Act, it is expected that 'reasonable and necessary supports' will support people with a disability to pursue their goals and maximise their independence, live independently and be included in the community as fully participating citizens. They are also intended to develop and support the capacity of people with disability to undertake activities that enable them to participate in the community and in employment. To meet these expectations, 'reasonable and necessary' supports must satisfy six criteria:

- support pursuit of the participant's stated goals;
- assist in undertaking activities that facilitate social and economic participation;
- represent value for money;
- be effective and beneficial, having regard to current good practice;
- complement what it is reasonable to expect families, carers, informal networks and the community to provide, and



- be appropriately funded or provided through the NDIS, rather than through other general systems of service delivery or support services.

When deciding whether the support should be described generally or more specifically in the statement, the CEO of the NDIA must have regard to the following:

- the cost of the support;
- any expected return or saving in costs from providing the support;
- any risks associated with the supply of the support, such as the need for, the support to, conform to State Territory laws;
- whether achievement of other goals in the plan or the effectiveness of other supports is contingent on a particular support being procured or used;
- whether a participant's disability requires a specialist, evidence-informed support provided by a qualified person or a particular delivery mode, and
- whether the participant accessed the NDIS by satisfying the early intervention requirements.

A support will not be provided or funded under the NDIS if it is likely to cause harm to the participant or pose a risk to others; is not related to the participant's disability; duplicates other supports delivered under alternative funding through the NDIS; or relates to day-to-day living costs (for example, rent, groceries and utility fees) that are not attributable to a participant's disability support needs. Day-to-day living costs do not include additional living costs that are incurred by a participant solely and directly as a result of their disability support needs, and costs that are ancillary to another support that is funded or provided under the participant's plan, and which the participant would not otherwise incur.

A participant will not be able to self-manage the funding for supports under their plan if they are an insolvent under administration, and neither will they be able to manage the funding if the CEO is satisfied that this would present an unreasonable risk to the participant. If the participant is a child, or is represented by a plan nominee, the CEO must consider the capacity of the child's representative or the plan nominee to manage finances and any potential conflicts of interest. If a participant does not make a 'plan management request', the statement of participant supports in the plan must provide that the funding for supports under the plan be managed by either a registered plan management provider specified by the NDIA, or by the NDIA.

## Canada

In outlining entitlements in the eight Canadian provinces examined in this review, the information on scope and process is organised according to the target population and the type of programme. Details of individual programmes in each province are summarised in Appendix 3.

### ***People with a physical disability – self-managed care/support services programmes (Table A2.1 in Appendix 2)***

Entitlements to self-managed care/support services for people with a physical disability include services relating to personal care, home support, respite, and equipment, i.e. assessed care needs and non-professional services needed to support independent living in the community. In Alberta, professional services (e.g. nursing, social work or physiotherapy) cannot be purchased with self-managed care funds, but in British Columbia community health workers may perform some specific nursing and rehabilitation tasks delegated by healthcare professionals. In Manitoba, the client (or substitute decision-maker) may make an application through the Self and Family Managed Care Program declaring his/her interest in hiring a family member. Funding is calculated in terms of hours of personal care and home support services needed and the specific hourly rate.

### ***People with a developmental disability (PDD) – individualised funding programmes (Table A2.2 in Appendix 2)***

Entitlements for people with a developmental disability (PDD) are much broader than those for people with a physical disability. They generally provide services to enable a person to move into and live in his or her own home and engage in productive and challenging daytime activities. The Alberta PDD programme provides special funds for those with 'complex service needs', i.e. those who pose a significant risk and/or are destructive to themselves, to others or to property, to purchase respite services and short-term specialised supports. The Ontario Passport Program provides funding to support person-directed planning and the administration of the funding. Services may be purchased from a wide range of providers, including community service providers, developmental services agencies, private service and support providers, adult education providers, personal support workers, neighbours, family members, and friends. The

Ontario Passport Program also lists categories of items that may not be purchased with the funding, including indirect respite services and supports such as cleaning, meal preparation, snow removal, and care of other family members; housing and home maintenance and other living expenses; drug benefits, medical aids, dental care, and therapies; assistive devices and specialised equipment; vehicle purchase and/or modifications, leases and rentals.

Individualised funding payments can be made directly to an individual and/or his or her family, or to a third party. For example, in Alberta, the individual and their family/guardian may manage the funds, or a funds administrator may be hired by the individual/family to manage the funds (Family Managed Services [FMS]); alternatively, a community service provider may manage the funds; or the Ministry may manage the funds. Under the Community Living British Columbia (CLBC) programme, individuals and families can select a combination of direct funding, host agency funding and/or contracted services.<sup>44</sup> Through direct funding, the individual or his/her agent receives money directly from the CLBC to pay for the supports and services. Host agency funding enables an individual and his/her family or representative (agent) to use a host agency to administer funding allocated by the CLBC to the individual. Host agency funding is only available when the request for CLBC-funded supports is over \$6,000 per year.

In Ontario, the maximum annual funding an individual can receive under the Passport Program is \$35,000; there are no caps on the amount for each type of support apart from administration (up to 10% of allocation) and person-directed planning (C\$2,500 annually). Under the CLBC programme, the amount of individualised funding allocated to an individual is based on the individual's disability-related needs, the estimated cost of the needed supports, and the CLBC's financial resources. The types of supports and services funded by the CLBC are described in the 'Catalogue of Services'. When the CLBC does not have funding available, requests for new or increased individualised funding is managed and prioritised in accordance with the CLBC Request for Service Policy (2014).

In Manitoba, Community Living disABILITY Services (CLDS) offers a range of day and residential services aimed at providing adults with a mental disability the opportunity for independence in a community setting to the extent possible for each individual, including residential services, day services and related support services. Within this suite of options the In Company of Friends Program gives adults with a mental disability the opportunity to create and manage their own services through direct funding. The person receives assistance to make his/her own decisions from their support network of family and friends. The CLDS programme uses the Supports Intensity Scale (SIS) as a standardised method of assessing the support needs of individuals receiving support from the CLDS programme. The SIS involves a detailed interview conducted by certified SIS facilitators with the CLDS participant and other individuals (family, support staff, etc.) who know the person well. The SIS is designed to measure the level of supports that a person with an intellectual disability needs in order to successfully participate in areas such as home living, community living, lifelong learning, employment, health and safety, and social activities.

***People with a physical and/or developmental disability – disability support programmes (Table A2.3 in Appendix 2)***

*New Brunswick Disability Support Program* offers the following options:

- home support worker;
- respite;
- personal supports and assistance within and outside the home;
- supports for community involvement and participation;
- personal living skills training;
- transportation supports that are disability specific;
- technical supports and assistive devices not covered under other programmes, and/or
- residential facility services.

Some supports and services provided under other government programmes are not provided or funded under the Disability Support Program such as:

- addiction services;
- vehicle retrofitting;
- major home adaptations or subsidised housing;
- mental health services;
- employment services (except if provided through adapt agencies);

- childcare services;
- income support;
- medical services or prescription drugs, and
- residential facility services.

*Nova Scotia Disability Support Program* includes a range of options from supporting families who care for a family member with a disability in their own home, to supporting people with disabilities in a 24-hour residential support option. Individualised funding is available for each of the three community-based (unlicensed) options:

- Direct Family Support for Adults (DFSFA) Program – provides funding for respite and special needs to assist families to support their family member with a disability who lives at home.
- Independent Living Support (ILS) Program – provides up to 21 hours a week of supports and services to persons with disabilities, who live in their own apartment or home, are semi-independent and who require minimal support. There is no overnight support available through the ILS Program.
- Alternative Family Support (AFS) Program – provides an approved, private family home, where support is given for up to two persons who are not related to the AFS provider. Participants may receive varying levels of support with activities of daily living, and routine home and community activities.

*Prince Edward Island Disability Support Program* focuses on the needs of the individual and/or family rather than on entitlement, and this allows for more flexible planning with individuals and families. Determination of unmet needs occurs during an eligible person's needs assessment, and on the basis of this, an applicant's level of functioning and maximum monthly funding is determined. Supports can take various forms including respite care, community living and participation supports, technical aids, and family support.

Once monthly funding has been determined, a support plan must be developed, including costs, and the client contribution must be calculated. As soon as the Individual Support Agreement, with the support plan attached, has been agreed to and signed, the Disability Support Worker may set up the payments to the individual, parent/guardian, or agent. The Disability Support Worker will request that a cheque for the pre-determined amount be sent directly to the individual, parents/guardians or agent at the beginning of each month. The individual, parents/guardians or agent will be responsible for paying all the funded expenses incurred as a result of the participant's special needs. Payments may be made to a third party if it is determined during the support planning process to be the most appropriate method.

## **England**

### **Scale**

According to *Factsheet 4*, published by the Department of Health, *The Care Act – personalising care and support planning* – once eligible need has been established, a local authority must undertake a planning process with the person with the need, any carer they have, and any other person they ask the authority to involve (see also Sections 24–30 of the Care Act 2014).<sup>23</sup> In order to meet their statutory obligation under the Care Act 2014 to promote 'well-being', local authorities must consider 'how to meet each person's specific needs, rather than simply considering what services they will fit into. The concept of meeting needs also recognises that modern care and support can be provided in any number of ways, with new models emerging all the time, rather than the previous legislation which focuses primarily on traditional models of residential and domiciliary care'.<sup>22(p. 2)</sup>

### **Scope**

Whether people are eligible for care and support from a local authority or not, the local authority is expected to provide preventive services and information and advice. Under Section 2 of the Care Act 2014, local authorities have a responsibility to provide services, facilities or resources that will help prevent or delay the development of care and support needs by people who do not have any current needs for care and support and by people with needs for care and support, whether their needs are eligible and/or met by the local authority or not. Under Section 4 of the Act, local authorities are required to establish and maintain a service providing information and advice relating to care and support options for adults and for carers for the whole population, irrespective of whether they are eligible for care and support or not. Section 8 of the Act gives examples of the types of care or support a local authority might provide in order to meet an adult's care and support needs:

- accommodation in a care home or in premises of some other type;
- care and support at home or in the community;

- counselling and other types of social work;
- goods and facilities, e.g. assistive technology in the home or equipment/adaptations, or
- information, advice and advocacy.

### **Process**

Under Sections 24–30 of the Care Act 2014, once eligible need for care and support has been established, the local authority must undertake a planning process with the person with the need, any carer they have, and any other person they ask the authority to involve (see *Factsheet 4* published by the Department of Health, *The Care Act – personalising care and support planning*, and Chapter 10 of *Statutory Guidance* published by the Department of Health, 2014).<sup>23, 22</sup>

The care and support planning process considers what needs the person has, what they want to achieve, what they can do by themselves or with the support they already have, and what types of care and support might be available to help them in the local area. The local authority must produce a plan that sets out the detail of what was agreed with regard to meeting the needs of the person. As part of the planning process, the local authority will tell the person about their personal budget (Section 26). This is the amount of money that the local authority has worked out it will cost to arrange the necessary care and support for that person, including any amount that the local authority is going to pay itself towards those costs (which might range from all to none). It is the mechanism that, in conjunction with the care and support plan, enables the person to exercise greater choice and take control over how their care and support needs are met by:

- knowing, before care and support planning begins, an estimate of how much money will be available to meet a person's assessed needs and, with the final personal budget, having clear information about the total amount of the budget, including the proportion the local authority will pay, and what amount (if any) the person will pay;
- being able to choose from a range of options for how the money is managed, including:
  - direct payments, which allows the person to purchase their own care and support;
  - the local authority directly providing some type of support, for example by providing a respite or short-term respite service;
  - the local authority managing the budget and a provider or third party managing the budget on the individual's behalf (an individual service fund); or
  - a combination of these approaches, for example, the local authority arranging a homecare service while also providing a direct payment to meet other needs;
- having a choice over who is involved in developing the care and support plan for how the personal budget will be spent, including from family or friends; and
- having greater choice and control over the way the personal budget is used to purchase care and support, and from whom.

According to Sections 31–33 of the Care Act 2014, a direct payment is a payment of money from the local authority, either to the person needing care and support or to someone else acting on their behalf, to pay for the cost of arranging all or part of their own support.<sup>45</sup> The local authority must provide a direct payment to someone who meets the conditions in the Act and regulations.

According to *Factsheet 8* published by the UK Department of Health, *The Care Bill – the law for carers*, a local authority and a carer will agree a support plan, which sets out how the carer's needs will be met.<sup>46</sup> This might include help with housework, buying a laptop to keep in touch with family and friends, or becoming a member of a gym, so that the carer can look after their own health. Carers should also receive a personal budget, which is a statement showing the cost of meeting their needs, as part of their support plan. It will include the amount the carer will pay, if any, and the amount the local authority will pay.

## **The Netherlands**

### **Scope**

Personal budgets are available under various pieces of legislation governing health and social care. The personal budget for long-term care regulated by the WLZ 2015. The WLZ is a mandatory national insurance scheme for long-term care in which all residents of the Netherlands are obliged to participate. It covers care for the elderly, chronically ill and the disabled, especially for care that could not otherwise be afforded.

Care under the Long-term Care Act (WLZ) may include:

- Stay in an institution;
- Care at home (if it is feasible and does not cost more than care in an institution);
- Personal care and nursing;
- Medical care (medical care which is necessary in connection with the illness, disability or disorder, as well as general medical care);
- Tools that are necessary for the care provided by the institution;
- Transportation to the place where the person receives counselling or treatment;

Possibilities for home care include:

- *Full home package (VPT)*  
This provides full care and support in the home, including meals, domestic help and outings. Rent or mortgage payments on the home remain the responsibility of the client.
- *Modular home package (MPT)*  
A client can receive care delivered by different providers. With MPT, no meals or household help are provided. Rent or mortgage payments on the home remain the responsibility of the client.
- *Personal budget (PGB)*  
With a personal budget, the client organises a contract for care with a carer of their choosing. The care must be of good quality, and the client must have the capability to manage their budget. The personal budget is deposited into an account in the State Bank, SVB, and the carer is paid from that account. (This measure was designed to prevent fraudulent use of the personal budget – an issue that has been highlighted in recent years.) The SVB offers this service and more to help administer and manage personal budgets for WLZ and WMO care. The personal budget for WLZ and WMO care is set at a rate of 66% of rates paid for services in kind.<sup>47</sup>

The objective of the Social Support Act 2007 (WMO) is that people arrange their own support as much as possible. When they are not able to arrange such help (through friends, family or others), the municipality steps in to offer social support. Under Article 4 of the WMO, the municipality has the duty to compensate, which requires that the municipality is responsible for making sure that people with a disability or chronic illness can run a household and are able to participate in normal activities both within and outside their homes. In addition, it has to ensure that people with a handicap have (local) means of transport at their disposal, in order to meet and socialise with others.<sup>26 (p. 16)</sup>

Under the WMO, there are specific policy areas that the municipalities must develop or address:

1. the promotion of social cohesion and quality of life in villages, districts and neighbourhoods;
2. prevention-focused support for young people experiencing problems as they are growing up and parents experiencing problems raising their children;
3. the provision of information, advice and client support;
4. supporting informal carers, including offering assistance with finding effective solutions if they are temporarily unable to carry out their tasks, and supporting volunteers;
5. the promotion of participation in society and the independent functioning of people with a disability or chronic mental condition, and of people with psychological problems;
6. the provision of services for people with a disability or chronic mental problem, and people with psychological problems, in order for them to be able to maintain and enhance their independency or participation in society;
7. the provision of social relief, including women's refuge and the pursuit of policies to combat acts of violence committed by an individual from within the victim's domestic circle;
8. the promotion of public mental health care, except for the provision of psychosocial aid in the event of disasters; and
9. the promotion of an addiction policy.<sup>26 (p. 21–22)</sup>

To compensate for limitations experienced by a person under items 4, 5 and 6 in the above list, the municipality should put in place measures to enable a person to:

- run a household;
- be able to move freely in and around the home;

- use transport for local mobility and,
- meet other people and, form social ties.<sup>26</sup>

The provisions include:

- domestic help, such as cleaning;
- home modifications, e.g. installing a stairs lift or a special toilet;
- transport in the region for people who are not capable of travelling with public transport (taxi expenses, or scooter);
- support for volunteers and informal caregivers;
- support with raising children;
- wheelchairs;
- delivery of groceries and meals;
- support to local initiatives, such as community centres and social clubs; or
- support to shelters for victims of abuse or homeless people.<sup>26</sup>

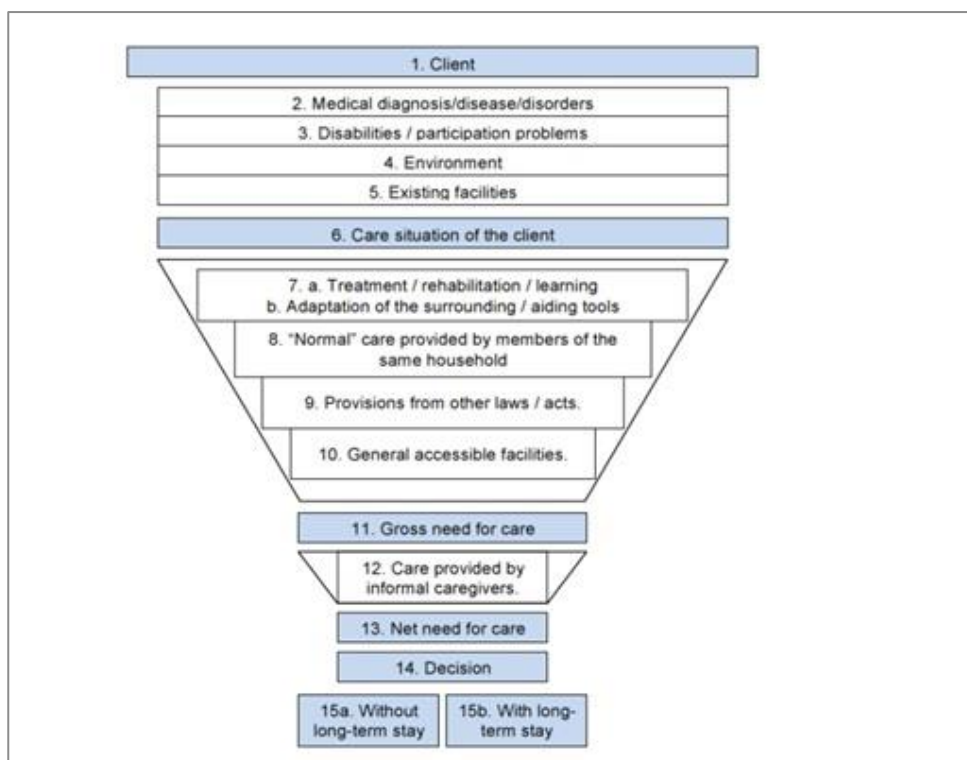
Those eligible for support from the WMO can receive a personal budget or direct assistance from a person or agency hired by the municipality.<sup>48</sup> Unlike care provided under AWBZ, social support (WMO) is not a right. Municipalities are obliged to help disadvantaged people to participate in society and the community, but they are essentially free to design and implement WMO policy as they see fit (Rolden 2013 Putters *et al.*, 2010; Van der Veen *et al.* 2010).<sup>26, 48, 49</sup> The WMO 2015 is an amended version of the WMO 2007 and includes provision for additional care; however, without access to a translated version of the legislation, it is impossible at the moment to be clear about the exact nature of this provision.

### **Process**

WLZ personal budgets are calculated as part of a broader long-term care package using a retrospective budget model. The CIZ (Centre for Needs Assessment) uses a standard assessment to determine if an individual is eligible for the various 'functions' of care available under the WLZ.

The personal budget process includes the following steps:

1. Assessment: The applicant has their needs assessed by the CIZ or the Youth Care Agency if they are aged under 18 years. The CIZ assesses the care need of an individual according to a 'funnel model' (see Figure 1; it is unclear as yet if this model has changed following the repeal of the AWBZ and the implementation of the WLZ.)
2. Budget calculation: The applicant receives a budget 'indication' based on fixed tariffs for the type and amount of care needed. Persons aged over 18 years have to make income-related personal contributions, calculated by the Central Administration Office (CAK).
3. Payment: The budget is paid into the Social Insurance Bank (SVB)
4. Accounting: The budget holder chooses and pays for the carer or carers they want. They must account for the money they spend.
5. Repayment: Around 10–15% of budget holders repay any unspent money from their annual allocation.<sup>50</sup>



**Figure 1: Assessment steps by the CIZ to decide on an individual's AWBZ care needs (funnel model)<sup>48</sup>**

The Social Insurance Bank (SVB) is an organisation that implements national insurance schemes and distributes payments for benefits and pensions in the Netherlands. Personal budget holders can use the SVB's PGB Service Centre free of charge. The SVB acts as a third party intermediary and can manage WLZ and WMO personal budgets. In addition, the SVB helps with salary administration for budget holders who have hired carers.

More than two-thirds of municipal authorities have the Personal Budget scheme carried out by the SVB. The remaining one-third still administer the scheme themselves; however, more municipalities are expected to use the SVB to implement the scheme. People who receive a budget under the WMO and the WLZ receive the same service.

In a move aimed at countering fraud in the personal budget system, since January 2015 personal budget payments have not been made directly to clients. Instead, carers are now paid by the SVB on behalf of the client. The introduction of this new system has caused significant delays in carers being paid, becoming a national issue in the media. In June 2015, a carer won a court case for compensation for late payment from the SVB. The judge decreed that the same employment law applies in this case as in the relationship between an employer and an employee, and gave the woman an increase of 25%. Since then, the SVB has appealed the verdict, but a larger class action suit of almost 2,800 carers is underway.

For the WMO personal budget, municipalities have discretionary power with regard to conducting a needs assessment and providing for assessed needs. They can formulate their own criteria to determine who qualifies for publicly funded services (including personal budgets).

Generally, the municipality outsources the provision of social support services to commercial organisations. Each municipality decides whether client contributions are required, and if so, how they are calculated. Municipal workers can calculate and bill these contributions themselves, or these tasks can be outsourced to the client. Contributions are usually required for domiciliary care, instrumental aids, home modifications and personal budgets.<sup>51</sup> Some municipalities use the CIZ process described above to conduct needs assessments; other municipalities have designed their own services. De Decken and Maarse note that this may lead to unequal access, where some municipalities pursue a generous policy but other municipalities may opt for a less generous policy. Individuals who wish to obtain WMO care must apply to their municipality, usually to a specific 'WMO Help Desk'.<sup>52, 53</sup>



## New Zealand

Since 2011, New Zealand has been piloting various elements of a 'new model of support for people with a disability', including two programmes providing opportunities for self-directed support – Enhanced Individualised Funding (EIF) and Choice in Community Living (CiCL). The origins of this approach are described in Section 2.4 above; entitlements under both programmes, as well as the original individualised funding programme, are described in the following paragraphs.

### Scale

The Ministry of Health is responsible for legislation, policy development and funding of disability support services, including EIF and CiCL, across the country. However, the Ministry contracts out service provision relating to EIF and CiCL to local support agencies, which fall into three functional categories:

- *Needs assessment and service coordination* (NASC) organisations are contracted to work with disabled people and their family, or carers, to identify their strengths and support needs, outline what disability support services are available, and determine their eligibility for Ministry-funded support services. NASCs allocate Ministry-funded disability support services and help with accessing other supports. NASCs play a role in relation to both EIF and CiCL.
- *Host providers* deliver support to disabled persons, meeting with the person to develop a plan, finding appropriate support and managing the money. The particular characteristics of host providers under EIF and CiCL, respectively, are explained below in descriptions of the processes for determining entitlements. With regard specifically to scale, it is noteworthy that the reviewers of the IF programme – following the expansion in the number of host providers in 2009/10 – suggested that the human resource support/advice and payroll functions carried out by host providers might be provided more efficiently by aggregated host entities operating at national or regional rather than local level.<sup>28(p. 27–30)</sup>
- *Local area coordinators* (LACs) have been trialled as part of the new EIF. Their role is to support disabled people and their families or family carers in strengthening connections with their communities in order to receive the support they need, and they also engage with and support communities to become more welcoming and inclusive of disabled people. An evaluation of LACs, tasked with inquiring into the reasons for the low take-up of the service in the trial areas, concluded that the reasons were 'contextual' rather than inherent in LACs as such, and called for a redesign of the wider national system of disability support services.<sup>32</sup>

### Scope

*Individualised funding (IF)*, which came on stream in 2003, entitles the person with a disability to purchase Home and Community Support Services (HCSS) provided by support workers (employees or contracted personnel or organisations), and to pay the costs relating to the employment of support workers. The HCSS scheme is intended to help disabled people to live at home, providing help with household management and personal care.

Although other Ministry-funded disability support services can be allocated as part of a wider support package, IF cannot be used to manage services such as day and/or vocational services, rehabilitation services, supported living, or respite provided in Ministry-contracted facilities, carer support, residential services in Ministry-contracted facilities, information and advisory services, equipment or housing modifications, child development services, or behaviour support services.

*Enhanced individualised funding (EIF)* has been piloted in two regions of New Zealand since 2013. The purpose of the 'enhanced' scheme is to enable people to achieve their goals and live 'a good life' (however they define a good life). People are allocated a budget and can decide what disability supports to buy with that money, rather than having to spend it on HCSS alone. The Ministry of Health<sup>54</sup> is trialling purchasing guidelines which set out what people can buy with the EIF funding allocated by the NASC. People will be able to purchase products, services and/or arrangements that meet each of the following three criteria:

1. They are a disability support, and do not cover the cost of goods and services that the person would reasonably be expected to provide for from their own money (such as wages or a benefit) if they did not have a disability. (The guidelines list 15 categories of goods and services that do not qualify for EIF.)
2. The disability support contributes towards the achievement of outcomes that are identified in a person's individual support plan (ISP) such as participating in education, paid and unpaid work, home and civic life, and in the community through assisting them to carry out their normal daily activities, including communicating, moving about, building relationships, looking after themselves and others, making decisions and finding out about things. (The guidelines list 11 types of outcomes that may be included in a person's ISP.)



3. The disability support is within the scope of relevant Ministry of Health policies and responsibilities. The guidelines list specific policies that may affect what disability supports can be purchased.

*Choice in Community Living (CiCL)* has been run as a demonstration project since mid-2012.<sup>30, 33</sup> Its aim is to 'support people to move out of a residential facility or family home and live independently in their own home in a fiscally neutral way'. The intention is that participants in the CiCL programme will be entitled to the same housing choices as are available to other people (e.g. being an owner or a tenant).<sup>55</sup> Roorda and colleagues<sup>33</sup> reported that participants interviewed had moved from residential or family accommodation, or some other unsustainable living arrangement, into one of several alternative arrangements including private rented accommodation, social housing, units attached to their parents' home, their own home, or a house rented by an extended family member.

Entitlements under the CiCL programme are also governed by the Purchasing Guidelines,<sup>54</sup> regarding which the reviewers of CiCL comment that they 'are not prescriptive, allowing interpretation on a person-by-person basis according to their individual circumstances and goals. This approach is intended to give effect to the principles of the new model, namely, disabled people have increased flexibility, choice and control over the support they buy'.<sup>33(p 28)</sup>

### **Process**

EIF is offered to disabled people who are perceived by the NASC assessor to be able to manage a budget, or who have an agent to do so on their behalf.<sup>33</sup> The Ministry contracts EIF host providers, who provide a mandatory level of service (level 1) which includes:

- working with the disabled person to develop an Individual Service Plan (ISP);
- supporting the person with advice on the management of support staff and budgets;
- receiving from the person information that verifies the delivery of the support services;
- making sure the person is fully informed of their entitlements;
- ensuring that all expenditure is within the purchasing guidelines;
- assisting and coaching the person in managing their funding;
- reviewing how the person is managing, and
- ensuring that appropriate administrative processes are complied with, and that appropriate records are maintained.

The disabled person decides the level of support they want from the EIF host provider. They can choose to self-manage (level 1) or to purchase additional supports from the EIF host, such as monthly statements, payroll services, completion of tax requirements (i.e. PAYE, Accident Compensation Corporation employer levies and KiwiSaver contributions), membership of the Employers' Association, additional budgeting tools, help with recruitment (levels 2 and 3).

The EIF demonstration project has included the trialling of two new processes – supported self-assessment, and local area coordinators (LACs). More information on these two elements is provided in Appendix 6.

*CiCL* is also accessed through the NASC assessor, who works with the applicant and his or her family to see if *CiCL* is appropriate, and then helps the participant through an assessment process to determine the amount of funding he or she will receive. The NASC assessor supplies the participant with a list of support agencies that can help the individual develop a plan and facilitate their move into independent living. The intention is that people 'shop' around for a support agency that works best for them. Once the plan has been signed off by the NASC, the provider helps the participant to make their plan a reality.

### **Scotland**

#### **Scale**

In Scotland, local authorities have the authority to determine what amount a person within their area may receive as a direct payment and for what purposes. Having established 'eligible need' according to national eligibility criteria that determine the level risk, local authorities then work with the person to identify how their needs will be met. 'Agreeing outcomes and choices' is the term used rather than 'entitlement'.

#### **Scope**

Generally speaking, the Self-Directed Support (Scotland) Act 2014 (SDS Act) provides that persons are entitled to receive a direct payment (Option 1 under the SDS Act) to purchase anything that can help to meet their 'eligible need',

provided it supports independent living in the community. The statutory guidance<sup>36</sup> sets some boundaries to the scope of the entitlement:

- Employing a personal assistant (PA) is permitted under Option 1 (direct payments). The statutory guidance outlines how local authorities should develop effective arrangements to ensure that all prospective employers are aware of, and discharge, their responsibilities in relation to safe and effective recruitment (pp. 70–72).
- Employing a family member is also permitted under Option 1, but it is carefully controlled within a clear framework that sets out appropriate and inappropriate circumstances, and the local authority retains the power to either agree or disagree to the arrangement (pp. 72–74).
- Personal and nursing care is deemed to be a form of social care and support, and the supported person is entitled to the full range of choices under the SDS Act (p. 95).
- Residential care is also deemed a social care service and the supported person is entitled to all of the SDS Act options, with the exception of option 1 (direct payment) (p. 94).
- Housing support services are provided to help people live as independently as possible in their own homes. If a local authority concludes that a particular form of housing service falls within the definition of community care services, then the 2013 Act applies, and the supported person is entitled to the full range of choices under the SDS Act (p. 95).
- Equipment and adaptations (including housing adaptations) must meet the assessed needs of the person. Where a direct payment is used to pay for an adaptation or for equipment, ownership and responsibility for arranging maintenance can pass to the supported person. The support planning process should be used to discuss and clarify questions of maintenance, ownership and issues such as the disposal of any equipment after it is no longer required. While there is no specific restriction on the use of direct payments to fund larger-scale adaptations it is a matter for the authority to determine if the relevant support relates to community care support. A direct payment is an alternative means by which to meet assessed social care needs. It is not a substitute for housing improvement grants (pp. 95–96).

## **Process**

### *Eligibility threshold*

While ‘eligible need’ is determined according to a national eligibility framework, entitlement is determined locally, according to the threshold decided by each individual local authority. If a citizen’s needs exceed the locally determined threshold, the local authority is required to provide support. The financial implications of this requirement are noted in the guidance accompanying the legislation.

The setting of the eligibility threshold is a critical decision, with significant service capacity and financial consequences. When determining the threshold, the authority may consider the total available resources it has access to as well as its local service priorities.

When determining eligibility criteria, the authority can take into account its overall resources. However once it has decided that the person’s needs are such that they require provision of services (i.e. are ‘eligible needs’), the authority cannot then refuse to meet those needs due to budgetary constraints.<sup>36</sup> (p. 34)

The government’s guide to the implementation of the legislation notes that local authorities should develop their approach to self-directed support within the context of their wider commissioning strategy and a broader framework of prevention, early intervention, support to carers and universal services. In adopting this type of approach, local authorities are in a position to take into account how a person’s needs and risk might change over time and whether failure to intervene may lead to escalation of need in the future. Moreover, when a person’s needs fall below the threshold, the local authority is also in a position to ensure that appropriate arrangements can be put in place, as the professional is able to direct the person to suitable alternative sources of support, including preventive and universal services.

### *Determining the resources needed*

Having decided that a person meets the eligibility threshold and is entitled to support, the local authority must calculate the resources needed to provide the support: ‘the amount that the local authority considers is a reasonable estimate of the cost of securing the provision of support for the supported person’ (SDS Act: Section 4). The person must be informed of the amount that has been calculated.

### *Support planning*

In line with the principles enshrined in the SDS Act, i.e. collaboration, involvement and informed choice, the local authority works with the person, their carers and support networks to draw up their support plan. This plan sets out the person's desired outcomes, the resources (both financial and non-financial) that will help to meet the outcomes, the choices available for procuring the support, and all associated information.<sup>36(pp. 62–63)</sup>

Noting that additional non-financial assets should be complementary to the provision of funded support and not a replacement for it, the government's statutory guidance clarifies what non-financial assets and resources might be identified in a person's support plan (p. 36):

- the person's attributes and assets (their skills, knowledge, awareness, background, decision-making skills and contacts);
- the person's well-being and inner strength;
- the person's extended family, close friends, work colleagues and community;
- the budget or local authority funding which the person can access so as to meet their eligible needs;
- the professional's knowledge, expertise, background and contacts;
- the local resources, shops, health and education services, community facilities (libraries, sports centres, community hubs etc.), and
- any other sources of information, advice and support available to the supported person.

## 3.5 Conclusions

Three different approaches to legislating for individualised budgets have been discerned across the countries that have been reviewed – legislative frameworks enabling a brand new and ideologically driven policy approach in Australia, England and Scotland; a consolidation of different pieces of relevant legislation in the Netherlands; and an incremental approach within broad legislative parameters found in New Zealand and different provinces of Canada.

In Australia, England and Scotland very recent legislation has grounded disability policy and services on principles of personalisation and self-direction. In each case, this new legislation has shifted the focus from determining the eligibility of the person for support that makes up any deficits due to disability, to determining 'eligible need', i.e. desired outcomes for the achievement of which extra supports are needed. As a result, specific lists of entitlements are not provided; rather, parameters are set including underpinning principles, innovation, i.e. supports provided not just through purchasing of services but through natural (non-monetary) supports and mainstream infrastructure, market development, regulation and maintenance, and monitoring, reporting and review.

In the Netherlands, legislation governing personal budgets is part of the legislative framework governing long-term care, i.e. care for people with physical and developmental disabilities or chronic illness, and the frail elderly. At the time of writing, reform of long-term care is a live issue in the Netherlands, with the most recent legislative changes coming into effect in January 2015. The Dutch government, the municipalities and the health insurer are jointly responsible for long-term care, including personal budgets, and the vast majority of personal budget payments (for personal care and domestic care) are made under the Social Support Act 2015. Personal budgets for elements of long-term care and for nursing care are also covered under the Long-term Care Act and the amended Healthcare Insurance Act, respectively.

In New Zealand, since 2000, legislation, development has been incremental, in response to emerging challenges and policy shifts. In 2002, an 'individualised funding' programme was piloted to provide funding for home care services for people with a disability; in 2010, the government adopted a new 'model for supporting disabled people', in which people with disabilities were to have improved access to information and advice, be allocated funding rather than services (called 'enhanced individualised funding'), and have more choice and control over the support that they could purchase. As part of this new approach, new programmes continue to be piloted and evaluated.

Historically, in Canada, there has been a focus on direct payments for purchasing services costed by the hour, but over since 2006 or thereabouts, disability policy has been evolving and gradually shifting towards a more self-directed care approach. The incremental nature of this development has led to a complicated pattern of different solutions in different provinces, based around three main axes – type of disability, type of need and type of service.

This chapter has also explored eligibility for a needs assessment and entitlements following an assessment. Four key factors are commonly used to determine eligibility for individualised budgets – age, the nature of the disability, the severity of the disability, and the likely trajectory and long-term effects of the disability.

With regard to entitlements following assessment and planning, personal care and home support services are the traditional approach funded through direct payments – found in the IF scheme in New Zealand that commenced in 2003, and the various home care programmes in Canada. The new legislative frameworks that focus on personalisation and self-direction shift from lists of specific services to which people are entitled or not entitled, to requiring that ‘eligible needs’ be met (England) or that ‘reasonable and necessary supports’ be provided (Australia). These broad terms are hedged around by specification of outcomes and underpinning principles and values, the requirement for planning and co-production, regular monitoring and reviewing, in order to ensure that appropriate services are provided. Support for day-to-day living costs not related to the participant’s disability support needs (such as rent, groceries, utility fees) are excluded.

Under the new legislative frameworks, even where a person may not be eligible for support, they may be entitled to information and advice and prevention, as these are regarded as a means of reducing demand or of delaying the emergence of needs that have to be met. Similarly, early intervention is a means of reducing a person’s future needs for supports in relation to disability, and mitigating or alleviating the impact of a person’s impairment on their functional capacity.

## Chapter 4. Limits on expenditure on individualised budgets

### 4.0 Introduction

This chapter addresses the question: ‘Describe expenditure or financial limits set on service provision. In particular, is there an upper limit on the cost or quantum of services provided to eligible people? Are social care services free at the point of delivery or is there cost sharing (e.g. co-payments) or a lower limit (i.e. is the first €x.xx amount of costs excluded, or the first x amount of home help hours)?

Information in relation to upper and lower expenditure limits was found in relation to a limited number of jurisdictions – the provinces of British Columbia and Prince Edward Island in Canada, and England. Information on upper expenditure limits alone was found for Ontario in Canada, and on lower expenditure limits for Scotland. An additional note is included at the end of this chapter regarding the treatment of individualised funding (IF) in relation to tax in New Zealand.

### 4.1 Upper limits

#### Canada

##### ***British Columbia – CLBC***

Under the CLBC programme, the amount of individualised funding allocated to an individual is based on the individual’s disability-related needs, the estimated cost of the needed supports, and the CLBC’s financial resources. The types of supports and services funded by the CLBC are described in the ‘Catalogue of Services’, and cover home activity (i.e. supports for people that allow them to live in a home setting), community inclusion activities (i.e. supports that allow individuals to join in activities in their community and to learn new skills), and family support (e.g. respite care). When the CLBC does not have funding available, requests for new or increased individualised funding are managed and prioritised in accordance with the CLBC Request for Service Policy.<sup>a</sup>

##### ***Prince Edward Island – Disability Support Program (DSP)***

The programme budget is not unlimited and therefore parameters around funding have been established (Disability Support Program 2010e). Overall monthly maximums for the DSP portion of the support plan are determined according to levels of functioning, as listed below:

- 75% or more functioning (high) = \$400/month,
- 51–74% functioning (moderate) = \$800/month,
- 26–50% functioning (low) = \$1,600/month, and
- 25% or less functioning (very low) = \$3,100/month (overall programme funding ceiling).

##### ***Ontario – Passport Program***

In Ontario, the maximum annual funding an individual can receive under the Passport Program, is C\$35,000; there are no caps on the amount for each type of support apart from administration (up to 10% of allocation) and person-directed planning (C\$2,500 annually).

#### England

##### ***Cap on care costs***

From April 2016, it was intended that adults up to the age of 25 would have a zero cap on care costs for life. Everyone else would have a cap of £72,000. In addition, the amount that people of working age outside a care home would be left with after charges was to be increased year on year until it was equalised with the level stipulated for older people. This was to be known as the Minimum Income Guarantee. However, in 2015, the government announced that it was

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<sup>a</sup> The Catalogue of Services and the CLBC Request for Service Policy are both described in CLBC policy documents cited in this evidence review, but the two documents themselves were not found on the official CLBC website.

deferring the introduction of the cap until April 2020. It stated that a decision on the level of the cap would be taken nearer the time of its introduction.

According to Section 28 of the Care Act 2014, progress towards the cap will be based on the costs of meeting a person's 'eligible needs' less any contribution to 'daily living costs' for people in a care home. These care costs will be set out in a person's personal budget (PB) if they are receiving local authority support, or, if they are meeting the costs themselves, their Independent Personal Budget (IPB). An IPB reflects the amount it would cost the local authority to meet a person's eligible care and support needs if it was required to do so.

Daily living costs are for items such as rent, food and utilities, and do not count towards the cap. To ensure fairness between people receiving care in different settings, a person in a care home will continue to contribute towards their daily living costs. As it is often difficult to separate the costs of care and support from daily living costs for a person in a care home, a notional amount for daily living costs (£230 per week) will be set in the regulations.

According to Section 29 of Care Act 2014, everyone will have a Care Account that will be held by the local authority to record their progress towards the cap. It will set out the rate at which a person is progressing and how much they have accrued towards the total. Local authorities will send statements at least annually. When a person reaches the cap, the local authority will have to meet the person's eligible care and support needs over and above the cap. Everyone will continue to be responsible for their daily living costs after they reach the cap.

#### ***Upper limit based on outcomes and value for money, rather than purely financial considerations***

The Care Act 2014 states that the personal budget (PB) must be an amount that is the cost to the local authority of meeting the person's needs, but that consideration should be given as to whether it is sufficient where needs are to be met via direct payments, especially considering the extra costs associated with direct payments such as the legal requirements associated with becoming an employer. While it is not required to provide direct payments when they are more expensive than direct provision by the local authority, Jarrett (2015, 20 May) notes examples given in the statutory guidance of where a PB should be increased to allow services to be purchased through direct payments:

*It may be that by raising the personal budget to allow a direct payment from a particular provider, it is expected to deliver much better outcomes than local authority-delivered care and support, or there may be other dynamics such as the preferred option of reducing the need for travel costs, or out-of-hours care. In addition, efficiencies to the local authority (for example through an individual making their own arrangements) should also be considered. Decisions should therefore be based on outcomes and value for money, rather than purely financially motivated.*

Jarrett goes on to point out that where a direct payment will cost more than is budgeted for in a PB, the statutory guidance advises that the care plan should be reviewed to ensure that it is accurate and that the PB allocation is correct. It may be that the person can take a combination of direct payment and local authority-arranged care and support, or the local authority can work with the person to discuss alternative uses for the PB.

#### **The Netherlands**

##### **WLZ PGB**

The amount of the personal budget should be sufficient to purchase the care needed. The CIZ determines the amount of care needed and for how many hours. The budget is calculated using tariffs set by the Dutch Healthcare Authority (NZa). In 2009, the average PGB was €18,000.<sup>25, 49</sup>

##### **WMO PGB**

Rates vary by municipalities. The budget should be sufficient to buy the necessary support required, as assessed by the municipality. The municipality calculates the budget based on the needs assessment. In addition, the municipality can use a lower hourly rate so that clients can hire a non-professional caregiver (e.g. a relative or carer).<sup>25</sup>

##### **ZVW PGB**

The ZVW PGB has no fixed rates. Health insurers determine the rates themselves, and these are explicit in the insurance policy. Individuals are encouraged to compare rates, and possibly switch to a different insurer.<sup>25</sup>

### ***Jeugdhulp PGB***

Rates vary by municipalities, but the assigned budget should be high enough to purchase the care required by the child (as determined by the needs assessment). The municipality calculates the amount of money required to purchase the support. It may use a lower hourly rate if a non-professional caregiver (e.g. a relative or carer) is being hired.<sup>25</sup>

## **4.2 Lower limits**

### **Canada**

#### ***British Columbia – Choice in Supports for Independent Living (CSIL)***

Recipients of CSIL services pay a daily rate based on their income (and the income of their spouse, if applicable). The daily rate is calculated by multiplying the recipient's 'remaining annual income' (as defined in the Continuing Care Fees Regulation) by 0.00138889. To determine the recipient's monthly contribution, the person's responsible assessor multiplies the daily rate by the number of days on which the person receives CSIL services in a month. The recipient's monthly contribution is deducted from the funding amount he or she receives from the health authority, and the recipient is expected to pay this amount into their CSIL bank account.

If a recipient or their spouse has earned income, he or she is not be charged more than \$300 per month for CSIL services. If payment of the person's assessed daily rate would cause the recipient or their family serious financial hardship, he or she may apply to the health authority for a temporary reduction of the daily rate. Serious financial hardship means that payment of the assessed daily rate would result in the recipient (or their spouse, if applicable) being unable to pay for adequate food, monthly mortgage/rent, sufficient home heat, prescribed medication, or other required prescribed healthcare services.

Recipients are not required to pay a daily rate for CSIL services for the first two weeks of receiving short-term home support services after being discharged from hospital, or if they are eligible for palliative supplies and equipment under the British Columbia Palliative Care Benefits Program. They are also not required to pay a daily rate for CSIL services if they receive one of the following government income benefits: the Guaranteed Income Supplement, the Spouse's Allowance or the Widowed Spouse's Allowance under the Old Age Security Act (Canada); support and shelter allowance under the Employment and Assistance Act or the Employment and Assistance for Persons with Disabilities Act; or a War Veterans Allowance under the War Veterans Allowance Act (Canada).

If a recipient and their spouse are both receiving publicly subsidised home support or CSIL services, they will both be assessed at the full daily rate. However, only one of them will be charged per service day. The monthly rate is recalculated if a recipient's living situation changes for any reason and they are no longer living with their spouse.

#### ***Prince Edward Island – Disability Support Program (DSP)***

The individual and/or family is expected to pay a portion of the cost of the services and supports needed based on their ability to contribute, as outlined in the Funding Sources and Program Rates and Client Contribution policies accessible through the Prince Edward Island Disability Support Program web site. Before determining an applicant's level of contribution for the DSP, eligibility for support, the level of functionality of the applicant, and the net income of all applicable household members must first be established. For a person with a disability, aged between age 18 and 64 years, household income includes the net income of the person and their spouse (by marriage or common law).

The schedule of client contribution as determined by the DSP sets \$2 as a minimum monthly contribution by persons in receipt of provincial Social Assistance, or eligible to receive provincial Social Assistance, and with adjusted net incomes of less than \$11,999. A monthly client contribution of \$7 is required for households with an adjusted net income of less than \$14,000 and not in receipt of provincial Social Assistance. Client contribution amounts increase progressively from a starting point of 2.0% of adjusted net income (based on the middle of the range), for household incomes from \$14,000 to \$15,999, and then increase in increments of 0.25% for each \$2,000 increase in Adjusted Net Income up to \$48,000. At that point, client contribution increments increase by 0.5% for each \$2,000 increase in adjusted net income above \$50,000, up to \$169,999, at which level the client contribution is 100%.

The schedule of client contribution sets a percentage of contribution for technical aids and assistive devices. Client contributions begin at 0.5% for household incomes below \$11,999, and are set at 1% for household incomes between \$12,000 and \$13,999 and increase by a further 1.0% for household incomes from \$14,000 to \$50,000. They then

increase in increments of 2.0% for incomes up to \$80,000. At that point, client contributions increase by increments of 3.0% up to \$169,999, at which level the client contribution is 100%.

DSP participants who have experienced a dramatic income or expense change may request to have their situation reviewed, and income levels adjusted accordingly, before their scheduled review date. Dramatic income or expense change may be defined as applicants beginning to be in receipt of provincial Social Assistance.

## **England**

### ***Charging***

According to the UK's Department of Health *Factsheet 2, The Care Act – who is entitled to public care and support?* some types of care and support are provided free of charge, for example reablement services or equipment and minor modifications to the home.<sup>56</sup> If a local authority believes that a person needs a service for which a charge can be made, it must decide what the person can afford to pay. The rules on how this financial assessment should be carried out are set in the regulations and guidance, so that people's finances are assessed in a consistent and transparent way.

The financial assessment will consider what sources of income a person has and what other assets they hold. There are different rules for the treatment of income, depending on whether the person is expected to need care in a care home, or other settings. In cases where the costs of care would reduce a person's income below a set level, a local authority will pay some of the costs to make sure that the person is left with a minimum level of income. This ensures that people will still receive the care they need in cases where they have only modest resources. In any other cases, the adult can still ask the local authority, regardless of their finances, to arrange their care and support for them. It ensures that people who are uncertain about the system, or lack confidence to arrange their care, do not go without. However, they will still need to pay for their care and support if they have adequate financial resources.

Sometimes, the local authority may only make a small charge for a particular service, and it would not be practical to carry out a detailed financial assessment. In these cases, the local authority may carry out a 'light touch' assessment to determine that the person can afford the charge, and will not need to adhere to every detail of the rules.. In other cases, a person who can afford to pay the full costs of their care may ask the local authority to carry out a 'light touch' financial assessment; for example, if they do not want to undergo the detailed process. If the local authority is satisfied that the person will continue to be able to afford the cost of their care, it may agree to this.

According to *Factsheet 8, The Care Act – the law for carers*, most local authorities do not charge for providing support to carers, in recognition of the valuable contribution that carers make to their local community. However, if a local authority does decide to charge a carer for support provided, it must carry out a financial assessment to decide whether the carer can afford to pay. If supporting a carer involves providing care to the person being cared for, and the local authority chooses to charge for that type of care, then the authority must carry out a financial assessment of the person who is being cared for. This is because the care would be provided directly to that adult, and not to the carer.

### ***Means testing***

Prior to the Care Act 2014, people with capital in excess of the upper limit (£23,250), in some circumstances including the value of their home, were not entitled to financial assistance with social care from their local authority. People whose capital was less than the lower limit (£14,250) received financial support from their local authority towards the cost of social care. Those whose capital fell between the two limits underwent a financial assessment of assets and a charge was made based on what the person could afford to pay.

Under the Care Act 2014, the upper and lower capital limits for means-tested support were to be increased in 2016 so that more people would become eligible for local authority financial support. For care home residents, whose property was included in the means test, the upper capital limit was to increase from £23,250 to £118,000 and to £27,000 for those whose property was not included. The lower limit was to increase to £17,000. However, in 2015 the government announced that it was postponing the new measures until 2020.<sup>57</sup>

## **Scotland**

### ***Charging***

According to Section 14.27 of the statutory guidance on implementing the Self-Directed Support (Scotland) Act 2014, under Section 87 of the Social Work (Scotland) Act 1968, local authorities can require a supported person to pay a



charge towards the cost of any services that meet his or her assessed needs. Historically, charges have tended to be based on service types. However, the statutory guidance goes on to comment:

*Where a supported person's package is predicated on an identified budget, it can be difficult to base any charge on the basis of a service. This requires the consideration of arrangements based on the proportion of the overall budget as opposed to one form of service or another. Local charging policies are a matter for the local authority and should be considered in light of the relevant COSLA [Convention of Scottish Local Authorities] guidance.*

According to Section 8.6 of the statutory guidance, a local authority can arrange for a direct payment to be paid in instalments or in a lump sum payment. Where a person is eligible for a charge towards their support, the direct payment can be made on a 'net' or a 'gross' basis, i.e. the charge can be removed prior to the provision of the monthly direct payment or following the provision of the monthly payment. The supported person may request that a gross payment be made.

According to section 14.28 of the statutory guidance, in 2013 the Scottish government consulted on draft regulations and guidance in relation to charging for a carer's support provided under Section 3 of the 2013 Act. The Scottish government confirmed that it intended to lay down regulations requiring local authorities to waive charges where services are provided to adult carers under section 3(4) of the 2013 Act and where services are provided to children in need (i.e. young carers) under section 22 of the 1995 Act.

### **Means testing**

According to Section 8.6 of the statutory guidance, a local authority may assess a direct payment user's ability to contribute to the cost of securing their support. If the authority decides to carry out such a means test, they must do so before the direct payment is made, or as soon as possible, and no later than one year after the direct payment has been made. If the authority determines the direct payment user's requirement to contribute to the direct payment, and if the means test has happened after the direct payment has been made, the local authority may make arrangements to recover some or part of the direct payment from the direct payment user.

## **4.3 Taxation**

In their evaluation of local area coordinators in New Zealand, Roorda and colleagues<sup>32</sup> reported that when funding for carer support was transferred into the 'enhanced individualised funding' (EIF) scheme, it was treated as taxable income, rather than a subsidy, which disadvantaged the person with the disability in terms of the support that they could access:

*Carer Support (\$76.00 per 8–24 hour period) is regarded as a subsidy and is therefore non-taxable income for the person providing the support. However, when Carer Support is transferred into EIF, the Inland Revenue Department (IRD) recognises it as taxable income. This makes it difficult for disabled people and whānau using EIF to find carer support workers for such a small amount of money. Therefore disabled people and whānau may choose not to take carer support into EIF. (p. 46)*

# Chapter 5. Relationship between individualised budgets and other income supports

## 5.0 Introduction

This chapter addresses the question:

Describe the relationship between individualised or personalised budgets and other income supports (expenditure or financial limits set on service provision). In particular:

- Is there a requirement on the person with a disability to cover the costs of certain items/services from support payments/personalised budgets?
- Is the level of income supports (e.g. social welfare) higher for individuals with disabilities?
- Is a person with a disability provided with income supports in one payment, or are there separate income supports?

The information available on the websites of the various jurisdictions used as case studies in this evidence review does not give any indication as to whether there is, or is not, a requirement on the person with disability to cover the costs of certain items/services from support payments/personalised budgets, or whether the level of income supports (e.g. social welfare) is higher for individuals with disabilities. However, on the relevant Australian and Scottish websites, it is clearly stated that funding provided as part of self-directed care or self-directed support programmes for people with disabilities is viewed as a quite separate and distinct funding stream, supporting needs associated with the disability and not other needs such as day-to-day living costs. The same distinction is made with regard to the administration of the Prince Edward Island Disability Support Program in Canada.

Regarding the third question about combined income supports, a pilot has been completed and evaluated in England, and another pooled funding pilot is under way in New Zealand. Provision is also made for pooled budgets for healthcare and social care in the recent Scottish and English legislation on individualised budgets and self-directed support.

A final note describes recent research in Canada with regard to the equity of service levels for people with developmental disabilities who are served by the CLBC, and people who have similar levels of disability-related needs but who are not eligible for CLBC services because their disability is not a developmental one.

## 5.1 Disability support payments and other income supports

### Australia

The NDIS does not allow the provision of funding and supports relating to day-to-day living costs that are not attributable to a participant's disability support needs. However, the scheme will fund additional living costs that are attributable to the participant's disability support needs, or costs that are ancillary to another funded support, which is funded or provided under the participant's plan. In other words, the scheme will assist where there is a clear connection between the support need and the participant's disabilities (*Supports for Participants Rules*: Paragraph 5.1).

The NDIS will not fund income support, as the intention of the scheme is to complement the social security system for people with disabilities which provide income support. In complementing the social security system, this is a positive engagement with the right to an adequate standard of living and social protection under Article 9 of the International Covenant on Economic, Social and Cultural Rights, Article 26 of the Convention on the Rights of the Child and Article 28 of the Convention on the Rights of Persons with Disabilities (*Supports for Participants Rules*: Paragraph 5.2).<sup>58</sup>

At the same time, Section 4 (14) of the Act provides that: 'People with disability should be supported to receive supports outside the National Disability Insurance Scheme, and be assisted to coordinate these supports with the supports provided under the National Disability Insurance Scheme.'

### Canada – Prince Edward Island

The Prince Edward Island Disability Support Program (DSP) is a social programme with a financial component. The programme offers support planning assistance to help develop a plan of action and to help determine supports that

are necessary. The programme may also provide referrals to other agencies where complementary services may be obtained. The financial component of the DSP is not intended to provide a living allowance, for which other programmes exist, or to duplicate existing funding sources. The financial component of the DSP pertains only to disability-related costs: to fund services and supports necessary to enable an individual with a disability to live as independently as possible or to obtain and maintain competitive employment, or to help a family with extraordinary child-rearing support needs directly related to their child's disability.<sup>59</sup>

### **The Netherlands**

The Dutch personal budget is not considered an income or compensation. For the beneficiary, it is not subject to income tax. Budget holders can have multiple personal budgets i.e. a WLZ PGB and a WMO PGB, in order to support different care needs.<sup>49</sup>

### **Scotland**

The direct payment option under the SDS Act is not a benefit and neither is it a gift. It is a means to meet eligible needs. As such, it should relate to the person's support plan, and should be used in flexible ways that relate to the outcomes set out in the support plan.<sup>36 (Section 8.4)</sup>

## **5.2 Combined payments**

### **England**

#### ***Right to Control pilot scheme***

Through Section 44(1) of the Welfare Reform Act 2009 and the Disabled People's Right to Control (Pilot Scheme) (England) Regulations 2010 (S.I. 2010 No. 2862), the English government put in place a right for disabled people to request choice and control over certain public funding they receive to go about their daily lives and to test the best ways of delivering that right in seven local authority areas in England, known as 'Trailblazers'. The pilot ran from 13 December 2010 to 13 December 2012, with a 12-month extension to 13 December 2013. All disabled people aged 18 years and over who were eligible for certain public funding, including people with learning disabilities and those with mental health support needs, could participate. The funding streams included in the pilot were:

- Access to Work (Department for Work and Pensions);
- Work Choice (Department for Work and Pensions);
- Independent Living Fund (Department for Work and Pensions);
- Disabled Facilities Grant (Department for Communities and Local Government);
- Supporting People – Non-statutory Housing-related Support (Department for Communities and Local Government), and
- Adult Social Care (Department of Health).

The aim of Right to Control was to ensure that disabled people had greater choice and control over the support they needed in order to go about their daily lives. It aimed to shift the balance of power from the State to the individual, by bringing together a number of different funding streams and allowing disabled people choice and control over how funding for them was used to provide the care, support (including employment support) and equipment they needed; and to test the costs and benefits to public authorities. In particular, Right to Control ensured that, for certain public funding streams, disabled people would have a right to:

- be told the monetary value of resources available to them;
- have choice and control over how resources were used to meet agreed outcomes;
- continue to receive the same support;
- ask a public body to arrange new support;
- receive a direct payment and buy their own support, and
- have a mix of these arrangements.

In an evaluation of the 'Right to Control Trailblazers', a synthesis of evaluations conducted by MORI, Bryson Purdon Social Partners and Matrix Knowledge on behalf of the Office for Disability Issues (ODI) 'did not find any evidence of the Right to Control having a significant positive impact on customers, both overall and by subgroup'. Potential explanations for this were that customers were not following the intended 'Right to Control customer journey' and

provider markets were not yet sufficiently developed to offer meaningful choice. The success of the Trailblazers initiative depended on a considerable culture change among staff, customers and providers which didn't materialise in the short time frame of the pilot.

The total economic cost of the pilot was £10.1 million, or £213 per customer, with an expectation that the annual cost, if rolled out across England would be £60 million, with a possible range of between £30 million and £120 million depending on factors such as the population covered and the delivery model. These estimates cover the period from the launch of the initiative in December 2010 to December 2012. The pilot was further extended until December 2013 to allow more time for the government to consider the evaluation findings.

Set-up costs amounted to 32% of the total and 50% to costs associated with ongoing training and promotion, and the remaining 18% to direct costs of dealing with customers. If Trailblazers continued, set-up costs would gradually become smaller. There was considerable variation across geographical locations, with the cost per person ranging from £125 to £538.

Impact analysis was carried out to look at the initiative's effect on quality of life and employment. It used a Social Care Quality-Adjusted Life Years (CALYs) level of 0.71 (the measured level before Right to Control) for each year of life, and assumed a monetary value of £20,000 per CALY. This value is based on the National Institute of Health and Care Excellence (NICE), Quality-Adjusted Life Years (QALY), also valued at £20,000. A CALY is a measure of quality of life where 0 measures no quality and 1 is a year of perfect quality of life. Quality of life, based on these assumptions, would need to increase by 1.5% or 0.011 CALYs in order for Right to Control to break even. Analysis showed that the improvement in quality of life was below 5% for those in the scheme.

Employment analysis was undertaken for those under 65 years of age. Prior to the initiative, employment was 16.2%, with an annual average salary of £17,634. In order to outweigh the total cost of Right to Control, employment would need to improve to an equivalent of 570 additional customers becoming employed, or an increase of 16.22%. In reality, the percentage increase in the employment rate required for the scheme was below 8%.

A measure of well-being found no significant difference between the Trailblazer group and a matched comparison group. Similar results were found for 'impact on quality of daily life'.

Following the evaluation, the Minister of State at the Department for Work and Pensions, Mark Harper MP, outlined the government's decision:

*...While the evaluation of this pilot may not have resulted in any measurable impact on outcomes, it was popular with those individuals who exercised their right to control and they valued the greater flexibilities it gave them. It also acted as a catalyst to developing local relationships and partnerships.*

*Since the Right to Control pilot began in 2010, developments in Government policy have increasingly recognised the importance of personalisation in the delivery of services. The Care Act 2014 enables greater choice and control for the individual in adult social care and also provides co-operation duties to support partnership working and the flexibility needed to maintain right to control-style approaches at local level. We are in the process of introducing personalisation within the context of the disability and health employment strategy [Department of Work and Pensions, 2013 and 2014], to develop a more personalised approach to delivering employment support for disabled people.*

*Taking these changes into consideration together with the evaluation findings of the Right to Control pilot, the Government have decided not to roll out the Right to Control nationally.<sup>60</sup>*

### **Personal, personal health and individual budgets and direct payments and their relation to other public funding sources**

A 'personal budget' (PB) is the amount of money a local authority allocates for a person's care, based on its assessment of the person's need. A 'personal health budget' is for an individual's NHS healthcare and support needs. An 'individual budget' includes an individual's social care and support needs plus other funding, such as independent living. A 'direct payment' is one way of managing these budgets, where the individual receives cash with which to buy the agreed care and support.

According to Section 26 of the Care Act 2014, a personal budget for an adult must specify not only the cost to a local authority of meeting an adult's eligible needs, and the amount which, on the basis of the financial assessment, the adult may be required to pay, but also any other amounts of public money that are available to the adult including, for example, amounts available for spending on matters relating to housing, healthcare or welfare.

The Care and Support (Personal Budget: Exclusion of Costs) Regulations 2014 provide that where intermediate and reablement support services, which have the purpose of assisting/enabling an adult to maintain or regain the ability needed to live independently in their own home, and are for a specified period of time, these costs must be excluded from the adult's personal budget if the local authority is not permitted to make such a charge for providing the services by regulations under Section 14 of the Care Act 2014.

While a personal budget is for an individual's social care and support needs, a personal health budget is for their healthcare and support needs; it works in a similar way to the personal budget. It is planned and agreed between the individual and their local NHS team. The aim is to give people with long-term conditions and disabilities greater choice and control over the healthcare and support they receive. Together with their NHS team (such as a GP) the individual develops a care plan, which sets out their personal health and well-being needs, the health outcomes they want to achieve, the amount of money in the budget, and how they are going to spend it. A personal health budget can be used to pay for a wide range of items and services, including therapies, personal care and equipment. It can be managed in three ways or a combination of them:

1. A notional budget, whereby no money changes hands. Having established how much money is available, the individual and their NHS team together decide on how to spend that money, and the NHS team arrange the agreed care and support.
2. A real budget held by a third party, an organisation legally independent of both the individual and the NHS, holds the money and pays for the care and support agreed in the care plan.
3. A direct payment for healthcare, whereby the individual gets the cash to buy the care and support which they and their NHS team have decided they need. They have to show what they have spent the money on, but the individual, or their representative, buys and manage services themselves.

The NHS team will periodically review an individual's care plan with the person.

Regulation 10 of the Care and Support (Direct Payments) Regulations 2014, regarding harmonisation of direct payments with payments made under other legislation, states that where a direct payment is made for an adult for whom direct payments are also made under the National Health Service Act 2006, the local authority must take reasonable steps to coordinate the systems, processes and requirements which it applies or imposes in relation to the direct payment with those that apply in relation to the payments made under the NHS Act 2006, with a view to minimising the administrative or other burdens which they place on the adult for whom, or the nominated or authorised person to whom, the local authority makes the direct payment.

Regulation 11 applies the Care Act (Direct Payments) Regulations 2014, with modifications, to cases where a direct payment is made under Section 117 (After Care) of the Mental Health Act 1983.

## **New Zealand**

As well as the Ministry of Health's New Model for Supporting Disabled People, which has included piloting local area coordination, supported self-assessment, enhanced individualised funding and choice in community living (see Appendix 5: New Zealand for details of these pilots), the Disability Support Services in New Zealand's Ministry of Health are participating in a three-year demonstration project, established in 2013 – Enabling Good Lives (EGL). This demonstration project is aimed at exploring how to blend different funding schemes in order to offer greater choice and control over the support that disabled people receive and the lives they lead.<sup>55, 61</sup>

*Enabling Good Lives (EGL) is a broader initiative involving the Ministries of Education, Health and Social Development. There are two three-year EGL demonstrations – one in Christchurch and one in Waikato. The demonstrations pool government funding and resources to provide disabled people with the freedom and support to plan their own good life and fund it from one personal budget. The Ministries have jointly designed*

*the project alongside disabled people, families and service providers. ACC (Accident Compensation Corporation) is also supporting the approach. The demonstration in Christchurch initially focused on school leavers with high disability support needs. It will expand over its demonstration period. The Waikato demonstration is currently in the planning phase.*<sup>62 (p. 10)</sup>

Evaluation of the demonstration is being undertaken jointly by the three Ministries, and includes annual formative assessments that will be followed by a summative evaluation after three years. The first formative assessment of the EGL Christchurch demonstration project has been published.<sup>63</sup> It focused on understanding how the project was being implemented and was intended to inform the next stage of the demonstration design. The evaluation found that there had been some early positive outcomes from the EGL demonstration project, despite a problematic implementation. The key mechanisms to be implemented as part of the project were co-design, planning and facilitation using navigators, funding for individuals that is pooled and portable, and provider, school and community development. Having considered this evaluation report, the government decided that in 2015 the demonstration would focus on developing, testing and implementing the 'highest priority new components of the EGL approach', including:

- further development of the new funding allocation tool based on the New Model work in the Bay of Plenty (i.e. enhanced individualised funding) that can be extended to include vocational and educational support needs;
- identifying alternative purchasing options for participants; and
- ensuring financial sustainability.<sup>55 (Para. 22)</sup>

## **Scotland**

### ***Joint assessment and delegated assessment***

This account of joint working between local authorities and the NHS in Scotland, and how budgets for shared healthcare and social care needs may be combined, is based on Section 13 of the statutory guidance on the SDS Act, titled 'Social Care and SDS – the Role of the NHS'. The relevant health professionals and/or senior managers can contribute their professional healthcare expertise to a single assessment and support plan, and where the supported person receives both health and social care, the NHS professionals and/or senior managers can arrange for the transfer of funding from the NHS Board to the local authority, in order to fund the relevant health outcomes within the person's joint plan. The funding can then be directed by the supported person under the four options laid out in the SDS Act.

Where the social care assessment function is delegated to the NHS, all of the legal powers and duties associated with that assessment will transfer to the NHS professional. The NHS Board must comply with this duty to assess and to meet the person's assessed needs under Section 12A of the Social Work (Scotland) Act 1968 or Section 22 of the Children (Scotland) Act 1995. It must offer the various choices to the supported person as defined by the SDS Act and it must 'give effect' to the supported person's choice. In addition, the relevant healthcare professional should discharge the relevant social care duties in line with this guidance.

### ***Joint funding***

The Public Bodies (Joint Working) (Scotland) Act 2014 retains and updates the powers provided by the Community Care (Joint Working etc.) (Scotland) Regulations 2002 (SSI 2002 No.533) ('the 2002 Regulations'). The 2002 regulations enable local authorities and health boards to transfer funding to each other. This flexibility applies to 'high-level' strategic budgets and at the micro level of the individual supported person.

Once a decision has been taken to pool budgets, consideration must be given as to who will take responsibility for this jointly funded agreement. The combined funding pot can be released in a variety of ways. Some possible scenarios are provided below:

- *Option 1:* Funding to address health needs is added to funding from the local authority. It is then released to the supported person as a jointly funded direct payment. The payment can be used to employ one or more personal assistants (PAs) to support their employer to achieve their health and social care outcomes. The PA is provided with the necessary training by health care professionals to deliver certain health interventions where they have demonstrated competence; this will be reviewed regularly by the relevant health team to ensure the duty of care placed on them continues to be met.

- *Option 2:* Health funding is added to a virtual budget in the form of an individual service fund; the budget is then released to a provider by the local authority. The budget can be used to purchase support from an agency with staff trained to assist with healthcare tasks that may otherwise have been provided by the NHS. The relevant healthcare professionals must be assured that the staff provided by the agency are sufficiently trained and are competent to meet the health needs of the supported person.
- *Option 3:* The relevant health and social care professionals work together to arrange a package of services on behalf of the supported person. The services may be provided by the local authority, a third sector or private sector provider, or by the NHS.

The Public Bodies (Joint Working) (Scotland) Act 2014 requires NHS boards and councils to establish new health and social care partnerships. Under these arrangements, NHS boards and councils are required, as a minimum, to combine their budgets for adult social care, adult primary healthcare and aspects of adult secondary healthcare. Although the SDS Act does not apply directly to health services, the SDS policy will have implications for health because NHS boards and councils will share money, staff and other resources under the new arrangements. For example, councils can charge people for some social care services, whereas NHS services are free at the point of contact.<sup>64</sup> (p. 20)

### 5.3 Equity of service levels

Under the CLBC programme, a key question is the equity of service levels for people with developmental disabilities who are served by the CLBC, and people who have similar levels of disability-related challenges but are not eligible for CLBC services because they have disabilities other than a developmental disability. A first step in bringing greater service-level equity across disability categories (so that services are based on need, not category or diagnosis), is to identify how service levels differ.<sup>65</sup>

Table 9 summarises the amount a CLBC client may receive on an annual basis on Disability Assistance (DA) and off DA, compared with the amount a person with a disability (PWD) who is not CLBC eligible receives. While there are strong caveats to these data, initial analysis suggests that CLBC clients are supported at a much higher level than are people who have disabilities other than a developmental disability.

**Table 9: Estimate of service levels for CLBC clients compared with people who have other disabilities**

Supports	CLBC	CLBC on Disability Assistance (DA)	Person with a disability (PWD)
CLBC services*	\$48,800	\$48,800	\$0
Disability Assistance (DA)**	\$0	\$10,872	\$10,872
Additional benefits***	\$0	\$2,026	\$2,026
Supplementary assistance****	\$0	Varies	Varies
<b>Total</b>	<b>\$48,800</b>	<b>\$61,698 +</b>	<b>\$12,898 +</b>

Source: Queenswood Consulting Group (2011) Review of Community Living BC Efficacy and Progress to 2011. [http://momsnetwork.ca/wp-content/uploads/2012/01/Queenswood\\_CLBC\\_Review\\_FINAL.pdf](http://momsnetwork.ca/wp-content/uploads/2012/01/Queenswood_CLBC_Review_FINAL.pdf)<sup>65</sup>

\* Indicates the average cost per client for all CLBC services. This amount could not be separated by CLBC clients of Disability Assistance versus those who are not on Disability Assistance.

\*\*Indicates the maximum annual rate for a single person with a disability (PWD), assuming full support and shelter and no deductions. Actual amounts will vary, depending on family size, shelter costs, and income.

\*\*\*Includes Community Volunteer Supplement (\$1,200), Bus Pass and Special Transportation Subsidy (\$790.56), and Christmas Supplement (\$35). This is a maximum, and not all PWD clients receive all these benefits.

\*\*\*\* Includes additional allowances (e.g. nutritional supplement, diet), medical equipment, medical supplies, dental and optical. The amount spent on Supplementary Assistance varies by client – not all clients receive all or any of these benefits.

The level of financial support is one indicator of service equity. However, the report by Queenswood Consulting Group pointed out that people with disabilities may not use disability support services because they do not need them, or because they are unable to access them for a variety of reasons.<sup>65</sup> Another consideration is whether or not people are receiving all the help they need, or whether they have support needs that are not being met. People with developmental disabilities have reported average amounts of access to help, with just under half (49%) reporting receiving all the help they needed. Although these data are for Canada, it suggests that across disability types and at a very broad level, people with disabilities have generally comparable access to the help they need, with learning, memory and psychological disabilities reporting the highest levels of unmet need.

According to the authors of the report, much work remains to be done in order to fully understand the differences between services provided to CLBC clients versus people with other disabilities but similar levels of need. Initial indications, however, suggest that there are significant inequities in the amount of funding that is available between these groups and that those with developmental disabilities feel relatively more well-served than those in other disability groups.



## Chapter 6. Evidence on the financial sustainability of different approaches in other jurisdictions

### 6.0 Introduction

This chapter addresses the question: ‘What is the evidence on the financial sustainability of different approaches to personal budgets in other jurisdictions and, in particular, the effects of eligibility and entitlement requirements on the financial sustainability of the approach at national level?’

Personal budgets are an international trend, with European countries, the US and Canada experimenting with some form of IF.<sup>66</sup> Australia and New Zealand are also experimenting with approaches to personalising the provision of supports for people with disabilities. In five of the six countries reviewed in the previous chapters, the personal budget schemes have all been introduced or completely revised in the period 2013–2016. The introduction of personal budgets is still very much a ‘work in progress’. As a result, there are almost no data on which to build an evidence base regarding the financial sustainability or otherwise of personal or individualised budgets for people with disabilities. In the final section of this chapter, some preliminary evaluated evidence from Australia, British Columbia in Canada and New Zealand is presented.

Some constraints on interpreting the evidence regarding financial sustainability are noted here.

#### Diversity of health systems

The problem with making any comparable evaluation between individualised budget schemes in different countries, either in health or social services, is that the context and system in each country is different. Also, the way schemes within individual countries are administered often means that there are huge disparities between the individual local authorities within each country.

In addition, different economic models underpin the provision of services. These models sometimes serve to shape the policy direction and the way plans are implemented. The Beveridge model envisaged a universal entitlement to services paid for from general taxation, whereas funding health services under the Bismarck model is provided through the payment of an employment or pensions-related health insurance. In the United States, there are limited government-supplied services, and the majority of services are provided by private suppliers and are funded by private insurance.

The introduction of reform or new initiatives can be driven by the recognition of unmet needs, by fashion and international trends, by ideology or by budgetary constraints.<sup>12, 67–70</sup>

Economic evaluation is used to convert observed improvements in the quality of life scales into monetary values such as The Adult Social Care Outcomes Toolkit (ASCOT), which measures social care-related quality of life, and EQ-5D, which measures healthcare-related quality of life. These are compared with the perceived costs involved to see if value for money is being achieved. Transaction costs, such as costs of implementation and the costs of commissioning and arranging services, are almost never fully accounted for in healthcare cost estimations.<sup>13</sup>

#### Health vis-à-vis social services

In some countries a distinction is drawn between what is healthcare and what is social care. For example, in England and Scotland healthcare is largely commissioned by the National Health Service (NHS) and social services are commissioned by local authorities and may be provided by a variety of different agents. In other countries there can be quite a blurred distinction between the two, with social services being administered through the health budget and the health system.

Although it may be tempting to make comparisons to identify best practice, health and social services are, as Saltman<sup>71</sup> writes, ‘deeply embedded within the social and cultural fabric of each society, and thereby defy simple economic or financial characterization’. Nevertheless, it is useful to make some comparisons, so that we can make limited judgements as to what has been perceived to have been successful from the point of view of financial sustainability and the effects of eligibility and entitlement requirements on financial sustainability. Moreover, many of the issues

involved in the setting up of personal or individualised budgets are common to both the health and social service systems. Although there is a clear distinction between 'health' and 'social services' in Scotland, Humphries notes that:

*'There needs to be fresh debate about the options for funding the quantity and quality of care we will demand in the future and about ways of overcoming the dividing lines between how healthcare and social care are paid for'.<sup>72</sup>*

### **The language of personalisation**

A study conducted by the Social Care Institute for Excellence (SCIE) in the UK found that the term personalisation (or individualisation) was devoid of clear meaning and adopted many different meanings when put into practice. In some cases, it was characterised as a means of transferring risk and responsibility away from the State. In others, it was promoted as a new model of social citizenship. It goes on to note that:

*'...most literature describes the theory and practice of personalisation, with many case studies and qualitative insights into the benefits; there is an overwhelming lack of long-term, reflective or quantitative evaluations or economic analyses.'<sup>73</sup>*

The vision and values of personalisation have been confused with the delivery method. Evaluation results in less than comprehensive results, particularly with regard to how it affects the different sub-groups within a personal or individualised budget community. Most importantly, there is virtually no economic analysis that could make meaningful comparisons between the adoption of individual budgets and the position which pertained before their implementation up to now. Future planning will require built-in systems of economic sustainability and acceptance by the taxpayer. Such studies as have been carried out suggest that:

*'virtually every analogous scheme in the EU has been based on an underestimate of costs, at least partly due to unpredicted demand and previously undetected or unmet needs'<sup>73</sup>*

Slasberg *et al.*<sup>74</sup> suggest that the model in the British system, initiated by the organisation In Control was implemented before it was fully tested or evaluated. They further state that early warnings were discernible from an evaluation of the individual budget pilots, in that estimated costs were speculative and there were a great number of different approaches and arrangements with different authorities.<sup>67</sup> These included the growth in the bureaucratic process and the problem of the initial upfront allocations not meeting the person's needs. They suggest that the delivery of personal budgets is possible if the relationship between resources and needs are successfully addressed.

### **Choice or savings?**

Those promoting change put emphasis on the availability of choice, giving people greater autonomy and the pursuit of a wider government policy, but some incentive for the pursuit of the policy can be traced to the aim of making savings in government expenditure. If all the aims can be accommodated, this would be a significant achievement. However, we must suspect that there is nearly always a trade-off between the quality of service and the budget that sustains it. Perceived savings may be the result of shifting cost centres. Although the original motivation for personal or individualised budgets was driven by disabled rights groups in order to give disabled people more control over their lives,<sup>66</sup> the effect of policy change on government financial resources cannot be overlooked. However, there is some emphasis in the literature on the aim of making savings in government expenditure.<sup>13 66, 67, 75</sup>

### **Eligibility and entitlement**

Eligibility criteria are the conditions that people need to fulfil in order to be entitled to be chosen to benefit from a scheme, in this case personal or individualised budgets. Narrowing eligibility criteria can help to keep control of the budgets, but result in limiting the number of clients who can avail of a service and/or limiting the range of services available to clients, whereas the broadening eligibility criteria has the opposite effect. Entitlement refers to the needs-based funding entitlement allocated to buy services.

In the Canadian province of British Columbia, a series of legal decisions led to the broadening of eligibility criteria for personal or individualised budgets. The broader eligibility criteria, combined with less available funds, higher labour cost and the rising expectation of service users, gave rise to considerable stress on the system. This led to a re-evaluation of the system for those with developmental disabilities.<sup>76</sup>

The Netherlands introduced personal (or individualised) budgets in 1997. Over the years, the profile of those who held personal budgets changed, with a large number of children and adolescents with learning difficulties becoming eligible.<sup>77</sup> Many of these children would have received informal (unpaid) care in the past. The increased cost caused the government to suspend all new applications in 2010 and put those seeking individual budgets on a waiting list.<sup>77</sup> As a result of this major change, unmet needs and increased costs were two of the legitimate issues that arose; however, the issue of fraud also arose. The frauds were not large in terms of total revenue, but were sufficiently newsworthy to stimulate public debate on the matter. Eligibility was not policed in a rigorous fashion, and information on the agencies that brokered arrangements between patients and service providers also emerged. To combat these issues, new regulations were introduced; these regulations restricted access or entitlement to the scheme to people who would otherwise have to have to be admitted a nursing home. Government estimates suggested that this would comprise only 10% of current individual budget holders. Since 2010, budget holders are required to hold a separate bank account to deal with their budget; in addition, specialised brokering agencies are no longer allowed to operate.<sup>77</sup>

## 6.1 Start-up costs and informal costs

A number of studies have pointed to the fact that start-up costs for personal or individualised budgets have rarely been fully accounted for in costings. Start-up costs, together with the unpaid care provided by families and out-of-pocket expenses in traditional care have, in many cases been underestimated. Almost all schemes in the EU have underestimated the costs of implementation and this has been partially due to a failure to realise the level of demand, due to the cost borne by families or paid for from other income.<sup>78,79, 80 (cited in 50)</sup>

Individual budgets will differ from those in place to deliver conventional care. There is a danger that rather than making the transition from one system to another, the new system may be added on to the old one. This results in double running costs. Therefore, it is critical to have the infrastructure in place and to use a strategic and phased approach to the introduction of such a scheme.<sup>81</sup>

## 6.2 Costs and welfare

Is it possible to introduce individualised budgets, improving choice and control for the patient and ensure that it is cost neutral? The argument in favour of personal or individualised budgets was originally from the viewpoint of the disabled, and some argued that it would simultaneously increase welfare and save money (Slasberg *et al.* 2012, Dickinson and Glasby 2010).<sup>74, 66</sup> Glendinning *et al.*<sup>7</sup> measured quality of life (ASCOT) against costs in order to determine cost-effectiveness. They used 268 records of people with individualised budgets compared with those receiving conventional support. The overall weekly social care cost for those with individualised budgets was £279 and the comparison group was £296. The difference is not large and the authors make the point that there may be hidden (transactional) costs in the calculation of individualised budgets not taken into account, and that this is likely to add considerably to the costs of introducing individualised budgets. Transaction costs again come into the frame in the individualised budgets calculation. When it came to healthcare, the individualised budgets cost significantly more than the conventional support: £83 per week against £59. There is a suggestion that higher costs may be related to lack of experience and a steep learning curve on the part of those managing the system. Much of Glendinning *et al.*'s research was carried out at a time when local authorities were still in a learning process with regard to individualised budgets, and therefore longer-term comparisons could not be made. This learning process gave rise to a lot more interaction between care managers and people opting for individualised budgets. Jones *et al.* (2012) suggest that individualised budgets were found to be cost neutral, compared with conventional social care delivery in a randomised controlled trial involving 959 service users.

## 6.3 Procurement

The UK Audit Commission identifies key financial risks in introducing individualised budgets for health, which particularly impact on the supply side and the effects of changing patterns of procurement. These include: double running costs, existing unmet need, infrastructure and working with the provider market (Audit Commission UK 2014). When changing the way things are done, or care pathways, there is likely to be a period when there is an overlap of services.<sup>81</sup> Individuals who have choice and control may make choices that are not traditionally supplied, or they may use a service provider who does not have a contract with the authorities. Staff dealing with a dual system may find that their workload reduces or increases, and either more staff or fewer staff may need to be employed in order to deal with the situation.<sup>82</sup>

Allowing personal choice may give rise to increasing popularity of some services and reduction in demand for others. This may contribute to financial risk for the service providers. As the numbers of people with individual budgets increases, providers may be left with sunk costs (i.e. costs that have already been incurred where there is no retrievable value) for services that are not in demand. Competition between private suppliers may result in cherry picking and may leave the State to provide the uneconomic service which the market will not support.

In Scotland, individualised budgets are referred to as self-directed support. In anticipating the introduction of SDS, both for health and social services, there was a perceived danger of a 'two-tier' care workforce emerging, with patients employing personal assistants (PAs) who might be unregulated and unprotected, but cheaper than regulated and protected workers, and therefore more expensive than staff employed by the local authorities or care agencies. They also found that for local authorities anticipating the full cost of SDS would prove difficult to measure and predict. They conclude with the surprising statement:

*'Given the potential for increased empowerment, choice and control for users and family carers, that "leap of faith" will, hopefully, prove justified'.<sup>83</sup>*

Individual health budgets may lead to increased health spending as patients may use some of their individualised budget to pay for things they may have paid for 'out-of-pocket' previously.<sup>12, 77</sup> Similarly, carers, who are family members, giving care without charge may be displaced by professionals who are paid. Indeed, paid carers and social workers have seen individualised budgets as a threat. They report that if individualisation is adopted as a means of introducing quasi-markets, the privatisation of services, competition and 'efficiencies' may force wages down and displace jobs in that sector.<sup>82</sup>

## 6.4 Cost-effectiveness

For cost-effectiveness, Glendinning *et al.*<sup>67</sup> used the Incremental Cost Effectiveness Ratio (ICER) to examine the differences in outcomes after six months in a number of user groups. The ultimate conclusion is that better outcomes are achieved at a higher cost. The authors state that savings can be made, but at the cost of lower quality of care. The question that arises is: Is the higher cost worth the expense? The authors conclude that individualised budgets are cost-effective, although the pattern of cost-effectiveness varies between four sub-sections of people with disabilities – people with physical disability, learning difficulty, mental health and older people. Outcome gains were noticeable for people with mental health problems and for younger people (aged 18–30) with a physical disability. The evidence for people with learning difficulties was not strong, and there was no evidence of cost-effectiveness for older people. Overall, they come down cautiously on the side of the introduction of individualised budgets. They also point to differences in social care costs and healthcare costs, noting that healthcare costs were higher for the people who had individualised budgets, whereas social care costs were the same for both groups.

Schemes which aim to improve the lives of people with disability will be universally welcomed, but it is essential that the financial arrangements which underpin them are robust (affordable now and into the future).<sup>84</sup> Expectation that required care in the future will be honoured, and that the taxpayer will be happy to subscribe, is dependent on such economic sustainability.<sup>84</sup> To achieve this, governments need to coordinate care resources and set eligibility criteria to deliver the appropriate level of service to a variety of different categories of people.<sup>84</sup> According to Glendinning,<sup>84</sup> the most efficient and sustainable way to fund such schemes is in maximum pooling of resources in the universalist tradition. There must also be a cap on how much funding any individual can receive. For example, Germany's long-term care insurance has a fixed maximum which can only be altered by legislation at a federal level. In countries where cutbacks have been enforced in this area, the risk is that wages will drop in the care sector and the workforce will comprise 'grey' labour, unregulated, unskilled and usually immigrant workers.<sup>84</sup>

Quality of life is expressed in monetary terms by applying 'willingness to pay' (WTP) thresholds to quality of life indicators. If an intervention improves a person's quality of life from being no better than being dead to full health in a year, the value of this improvement in monetary terms is between £20,000 and £30,000, according to the UK's National Institute for Health and Clinical Excellence (NICE). Willingness to pay multiplied by quality of life level less the cost of the services used equals the net quality of life. Jones *et al.*<sup>85</sup> used 'willingness to pay' measures to compare a cohort of individual health budget (IHB) group to a control group in order to estimate whether the IHB group was more cost-effective than conventional service delivery. They found in favour of IHBs and say that this finding provides support for the further implementation of such budgets.

Both the IHB group and the control group comprised 1,000 individuals. The IHB group demonstrated greater benefit (quality of life) at less cost, on average, than the control group. Net quality of life benefit was between £1,520 and £2,690 greater for the IHB group than for the control group.

## 6.5 Value for money

From a financial sustainability standpoint open-ended budgets are difficult to justify. The experience in the Netherlands shows that a very liberal approach to eligibility for personal or individualised budgets gave rise to increasing expectations and created new demand. It is also notable that better educated, higher income budget holders, or their parents, were well placed to navigate around complicated regulations in the Netherlands.<sup>77</sup>

Patient satisfaction, well-being, and quality of life are constant positive outcomes of individualised budget evaluations, although measurement of these is often subjective.<sup>12</sup> It is difficult to evaluate the cost or value for money of these budgets given the paucity of expected outcomes, dearth of financial information and lack of accurate costings available (Health Foundation 2010). Gadsby states:

*‘The paper examines the motivating factors behind personal budget schemes in light of this evidence. It concludes that there is little in the evidence to suggest that international governments’ expectations for personal budget programmes are well-founded.’<sup>12</sup>*

According to Gadsby *et al.* there is some evidence of increased satisfaction and well-being, in the short term, among budget holders, but no evidence of better health per se. It must be acknowledged that increased satisfaction and well-being are in themselves a health benefit. If individualised budgets result in some cost saving on a personal level, this may be the result of lower quality or standards, as has been observed in other countries.<sup>84</sup> The level of control that individual budget holders have over their individualised budget varies greatly between different programmes and also within programmes, depending on the person’s level of independence. The availability of choice should be a positive thing, but the exercise of choice can lead to apprehension and worry. Choice would suggest a greater availability of services, but the proliferation of services does not necessarily mean an increase in quality.<sup>76</sup> Choice emphasises the individual’s preferences, but this is not to say that they are necessarily cost-effective or that they represent the best use of resources needed for themselves or for society as a whole.

## 6.6 Case histories

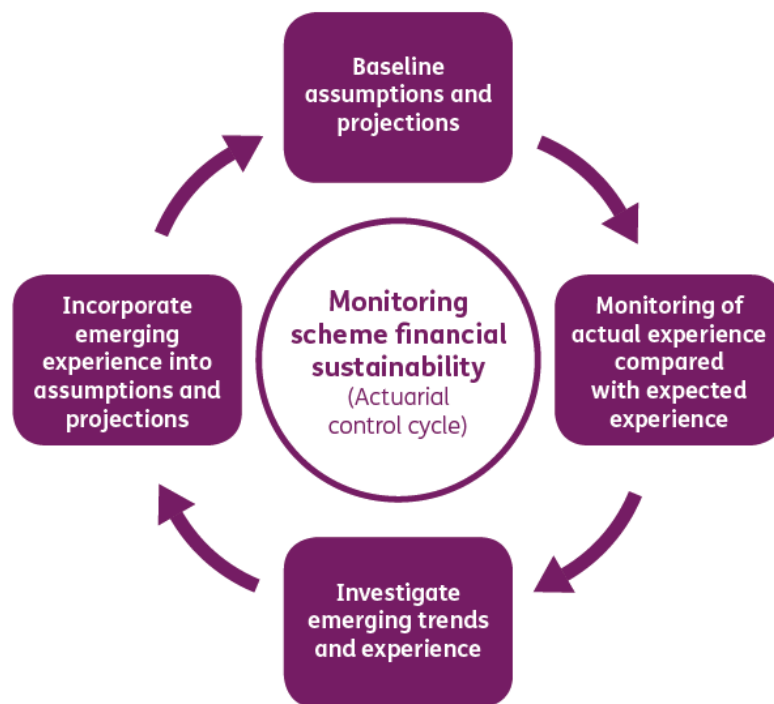
The following case histories present work completed on financial sustainability and work required to build the evidence base in the future.

### Australia

Australia’s National Disability Insurance Agency (NDIA), established in 2013, was designed to streamline supports for people with disabilities which previously had been administered by the Commonwealth, States and Territories. It was designed, and is governed, using insurance principles. Having completed its first year, the NDIA reported that the scheme was successful and financially sustainable:

*The scheme is successful on the balance of objective measures and projections of economic and social participation and independence, and on participants’ views that they are getting enough money to buy enough goods and services to allow them reasonable access to life opportunities – that is, reasonable and necessary supports.*

*Contributing governments think that the cost is and will continue to be affordable, is under control, represents value for money and, therefore, remain willing to contribute.<sup>39</sup>*



**Figure 2: Framework for monitoring financial sustainability**

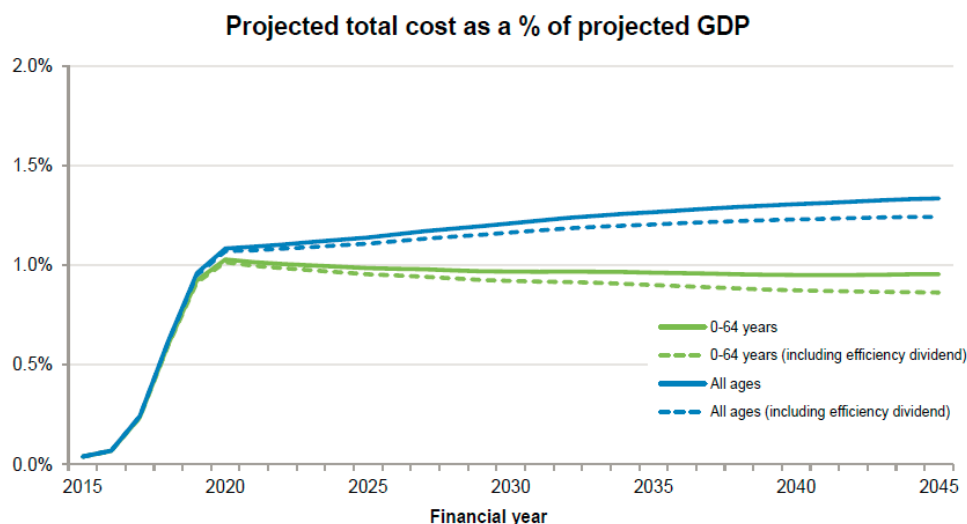
Source: National Disability Insurance Agency<sup>86</sup>

To achieve financial sustainability, the agency engages in continuous monitoring and evaluation of its outcomes and costs monitoring, comparing actual experience with expectations. This involves collecting data on the number of participants, their characteristics (to allow analysis of reference groups), the outcomes for these participants, and the cost of supports provided to them. This gives, or is expected to give, an understanding of variations between actual and expected experience, and can identify cost drivers. This information can be used to make changes where necessary to ensure that the scheme remains financially sustainable. The NDIA identified factors which contribute to these variations as the cost of support, characteristics of participants, geography, availability of support, service providers, and family and friends. As of June 2015, following two years of operation, 22,516 people applied for the scheme, 19,817 (88%) were eligible and 17,303 (77%) were given an approved plan.<sup>86</sup>

To project its financial sustainability into the future a number of assumptions were required, which included:

- incidence of disability by age;
- rates of exit from the scheme, both through mortality, increasing morbidity and recovery;
- ageing in the scheme;
- package costs over the participant's lifetime;
- inflation;
- estimates of the impact of accident compensation schemes (other possible source of income);
- operating costs (transactional costs).

The 25-year projections as a percentage of gross domestic product (GDP) are presented in Figure 3. The scheme will be fully operational in 2019/20 and projections were estimated for 25 years after that. For example, the number of people aged over 65 years will comprise a far greater proportion of the participants in 2044/45 than in 2019/20, and so the cost of the scheme will rise from 0.9% of GDP in 2019/20 to 1.3% in 2044/45.



**Figure 3: Projected total cost of individualised budgets as a percentage of GDP for Australia, 2019/20 to 2044/45**

To achieve outcomes for people with disability, and to do this at a continuing affordable cost, requires that certain measures be taken, such as pre-empting potential cost escalation and ensuring operational efficiency. To avoid cost escalation, funding needs to be adequate for necessary support and must be based on the most up-to-date and reliable estimates of future costs. A reduction in family and community support over time must be anticipated and alleviated. In order to achieve the outcomes expected, there must be constant communication with the participants. The participants need to be satisfied with the scheme; in addition, the general population needs to perceive that it is getting good value for money.<sup>39</sup>

### British Columbia, Canada

In British Columbia (BC) personal or individualised budgets are referred to as individualised funding (IF). IF has been in place since 2005, delivering support services to adults with developmental disabilities and their families. In a recent study, Stainton *et al.* (2013) analysed data on service usage and the cost of four IF modes compared with block funding methods offered by the CLBC. They found that costs were either lower or on a par with traditional methods, but with some variation across modes. IF is available through different options. These include direct-funded respite, direct funding, host agency funding, and Microboard funding (Table 10).

**Table 10: Individualised funding payment options, CLBC**

<b>Direct funding</b>	Allows the individual, family or their representative(s) to receive funding directly to retain and manage agreed supports
<b>Host agency funding</b>	IF channelled through an agency selected by the individual or family. The agency then supports the individual and/or their family or representative to utilise and manage their funds for agreed supports
<b>Microboard funding</b>	The microboard, an incorporated entity, is a small (micro) group of committed family and friends (a minimum of five people) who join together with the individual to create a non-profit society to receive and manage the funding. In this structure, the individual requiring support, and their network, are the members of the board, and the board's only purpose is to support the single individual.
<b>Direct-funded respite</b>	As with direct funding above, but exclusively for respite

Source: Vela Canada<sup>87</sup>

Stainton and colleagues reported that direct payment and host agency were the most economical, but microboards offered a lot in the form of improved network support and building social capital. Whereas IF bestowed many benefits, such as greater independence, choice and flexibility, the administrative burden can be very onerous for individuals and



families (Stainton *et al.* 2013). A number of types of services were provided under the different types of payment mode (see Table 11). Two IF methods, (host agency and direct funding), had lower costs than block funding, whereas microboards had a higher overall cost, which was due to funding some high-needs and high-cost individuals. Depending on age group, some services were used more frequently than others. IF modes were used to a greater extent by younger people (aged 19–30) and to a lesser extent by those aged over 61 years. Another issue highlighted was the lack of consistency of the cost of services in different parts of the province.

**Table 11: All funding modes and funding allocated by service\* British Columbia**

Services	Direct funding (N=101)	Host agency data (N = 100)	Microboards (N = 262)	Block funding
<b>Outreach support</b>	\$12,549.59	\$10,489.96	\$55,434.63	\$25,700
<b>Cluster living</b>			\$37,331.88	\$51,300
<b>Direct home sharing</b>				\$27,600
<b>Agency-coordinated home sharing</b>				\$38,700
<b>Home sharing</b>	\$30,029.94	\$29,472.78	\$43,852.20	\$32,200
<b>Live-in support</b>	\$39,706.94	\$17,176.95	\$70,968.80	\$48,700
<b>Staffed residential</b>			\$135,205.41	\$110,000
<b>Employment</b>	\$13,880.84	\$4,202.80	\$14,427.00	\$13,600
<b>Skills development</b>	\$19,663.61	\$20,727.51	\$57,284.85	\$23,200
<b>Individual services</b>		\$21,115.32	\$43,841.14	
<b>Community-based</b>	\$23,250.04	\$34,237.51	\$42,741.68	\$18,900
<b>Home-based</b>			\$40,476.20	\$29,700
<b>Contracted respite</b>			\$14,958.76	\$5,000
<b>Behavioural</b>	\$3,708.00		\$5,562.00	\$5,000.00
<b>Psychological</b>				\$5,000.00
<b>Homemaker</b>	\$19,453.54		\$25,636.00	\$5,000.00

Source: Stainton<sup>88</sup>

\*Funding allocations are the mean amount per person.

## New Zealand

In New Zealand, the Ministry of Health (MoH) commissioned Synergia to undertake a wide-ranging evaluation of the IF scheme, which included financial analysis and modelling of the scheme for sustainability. The MoH expressed its commitment to IF and its commitment to increasing the number of people who use IF. From this perspective, they carried out an evaluation to capture what had been learned from IF so far, and to use this information to roll out further expansion of the scheme. The question of whether IF would continue in operation or be terminated did not arise. Most stakeholders considered IF to be the ideal way to support disability into the future.

In many cases, costs for people who moved from traditional methods of resource allocation to IF were on average 14.9% higher in year one and a further 25.5% higher the following year. Non-IF users' allocation increased by 2.9%. However, these increases could be explained by the fact that many people moving to the new system had been re-



evaluated, which identified unmet needs. Many of the people who opted for IF initially were well informed and able to articulate their needs. Much of this evaluation concerned only two years of the scheme (2010 and 2011) and did not evaluate the potential for the coming years. In 2010, there were 421 users of IFs and this increased to 934 in 2011. The first people who adopted the IF scheme were those who needed higher allocation of funds in the existing system. The pre-IF cost for these users was \$21,624. The annualised cost for these users under the IF scheme was \$24,840.<sup>28</sup> Synergia's conclusion was that the higher payments for support were driven by higher need and it expected the average to level off as more people transitioned to the IF scheme.

## 6.7 Facilitators of, and barriers to, self-directed help

In a review of what helps and hinders the move to self-directed support and individualisation, Manthorpe *et al.*<sup>89</sup> completed a systematic search of the literature examining the issues in the UK as a whole and then applied some of this knowledge to what was happening in Scotland at the time. They found that many barriers and facilitators were linked. For example, lack of information and legal clarity can create the greatest challenges for potential users and other stakeholder, but when these are positives, they act as facilitators. This review, in common with many others, concludes that there is virtually no evidence concerning risks and cost outcomes. Working to reduce bureaucracy, Scottish authorities suggested 'light touch' regulation in their pilot projects; however, the review concludes that such an approach gives rise to risks on a number of levels, including administration burden and cost overruns. Good leadership and training for all those involved was seen as important, as was specific funding for the transition between the old and new systems.

Specific barriers identified were:

- new systems insufficiently publicised;
- lack of clarity as to how the self-directed support interacts with other welfare services;
- a lot of the processes and procedures were under-developed, leading to uncertainty;
- staff were concerned about their job security and continuing role in the light of change;
- fear that self-directed support may worsen working conditions for social workers;
- some feel that the administrative burden is too great;
- users do not always want the responsibility of managing their own money or services;
- employing personal assistants is not simple;
- employing family members is not always best;
- rules and legal procedures may not be clear and may change, causing confusion;
- what happens a pilot scheme may not be sustainable.

Specific facilitators identified were:

- agreement on policy helps to clarify what is permitted and what the new system is intended to bring about (managing expectations);
- action plans to translate aspirations into working practices;
- clear procedures to reassure staff about employer's aims;
- training and skills development are needed so that practitioners can be better equipped in the new system and explain it to others;
- information on self-directed support needs to be accessible and widely available;
- comprehensive support for carers and users can help when they are thinking about change and what might be needed over time;
- employing family members is welcome by some;
- brokers and advocates, independent of local authorities, can help;
- plans to deal with emergencies;
- inspirational leadership and champions of self-directed support can help with start-up;
- a steering group helps spread the load and enables messages about good practice and knowledge.<sup>89</sup>

## 6.8 Conclusions

In many cases, personal budget schemes for people with disabilities underestimated, by a considerable margin, the costs that would be incurred. Some sources suggested that although initial costs were higher than expected, uptake of the schemes was dominated by those whose needs were greatest, and costs would eventually even out. They also claimed that outcomes were better and that perhaps the money was well spent. Loose eligibility criteria at the when these schemes were first introduced led to a large increase in cost over runs due to re-assessment of some people's needs, the realising of unmet needs and the transfer of out-of-pocket expenses to the state. It appears that those who benefit most from personal budgets are young adults (18–30 years) with physical/mobility disabilities. The fragmented nature of delivery in many jurisdictions means that there is little consistency in the quality of the service or the method by which it is delivered. This makes the study and evaluation of the subject more difficult. One thing becomes clear: there are lots of hidden transaction costs at the start-up. This may be in the form of extra workload for those tasked with implementation, or the costs incurred during a transition from one system to another, where two systems are running side by side. To mitigate these difficulties, good forward planning is needed in order to maintain sustainability (and the goodwill of the taxpayer). Short-term savings are unlikely in any case, but over time the increased benefit to participants may reap financial rewards of greater employment, better integration with society and, ultimately, less dependency on State supports.

## Chapter 7. Conclusions

Approaches to introducing individualised budgets for social care for people with disabilities have evolved rapidly since 2006 or thereabouts, and this process of change is still ongoing. A new equilibrium has not been reached in any of the jurisdictions examined in this evidence review. There are indications, however, that policy thinking is tending towards the concept of ‘self-direction’, by means of which people are enabled to have choice and control and to be empowered in relation to most if not all aspects of their care and support, including financial management.

Three different approaches to legislating for individualised budgets have been discerned – legislative frameworks enabling a brand-new and ideologically driven policy approach, a consolidation of different pieces of relevant legislation (e.g. in the Netherlands), and an incremental approach within broad legislative parameters (e.g. in New Zealand and Canada).

In Australia, England and Scotland very recent legislation has grounded disability policy and services on principles of personalisation and self-direction. In each case, this new legislation has shifted the focus from determining the eligibility of the person for routine supports to correct perceived deficits due to an individual disability, to determining ‘eligible need’, i.e. desired outcomes defined by the disabled individual (with or without other interested parties) and methods to achieve these outcomes. As a result, specific lists of entitlements are not provided; rather, parameters are set, which include: underpinning principles, innovation, market development, regulation and maintenance, and monitoring, reporting and review. Innovation includes supports provided through natural (non-monetary) supports and mainstream infrastructure. At the other end of the policy spectrum, in Canada there has historically been a focus on direct payments for purchasing services costed by the hour, but since 2006, disability policy has begun to evolve gradually towards a more self-directed care approach.

With regard to eligibility, four key factors are commonly used across all of the jurisdictions examined to determine eligibility for individualised budgets. Those factors are age, the nature of the disability, the severity of the disability, and its likely trajectory and long-term effects.

With regard to entitlements, following assessment and planning, personal care and home support are the services traditionally funded through direct payments; examples may still be found in the IF scheme commenced in 2003 in New Zealand, and the various home care programmes in Canada. In countries that introduced new legislative frameworks that focus on personalisation and self-direction, there is a shift from lists of specific services to which people are entitled to requiring that ‘eligible needs’ be met (England) or that ‘reasonable and necessary supports’ be provided (Australia). These broad terms are hedged around by statements of the desired outcomes and underpinning principles (mentioned in the policy paragraph) and values, and requirements for planning and co-production, regular monitoring and reviewing, in order to ensure that appropriate services are provided. Under the new legislative frameworks, information and advice and prevention are all regarded as additional means of reducing demand, or of delaying the emergence of needs that have to be met. Early intervention similarly is a means of reducing a person’s future needs for supports.

Because the implementation of personal budgets is still very much a ‘work in progress’, there are almost no data on which to build an evidence base regarding their financial sustainability or otherwise. An evaluation in British Columbia has shown that individualised funding costs were similar to those associated with traditional delivery, but there were variations with regard to types of services and age groups. In New Zealand, an evaluation showed that the IF scheme was more expensive when it was first introduced because people with the greatest need were early adopters.

In a review of what helps and hinders the move to individualisation, research shows that lack of information and lack of legal clarity can work against successful implementation. Scottish authorities suggested ‘light touch’ regulation in their pilot projects to reduce bureaucracy, but research concludes that such an approach gives rise to risks on a number of levels, including administration burden and cost overruns. The new Australian insurance-based model, which is still being rolled out, explicitly requires that the scheme be financially sustainable. To this end, a sustainability plan was developed at the outset, modelling financial sustainability from 2019 to 2045. Regular quarterly and annual financial sustainability reports, which are a statutory requirement, are intended to help ensure that adjustments can be made in real time and that the sustainability plan is adhered to.

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# Appendix 1 Australia

## 1. A1.1 Legislative and governance frameworks

In March 2013 the National Disability Insurance Scheme Act 2013 (NDIS Act) came into force, giving effect to the commitment by the Commonwealth, State and Territory Governments to establish such a scheme, and for its progressive implementation from July 2013. In introducing the Bill for its second reading in 2012, the Prime Minister stated:

*The risk of disability is universal, so our response must be universal. The only solution is therefore a nation-wide, demand-driven system of care tailored to the needs of each individual and established on a durable, long-term basis. ... The current funding model, based on historical budget allocations, will be replaced by an insurance approach, based on actuarial analysis of need and future costs. The scheme will respond to each individual's goals and aspirations for their lifetime, affording certainty and peace of mind for people with disability and their carers alike. ... The National Disability Insurance Agency (NDIA) will work with people to plan, and to take account of their individual circumstances and needs. The scheme will give people the care and support that is objectively assessed as being reasonable and necessary over the course of their lifetime. It will give people real choice and control over these supports, including the ability to manage their own funding, if they wish. (Gillard 2012: 13877).*

The Act came into force in March 2013, giving effect to the commitment by the Commonwealth, State and Territory Governments to establish such a scheme, and for its progressive implementation from July 2013. The Act sets out the statutory framework for the scheme, and for the National Disability Insurance Scheme Launch Transition Agency (DisabilityCare Australia) to administer the scheme. The Act is supplemented by National Disability Insurance Scheme rules, which address the more detailed operational aspects of the scheme.

The NDIA is established under the Commonwealth Authorities and Companies Act 1997. This gives the agency a high degree of autonomy and legitimacy, placing it beyond the vagaries of politics, or electoral and budget cycles. The Public Governance, Performance and Accountability Act 2013, which deals with matters relating to corporate Commonwealth entities, including reporting and the use and management of public resources, also applies to the NDIA. All Australian governments are involved in decisions relating to the scheme's policy, funding and governance.<sup>b</sup>

The Australian government will provide \$19.3 billion over seven years from 2012/13 to fully roll out the NDIS across the country by 2018/19. Once roll-out is completed, 460,000 people with significant and permanent disability will receive the support they need; in 2019/20, the first year after full roll-out, the Australian government will provide funding of \$11.7 billion to the NDIS. This represents 53% of the \$22.2 billion total cost of running the NDIS, with the States and Territories providing the remaining funding. Funding for the NDIS is being raised through a small increase in the Medicare levy. Every dollar raised by this levy funds the NDIS, with revenue from the extra levy being paid into the NDIS fund, and only drawn down to meet the costs of the scheme.

The key governance arrangements are:

- The scheme is administered by the National Disability Insurance Agency, which has been established under Commonwealth legislation, and is governed by a Board.
- The Standing Council on Disability Reform (the Standing Council), a Council of Australian Governments (COAG) Ministerial Council comprising Treasurers and Ministers responsible for disability from the Commonwealth and each State and Territory, is the decision-maker on the National Disability Insurance Scheme policy issues.
- The National Disability Insurance Agency holds all funds contributed by the Commonwealth, States and Territories in a single pool, manages scheme funds, administers access to the scheme, and approves the payment of individualised support packages.

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<sup>b</sup> This account is based on information provided on the NDIS website at <http://www.ndis.gov.au/about-us/governance/federal-funding>

- The Board of the National Disability Insurance Agency is responsible for the performance of these functions and the strategic direction of the National Disability Insurance Agency. The Board manages its costs and liabilities from year to year, including through the development of a reserve and investment of funds.
- The National Disability Insurance Agency Board is advised by the National Disability Insurance Scheme Independent Advisory Council.
- The Commonwealth Minister is responsible for administering the NDIS Act, and exercises statutory powers with the agreement of states and territories, including a power to make the NDIS Rules and direct the National Disability Insurance Agency.

Each year, the Board must prepare an annual report for the Minister. This report must include the summary of the annual financial sustainability report and the report of the reviewing actuary's review of this summary. Each year, the Board must also submit a quarterly report to the Ministerial Council, providing information (including statistics) on participants in each host jurisdiction, and funding or provision of supports by the NDIA in relation to each host jurisdiction.

In preparing its corporate plan, the Board must ensure that it includes details of the financial sustainability of the NDIS (including estimates of current and future expenditure), and the risks and issues relevant to the financial sustainability of the NDIS and the management of those risks and issues.

Further information on the role of the scheme actuary in relation to ensuring the financial sustainability of the NDIS and the contents of the annual financial sustainability report is provided in the answer to Question 2 later in this report.

#### **1.A1.2 Primary motivation**

Sections 4 and 5 of the NDIS Act clearly set out the principles and values underpinning the NDIS, and specifically, the rights, types of support available and the legitimate expectations of people with disability, their families and carers within the NDIS.

People with disabilities have the right to:

- realise their potential for physical, social, emotional and intellectual development;
- respect for their worth and dignity and to live free from abuse, neglect and exploitation;
- pursue any grievance;
- be able to determine their own best interests, including the right to exercise choice and control, and
- engage as equal partners in decisions that will affect their lives, to the full extent of their capacity.

The Act also provides that people with disability should have their privacy and dignity respected, and that they and their families and carers should have certainty that people with disability will receive the care and support they need over their lifetime.

People with disabilities should be supported:

- to participate in and contribute to social and economic life to the extent of their ability;
- to exercise choice, including in relation to taking reasonable risks, in the pursuit of their goals and the planning and delivery of their supports;
- to receive reasonable and necessary supports, including early intervention supports;
- to receive supports outside the National Disability Insurance Scheme, and be assisted to coordinate these supports with the supports provided under the National Disability Insurance Scheme, and
- in all their dealings and communications with the NDIA, so that their capacity to exercise choice and control is maximised in a way that is appropriate to their circumstances and cultural needs.

The role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and respected. The role of advocacy in representing the interests of people with disability is also to be acknowledged and respected.

The following are to be promoted:

- innovation, quality, continuous improvement, contemporary best practice and effectiveness in the provision of supports to people with disability, and
- positive personal and social development of people with disability, including children and young people.

Where an act or to be done in relation to a person with disability is to be carried out by another person, some additional principles are specified:

- people with disability should be involved in decision-making processes that affect them, and where possible make decisions for themselves;
- people with disability should be encouraged to engage in the life of the community;
- the judgements and decisions that people with disability would have made for themselves should be taken into account;
- the cultural and linguistic circumstances, and the gender, of people with disability should be taken into account;
- the supportive relationships, friendships and connections with others of people with disability should be recognised, and
- if the person with disability is a child, the best interests of the child are paramount, and full consideration should be given to the need to protect the child from harm, promote the child's development, and strengthen, preserve and promote positive relationships between the child and the child's parents, family members and other people who are significant in the life of the child.

The Act also gives effect in part to Australia's obligations under the Convention on the Rights of Persons with Disabilities.

### **1.A1.3 Eligibility – 'access requirements'**

The following outline of the rules regarding 'access' to the NDIS is taken from Chapter 3 of the NDIS Act and the *National Disability Insurance Scheme (Becoming a Participant) Rules 2013*. A person, or someone who is able to act on their behalf, may make a request under the NDIS Act to become a participant in the NDIS launch (an access request). A person becomes a participant in the NDIS launch on the day the CEO decides they meet the access criteria, which include age, residence and either disability requirements or early intervention requirements.

#### **Age**

A person meets the age requirements if they are aged under 65 years when the access request is made, and if they meet any other age requirements that the NDIA may establish. For example, the NDIA may require that a person be a prescribed age on a prescribed date or a date in a prescribed period if the person resides in a prescribed area, and may prescribe different ages and different dates in relation to different areas of Australia.

#### **Residence**

A person meets the residence requirements if they reside in Australia, and are one of the following – an Australian citizen, the holder of a permanent visa, or a special category visa (SCV) holder who is a protected SCV holder. In deciding whether or not a person resides in Australia, regard must be had to:

- the nature of the accommodation used by the person in Australia;
- the nature and extent of the family relationships the person has in Australia;
- the nature and extent of the person's employment, business or financial ties with Australia;
- the nature and extent of the person's assets located in Australia;
- the frequency and duration of the person's travel outside Australia, and
- any other matter relevant to determining whether the person intends to remain permanently in Australia.

NDIS rules may require that a person:

- reside in a prescribed area of Australia on a prescribed date or a date in a prescribed period in order to meet the residence requirements;
- has resided in a prescribed area for a prescribed period in order to meet the residence requirements;
- continue to reside in a prescribed area of Australia in order to meet the residence requirements;
- satisfy a prescribed requirement relating to the following: (a) the purpose for which the person resides in a particular geographical area, and/or exceptional circumstances applying in relation to the person.

## **Disability**

A person meets the disability requirements if:

- they have a disability that is attributable to one or more intellectual, cognitive, neurological, sensory or physical impairments, or to one or more impairments attributable to a psychiatric condition;
- the impairment/s are, or are likely to be, permanent;
- the impairment/s result in substantially reduced functional capacity to undertake, or reduced psychosocial functioning in undertaking, one or more of the following – communication, social interaction, learning, mobility, self-care and self-management;
- the impairment/s affect the person's capacity for social or economic participation, and
- the person is likely to require support under the NDIS for their lifetime.

An impairment that varies in intensity may be permanent, and the person is likely to require support under the NDIS for the person's lifetime, despite the variation.

## **Early intervention**

A person can access the NDIS through the early intervention requirements without having substantially reduced functional capacity. Instead, the early intervention requirements consider the likely trajectory and impact of a person's impairment over time and the potential benefits of early intervention on the impact of the impairment on the person's functional capacity. The CEO may consider a range of evidence in deciding the potential benefit of early intervention on a person's impairment. The CEO may consider existing evidence or information from an individual or their family or carer. Where a young child has an impairment resulting in developmental delay, or resulting from a condition on a list published by the CEO for which the benefits of early intervention have already been established, no further evidence of the benefit of early intervention supports to the child is required in order to meet the early intervention requirements. A young child or other person can still meet the early intervention requirements without having one of these conditions, provided there is evidence that the requirements are satisfied. In certain circumstances, a person with a degenerative condition could meet the early intervention requirements and therefore become a participant.

A person meets the early intervention requirements if the CEO is satisfied that provision of early intervention supports is likely to benefit the person by:

1. reducing the person's future needs for supports in relation to disability, and
2. mitigating or alleviating the impact of the person's impairment on the functional capacity of the person to undertake communication, social interaction, learning, mobility, self-care or self-management, for example by preventing the deterioration of such functional capacity, by improving such functional capacity, by strengthening the sustainability of informal supports available to the person, including through building the capacity of the person's carer.

A person does not meet the early intervention requirements if the CEO is satisfied that early intervention support for the person is more appropriately funded or provided through other general systems of service delivery or support services offered by a person, agency or body, or through systems of service delivery or support services offered as part of a universal service obligation, or in accordance with reasonable adjustments required under a law dealing with discrimination on the basis of disability.

## **Process for determining eligibility**

According to the NDIS Act:

3. A person makes an '*access request*' to the NDIA to become a participant in the NDIS, and is then referred to as a '*prospective participant*'. The access request must include all the information required by the NDIA and all the necessary documents.
4. The NDIA will assess whether the prospective participant meets the '*access requirements*' specified in the legislation, which relate to residence (including citizenship), age, disability and early intervention, as outlined above.
5. A person becomes a '*participant*' in the NDIS if they are deemed to meet the access requirements. Once a person becomes a participant, the NDIA must facilitate the preparation of the person's plan. This process is described below in Section 1.4.

### **Participation ceases**

Participation ceases when a person dies, or when they enter a residential care service on a permanent basis, or start being provided with home care on a permanent basis, and this first occurs only after they turn 65 years of age. The CEO of the NDIS may also revoke a person's status as a participant in the NDIS if the person no longer meets the residence, disability or early intervention requirements. Finally, a participant may themselves notify the CEO in writing that he or she no longer wishes to be a participant.

### **A1.4 Entitlements – 'general' and 'reasonable and necessary' supports**

The NDIS offers early intervention therapies and supports to improve a person's functioning, or to slow down or prevent the progression of their disability over their lifetime. The scheme moves away from the crisis model, where families only receive support if they are unable to continue in their caring role and there are no other options. Instead, it works with families before they reach crisis to make sure that the valuable informal care they provide is sustainable. The scheme also aims to foster innovative services that are delivered and coordinated by local people.

Once a person becomes a participant, they develop a personal goal-based plan which may provide for supports for the participant. A number of principles apply in relation to the preparation and management of a participant's plan, which are set out in section 31 of the Act. Separate rules determine reasonable and necessary supports that a person may get, including support in the nature of early intervention.

### **Participant's statement of goals and aspirations**

A participant's plan must include a statement prepared by the participant that specifies the goals, objectives and aspirations of the participant, and the participant's living environment and personal context, including the participant's living arrangements, informal community supports and other community supports, and social and economic participation.

### **Statement of participant supports**

A participant's plan must also include a statement prepared by the participant that specifies:

- the general supports (if any) [e.g. a coordination, strategic or referral service or activity] that will be provided to, or in relation to, the participant;
- the reasonable and necessary supports (if any) that will be funded under the NDIS;
- the date by which, or the circumstances in which, the NDIA must review the plan;
- the management of the funding for supports under the plan; and
- the management of other aspects of the plan.

General supports are defined in the legislation as being in the nature of a coordination, strategic or referral service or activity, and are described by reference to a specified purpose or otherwise; with regard to general supports, the participant has a high degree of flexibility over provision and implementation. The Agency may also provide general supports to people who are not covered by the NDIS; for example, a service or an activity that includes coordination, strategic or referral service. By contrast, reasonable and necessary supports are more closely defined, including specifying the funding and the way in which they are to be provided, in order to help ensure that the expected outcomes are attained.

When deciding whether or not to approve a statement of participant supports, the CEO of the NDIA must identify the participant's goals, aspirations, strengths, capacity, circumstances and context; assess activity limitations, participation restrictions and support needs arising from a participant's disability; assess risks and safeguards in relation to the participant; and relate support needs to the participant's statement of goals and aspirations. Guidance on the use of assessment tools is provided in Part 4 of the NDIS Support for Participants Rules.

The CEO must be satisfied with all of the following in relation to the funding or provision of each reasonable and necessary support:

- the support will assist the participant to pursue the goals, objectives and aspirations included in his or her statement of goals and aspirations;
- the support will assist the participant to undertake activities, so as to facilitate his or her social and economic participation;

- the support represents value for money in that the costs of the support are reasonable, relative to both the benefits achieved and the cost of alternative support;
- the support will be, or is likely to be, effective and beneficial for the participant, having regard to current good practice;
- the funding or provision of the support takes account of what it is reasonable to expect families, carers, informal networks and the community to provide;
- the support is most appropriately funded or provided through the NDIS, and is not more appropriately funded or provided through other general systems of service delivery or support services offered by a person, agency or body, or systems of service delivery or support services offered as part of a universal service obligation, or in accordance with reasonable adjustments required under a law dealing with discrimination on the basis of disability.

Detailed guidance on assessing 'value for money', 'effective, beneficial and good practice', 'reasonable family, carer and other support' and 'supports appropriately funded or provided through the NDIS' (i.e. not through agencies related to health, mental health, child protection and family support, early childhood development, school education, higher education and vocational education and training, employment, housing and community infrastructure, transport or justice) is provided in Part 3 of the *National Disability Insurance Scheme Supports for Participants Rules (2013)*.

Some supports in the statement may be described generally, whether by reference to a specified purpose or otherwise. For such supports, the participant will have a high degree of flexibility over the implementation of the supports. In contrast, some supports may be specifically identified in the statement. In the case of reasonable and necessary supports, the statement could specify the type of supports that are to be funded and the way in which they are to be provided, where to do so would help ensure that the expected outcomes from the supports are attained by the participant. Such supports will have to be purchased in the way described in the statement.

When deciding whether the support should be described generally or more specifically in the statement, the CEO is to have regard to the following:

1. the cost of the support;
2. any expected return or saving in costs from providing the support;
3. any risks associated with the supply of the support, such as the need for the support to conform to State Territory laws;
4. whether achievement of other goals in the plan or the effectiveness of other supports is contingent on a particular support being procured or used;
5. whether a participant's disability requires a specialist, evidence-informed support provided by a qualified person or a particular delivery mode, and
6. whether the participant accessed the NDIS by satisfying the early intervention requirements.

To the extent that the funding for supports under a participant's plan is managed by the Agency, the plan must ensure that the supports are to be provided only by a registered provider of supports. The Rules also provides guidance on when the CEO should consider requiring that supports be provided directly by the NDIA (e.g. using bulk purchasing of goods), by a provider funded by the NDIA, or by a specially qualified person or particular service mode.

A support will not be provided or funded under the NDIS if it:

- is likely to cause harm to the participant or pose a risk to others;
- is not related to the participant's disability;
- duplicates other supports delivered under alternative funding through the NDIS, or
- relates to day-to-day living costs (for example, rent, groceries and utility fees) that are not attributable to a participant's disability support needs.

Day-to-day living costs do not include additional living costs that are incurred by a participant solely and directly as a result of their disability support needs, and costs that are ancillary to another support that is funded or provided under the participant's plan, and which the participant would not otherwise incur.



### **Information and reports for the purposes of preparing and approving a participant's plan**

For the purposes of preparing a statement of participant supports, or deciding whether to approve a statement of participant supports, the CEO may make one or more requests, as follows:

- that the participant, or another person, provide information that is reasonably necessary for the purposes of preparing the statement of participant supports, or deciding whether to approve the statement of participant supports;
- that the participant undergo an assessment and provide to the CEO the report, in the approved form, of the person who conducts the assessment and/or undergo, whether or not at a particular place, a medical, psychiatric, psychological or other examination, conducted by an appropriately qualified person, and provide to the CEO the report, in the approved form, of the person who conducts the examination.

### **Individual plan management**

A participant for whom a plan is in effect may make a request that:

- he or she manage the funding for supports under the plan;
- the funding for supports be managed wholly, or to the extent specified in the request, by a registered plan management provider that he or she nominates, or
- the funding for supports be managed wholly, or to the extent specified in the request, by a person specified by the NDIA.

There are some restrictions on the extent to which participants are able to self-manage the funding for supports under their plan. A participant will not be able to self-manage the funding for supports under their plan to any extent if they are an insolvent under administration, and neither will they be able to manage the funding if the CEO is satisfied that this would present an unreasonable risk to the participant (*National Disability Insurance Scheme (Plan Management) Rules 2013: Part 3*).

If the participant is a child, or is represented by a plan nominee, the CEO must consider the capacity of the child's representative or the plan nominee to manage finances, whether this individual has an interest that could lead a reasonable person to consider that NDIS amounts within their control might be spent other than in accordance with the participant's plan, and whether, and the extent to which, any risks could be mitigated by any safeguards or strategies the Agency could put in place through the participant's plan.

In other cases, the CEO is to consider:

- whether material harm, including material financial harm, to the participant could result if the participant were to manage the funding for supports to the extent proposed, taking into account the nature of the supports identified in the plan;
- the vulnerability of the participant to physical, mental or financial harm, to exploitation, or to undue influence;
- the ability of the participant to make decisions;
- the capacity of the participant to manage finances;
- whether a court or a tribunal has made an order under law, under which the participant's property (including finances) or affairs are to be managed, wholly or partly, by another person;
- whether, and the extent to which, any risks could be mitigated by the participant's informal support network, or by any safeguards or strategies the NDIA could put in place through the participant's plan, such as setting a shorter period before the participant's plan is reviewed, setting out regular contacts between the NDIA and the participant, or providing funding for supports (e.g. budgeting training) that would assist the participant to manage their own plan.

If a participant does not make a 'plan management request', the statement of participant supports in the plan must provide that the funding for supports under the plan be managed by either a registered plan management provider specified by the NDIA, or by the NDIA. If the funding for supports under a participant's plan is to be managed to any extent by a registered plan management provider specified by the NDIA, or by the NDIA, the CEO must, so far as reasonably practicable, have regard to the wishes of the participant in specifying who is to manage the funding for supports under the plan to that extent (*National Disability Insurance Scheme Act 2013: Section 43: 4–5*).

## Sources

### Legislation

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*National Disability Insurance Scheme (Becoming a Participant) Rules 2013* – Federal Register of Legislative Instruments F2014C00940. Retrieved 1 October 2015 at <https://www.comlaw.gov.au/Details/F2014C00940>  
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National Disability Insurance Agency and National Disability Services (2014) *Final report of Pricing Joint Working Group* Retrieved 8 September 2015 at

[http://www.ndis.gov.au/sites/default/files/documents/final\\_report\\_of\\_pricing\\_joint\\_working\\_group.pdf](http://www.ndis.gov.au/sites/default/files/documents/final_report_of_pricing_joint_working_group.pdf)

Productivity Council (2011) *Disability Care and Support* Report No 54, PC, Canberra. Retrieved 1 October 2015 at <http://www.pc.gov.au/inquiries/completed/disability-support>

## Appendix 2 Canada

**Table A2.1: People with a physical disability – home care programmes, Canada**

Province and Programme	Eligibility	Entitlement	Finance and delivery of service	Outcomes	Legislation
<b>Alberta</b>  Home Care Self-Managed Care (SMC) Program	Clients must: <ul style="list-style-type: none"> <li>– be eligible to receive Home Care services in Alberta, i.e. have a valid Alberta Health Care Card and live in a community setting;</li> <li>– have assessed unmet healthcare needs, stable health and predictable care needs, and ongoing needs for personal care and home support services (e.g. longer-term needs); and</li> <li>– be willing and able to assume the responsibilities and risks associated with contracting services for their own personal or home support services.</li> </ul>	<ul style="list-style-type: none"> <li>– ‘Personal care’ includes assistance with personal hygiene, dressing, toileting, mobilisation and transferring, eating, oral care and with medications.</li> <li>– ‘Home Support Services’ includes services that meet the therapeutic and socialisation needs of clients. It may also support activities needed to live independently in the community, such as assistance with preparing meals, homemaking, and recreation activities.</li> <li>– ‘Respite’ includes respite care, such as a break from caring duties, for primary caregivers.</li> </ul> <p>Professional services (e.g. nursing, social work or physiotherapy) cannot be purchased with self-managed care funds, but will be arranged by the Home Care case manager, based on the client’s assessed unmet need.</p>	<p>Once approved, the client and/or their legal representative enters into a legal agreement with Alberta Health Services. This will expire after one year and the client’s unmet needs and funding requirements will be re-assessed.</p> <p>The ‘agreement holder’ shall:</p> <ul style="list-style-type: none"> <li>– recruit, interview, hire, train, supervise, schedule employee(s) and direct the employee(s) in the provision of care;</li> <li>– develop a back-up plan to ensure that care can be provided at short notice if the regular employee is unavailable;</li> <li>– evaluate employee(s) performance, and, when necessary, terminate the employee(s) contract;</li> <li>– manage salary and payroll;</li> <li>– complete and submit financial reports that reconcile the self-managed care funds provided and those actually spent each quarter;</li> <li>– meet Canada Revenue Agency (CRA) federal tax regulations.</li> </ul>	–	Home Care Act of Alberta  Co-ordinated Home Care Act 1990

Province and Programme	Eligibility	Entitlement	Finance and delivery of service	Outcomes	Legislation
			Funding and regulations are determined by the Alberta Department of Health, and administered through health authorities.		
<b>British Columbia</b>  Choice in Supports for Independent Living (CSIL)	General eligibility criteria for Home and Community Care Services relating to citizenship, residency, age and health condition. An applicant must also: <ul style="list-style-type: none"> <li>– have been assessed as requiring home support services as part of his or her care plan;</li> <li>– have a physical disability or a physical disability and a developmental disability, and high-intensity care needs;</li> <li>– have assessed needs that can be met within CSIL, within available resources;</li> <li>– have agreed to pay the assessed client rate (i.e. people who have a certain level of income are required to pay a ‘client rate’ towards their home support); and</li> <li>– can safely coordinate and manage CSIL services or have a client support group or a CSIL representative acting as a CSIL employer.</li> </ul>	Home support services include: <ul style="list-style-type: none"> <li>– direct care services provided by community health workers to clients who require personal assistance with activities of daily living, such as mobility, nutrition, lifts and transfers, bathing and dressing, cueing (providing prompts to assist with the completion of tasks), and grooming and toileting;</li> <li>– safety maintenance activities may be provided as a supplement to personal assistance when appropriate, including clean-up, laundry of soiled bedding or clothing, and meal preparation;</li> <li>– Community health workers may perform some specific nursing and rehabilitation tasks that have been delegated by healthcare professionals.</li> </ul>	A CSIL client receives directly a set amount of funding each month from the health authority to directly purchase his or her own home support services. The amount of funding received is calculated by multiplying the CSIL hourly rate by the number of hours of home support service required each month (based on a clinical assessment performed by the relevant health authority). For example, if a person were assessed as requiring 100 hours of home support per month and the hourly rate is \$29.50, the person would receive \$2,950 per month (100 hours x \$29.50 per hour).	–	British Columbia Society Act
<b>Manitoba</b>  Self- and Family-Managed Home Care (SFMC)	Eligibility for the Home Care Program must first be established. This includes: <ul style="list-style-type: none"> <li>– be a Manitoba resident, registered with Manitoba Health, Healthy Living and Seniors (the department);</li> </ul>	The Regional Health Authority will provide payments to Self/Family Managers based on the following allowances. <b>a) Assessed Hours:</b> Payments to Self/Family Managers are based on the assessed units (hours) of service.	<b>a) Assessed Hours:</b> Money for the purchase of these hours are paid to the recipient, in advance, by direct deposit to their SFMC account. The deposits are made biweekly and are calculated as follows: <ul style="list-style-type: none"> <li>– For each assessed unit (hour) of</li> </ul>		

Province and Programme	Eligibility	Entitlement	Finance and delivery of service	Outcomes	Legislation
Program	<ul style="list-style-type: none"> <li>– require health services or assistance with activities of daily living;</li> <li>– require service to stay in their home for as long as possible; and</li> <li>– require more assistance than that available from existing supports and community resources.</li> </ul> <p>Prior to acceptance into the Self/Family Management Home Care Program, a Case Coordinator will conduct an assessment of the required care.</p> <p>A person may request a reassessment if they feel their needs and/or living circumstances have changed. The Home Care Program's usual review/appeal processes apply if a person disagrees with the assessment.</p>	<p><b>b) Contingency Services:</b> These are additional service times required as a result of unexpected health needs arising from occurrences such as brief illness or personal care accidents. You will need to provide reasons for this additional time. If you require extra time on a regular basis, your Case Coordinator will review this need with you.</p> <p><b>c) Transportation Allowance:</b> These funds will be provided to the Self/Family Manager on request. The following guidelines will apply:</p> <ul style="list-style-type: none"> <li>– For the first assessed visit per 24-hour day, no transportation allowance is provided.</li> <li>– Where SFMs find it necessary to pay for Employee Transportation <ul style="list-style-type: none"> <li>a) In Winnipeg region – for all assessed visits following the first visit per 24-hour day, an allowance of the round trip bus fare equivalent will be provided</li> <li>b) In other regions – for all assessed visits following the first visit per 24-hour day, mileage will be provided for the first 10 km.</li> </ul> </li> </ul> <p><b>d) Emergency Backup:</b> During the first year a recipient may request assistance from the Regional Health Authority Home Care Attendant Service in the event of an emergency. The use of the Attendant Service will enable the recipient to have emergency backup services until their own backup plans are in place.</p>	<p>household maintenance activities – \$13.58;</p> <ul style="list-style-type: none"> <li>– For each assessed unit (hour) of personal care services – \$19.81.</li> </ul> <p>These income factors of \$13.58 and \$19.81 are NOT WAGES. They are the amounts used to calculate your salary scales and payroll budget.</p> <p><b>b) Contingency Services:</b> Up to two hours per month are allowed.</p> <p><b>c) Transportation Allowance:</b> Until a regular pattern of use is established, the payment for transportation is retroactive. Once a pattern is established, payment for transportation is made in advance.</p> <p><b>d) Emergency Backup:</b> The recipient is charged for the use of this service. The charge will later appear as a deduction on your payroll direct deposit statement.</p> <p><b>Employee Recruitment, Training, and Payroll Administration:</b> The following formula is used to establish the 'number of employees' for the purpose of calculating training, recruiting, and payroll administration allowance. This may not reflect the actual number of employees. It only determines the number of employees for Home Care funding allowances based on:</p> <ul style="list-style-type: none"> <li>– Up to 20 assessed units (hours) biweekly = 1 'employee'.</li> <li>– Between 21 and 40 assessed units (hours) biweekly <b>or</b> over</li> </ul>		

Province and Programme	Eligibility	Entitlement	Finance and delivery of service	Outcomes	Legislation
		<p><b>e) Employee Recruitment, Training, and Payroll Administration:</b> As an employer, the recipient has to pay for certain employee-related expenses. Allowances are provided to cover hiring, training and administrative costs.</p>	<p>40 assessed hours biweekly, within a 5-day period per week = 2 'employees'.</p> <ul style="list-style-type: none"> <li>Over 40 assessed units (hours) biweekly, within a 6 or 7 day period per week = 3 'employees'.</li> </ul> <p>HIRING: An allowance for the cost of recruiting staff is provided on the following basis – for first-time recruitment, \$25.00 (in order to defray recruiting and advertising costs encountered. If required, the same rate will be authorised for a further two recruitments per year.</p> <p>TRAINING: It is expected that the recipient provides most of the training for their staff. For other necessary training, an allowance for training costs may be provided. This allowance will be a maximum of eight hours pay per employee hired. A training plan has to be provided to the Case Coordinator for approval prior to this allowance being paid.</p> <p>ADMINISTRATIVE COSTS: An allowance of \$50.00 per year per approved employee will be provided for payroll and other employer-related expenses. This disbursement is to cover specific expenses such as office supplies, postage, bank charges, etc. The amount will be paid in advance. The recipient is, however, not paid for their own time in undertaking their employer</p>		

Province and Programme	Eligibility	Entitlement	Finance and delivery of service	Outcomes	Legislation
<b>Ontario</b>  Self-Managed Attendant Service Direct Funding Program	<p>Applicants must:</p> <ul style="list-style-type: none"> <li>– be aged 16 years or over;</li> <li>– reside in Ontario;</li> <li>– have a permanent physical disability;</li> <li>– be able to complete the written application on own initiative and in own words;</li> <li>– be able to meet with a Selection Panel to discuss needs and determine eligibility;</li> <li>– be able to schedule attendants, hire (and fire, if necessary), train and supervise one or more attendant workers;</li> <li>– be able to meet all the legal requirements associated with being an employer, and</li> <li>– be capable of managing and accounting for funding.</li> </ul>	<p>Recipients are paid a monthly fund for attendants of their own choosing, to schedule as they please – whether their needs are at home, at work, or in the community. A recipient must have attendant services requirements that have been stable over a period of at least one year, and that can be met while residing in his/her home.</p> <p>The recipient must require the attendant services referred to in at least two of (numbers) 1 to 8 below, and at least one from (numbers) 1 to 4 below:</p> <ol style="list-style-type: none"> <li>1. turning in bed, lifting, positioning or transferring;</li> <li>2. washing, bathing, showering, shaving or personal grooming;</li> <li>3. dressing or undressing;</li> <li>4. catheterisation, emptying and changing a leg bag, using the toilet, urination or bowel routines;</li> <li>5. breathing, or caring for a tracheostomy or respiratory equipment;</li> <li>6. eating;</li> <li>7. meal preparation, dish washing, laundry or other housekeeping tasks, and</li> <li>8. essential communication.</li> </ol>	<p>responsibilities.</p> <p>The Direct Funding Program is funded by the Ontario Ministry of Health and Long-term Care through the Toronto Central Local Health Integration Network. The Direct Funding Program is administered by the Centre for Independent Living in Toronto (CILT), Inc., in partnership with the Ontario Network of Independent Living Centres (ONILC).</p>	<p>Individuals self-manage their lives, making their own choices with greater flexibility and control.</p>	–
<b>Saskatchewan</b>  Home Care Program	<p>Residency requirements and level of need and associated risks appear to be the only eligibility requirement. No mention is made of any age restrictions.</p>	<p>Individualised funding is guided by two principles:</p> <ul style="list-style-type: none"> <li>– People with the greatest need for home care should receive priority for service.</li> </ul>	<p>The consumer/guardian is responsible for all aspects of employing workers. The consumer/guardian will open a bank account specifically for</p>		

Province and Programme	Eligibility	Entitlement	Finance and delivery of service	Outcomes	Legislation
	<p>Individuals requiring a single service shall be assessed to determine need and risk if the service is not provided. The provision of a single service shall not be linked to the requirement of an additional service (e.g. homemaking is not to be linked to another service).</p> <p>When an applicant is accepted to the programme and there are serious reservations about safety, either for the individual requiring care or the home care provider, the Home Care Program must:</p> <ul style="list-style-type: none"> <li>– set any conditions it believes are necessary to make service arrangements workable;</li> <li>– ensure that any conditions for admission are clearly explained to the applicant and to involved family members and supporters;</li> <li>– ensure ongoing documentation of client needs and circumstances, factors affecting service arrangements, and all discussions and agreements with clients and supporters regarding service arrangements; and,</li> <li>– ensure that the service arrangements are reviewed at least once a month.</li> </ul> <p>The representative of a collective group, acting in the best interests of the individuals, accepts the responsibility of arranging and</p>	<ul style="list-style-type: none"> <li>– Funded Home care does not usually provide services to allow caregivers to work at a long-term job. Home care is not normally provided to relieve parents from routine childcare.</li> </ul> <p>The funding level for supportive services is based on assessed need and calculated at a per unit of service rate as determined by the Saskatchewan Ministry of Health, with one unit of service equal to one hour. A monthly administrative allowance and insurance costs are included in addition to the calculated funding level. The total maximum monthly client care cost to the Home Care Program will not exceed the amount paid by the Saskatchewan Ministry of Health for long-term care funding for the same period.</p> <p>Saskatchewan also offers a ‘collective funding’ option, which is intended to simplify the managing, funding and accounting process for groups of people living together who are eligible for individualised funding through the Home Care Program.</p> <p>Collective funding may not be used to purchase services from a person or organisation when that person or organisation owns, leases, rents or otherwise manages the residence and provides care in which the individual</p>	<p>individualised funding that provides monthly statements and cancelled cheques, and allows for direct deposit. The consumer/guardian will submit a copy of their employee time sheets to the Regional Health Authority on a monthly basis, and a quarterly financial report, including monthly banking statements.</p>		



Province and Programme	Eligibility	Entitlement	Finance and delivery of service	Outcomes	Legislation
	managing the support services for the individuals, and reporting to the Regional Health Authority. The needs of each eligible individual will be assessed using the current needs assessment process. The assessment will identify unmet needs of the individual for supportive care services. These services will be consistent with services normally provided by the Home Care Program. Efficiencies in the care plan for the collective group may be gained when the congregate setting of the individuals is considered. The monthly funding level will be calculated by multiplying the hours of care required by the collective group per month, by a per hour rate as determined by the Saskatchewan Ministry of Health.	lives.			

This table has been compiled based on Spalding and colleagues (2006) and more recent information retrieved from the following websites in July 2015:

Alberta: <http://www.albertahealthservices.ca/assets/info/seniors/if-sen-self-managed-care-brochure.pdf>

British Columbia: <http://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/care-options-and-cost/choice-in-supports-for-independent-living>

Manitoba: <http://www.gov.mb.ca/health/homecare/> and [http://www.ilrc.mb.ca/programs/sfmc/resources/sfmc\\_information.pdf](http://www.ilrc.mb.ca/programs/sfmc/resources/sfmc_information.pdf)

Ontario: <http://www.dfontario.ca/>

Saskatchewan: <http://www.publications.gov.sk.ca/details.cfm?p=22841>

**Table A2.2: People with a developmental disability – individualised funding programmes, Canada**

Province and Programme	Eligibility	Entitlement	Financial management – payments and delivery of services	Outcomes	Act
<b>Alberta</b>  Persons with Developmental Disabilities (PDD) Program	<p>Applicant must:</p> <ul style="list-style-type: none"> <li>– be at least 18 years old when services commence;</li> <li>– have a developmental disability;</li> <li>– have acquired the developmental disability before turning 18 years of age;</li> <li>– be a Canadian citizen or permanent resident;</li> <li>– reside and plan to receive services in Alberta;</li> <li>– not reside in a facility or institution under the jurisdiction of another legislative authority.</li> </ul> <p>To meet the eligibility criteria for a ‘developmental disability’, the individual must meet all three of the following conditions:</p> <ul style="list-style-type: none"> <li>– Childhood onset: the developmental disability must be evident prior to the individual’s 18th birthday;</li> <li>– Intellectual capacity: evidence of significant limitations in intellectual capacity;</li> <li>– Adaptive skills:</li> </ul>	<p>Supports Intensity Scale (SIS) interview to:</p> <ul style="list-style-type: none"> <li>– assess level of needs;</li> <li>– compile a support profile on basis of needs assessment;</li> <li>– draw up a plan for how type and amount of PDD-funded supports are to be provided.</li> </ul> <p>The PDD Program funds four types of service:</p> <ul style="list-style-type: none"> <li>– home living supports;</li> <li>– employment supports;</li> <li>– community access supports;</li> <li>– specialised community supports.</li> </ul> <p>Special funds are available for those with complex service needs. Individuals with complex service needs are defined as those who pose a significant risk, and/or are destructive to themselves, to others, or to property. They require intensive service and have, or have had, a history of one of more of the following diagnoses or life experiences: a mental health disorder; termination from services due to challenging behaviours; specialized treatment for psychiatric and/or behavioural issues; multi-system involvement; incarceration(s) or criminal justice involvement; or chronic substance abuse/dependency problems.</p>	<p>There are three ways services can be provided:</p> <ul style="list-style-type: none"> <li>– by the individual and their family/guardian, known as Family Managed Services (FMS);</li> <li>– by a Community Service Provider; and/or</li> <li>– by the Ministry.</li> </ul> <p>FMS means that an individual, their family or a person close to the individual can hire paid supports either through a private citizen or an approved service provider. While most FMS are arranged and directed by family members, this role may also be fulfilled by a non-related member of the individual’s close personal network. This person is known as the funds administrator.</p> <p>The funds administrator will lead the development of an Individual Support Plan; hire, supervise and pay employees, or provide payment to an approved community service provider upon receipt of service; and report on services to the PDD Director.</p>	<p>The Act lists the following outcomes:</p> <ul style="list-style-type: none"> <li>– dignity and equal worth of adults with developmental disabilities;</li> <li>– opportunities to exercise self-determination and to be fully included in community life;</li> <li>– services that are based on equitable opportunity, funding and access to resources;</li> <li>– communities responding to the needs of adults with developmental disabilities; and</li> <li>– provision of programmes, resources and services to adults with developmental disabilities.</li> </ul>	Persons with Developmental Disabilities Community Governance Act

Province and Programme	Eligibility	Entitlement	Financial management – payments and delivery of services	Outcomes	Act
	<p>evidence of significant limitations in adaptive skills.</p> <p>Specific provincial Developmental Disabilities Guidelines have been established for use by PDD staff in determining a significant limitation in intellectual capacity and adaptive skills.</p>	<p>The PDD Program has available the following resources for funds administrators who are providing PDD-funded services to an individual with complex service needs:</p> <ul style="list-style-type: none"> <li>– respite services</li> <li>– specialised supports that are intended to be a short-term service to assist caregivers and staff in determining and delivering appropriate services to better support individuals, such as behavioural and professional consultative services.</li> </ul> <p>The PDD Program provides funding, by contract, to funds administrators to manage the delivery of services to the individual. The funds administrator may choose to purchase services through an approved service provider or may choose to hire staff directly using the Family Managed Service Agreement (FMSA). The FMSA is a contract between the PDD and the funds administrator.</p> <p>Under exceptional circumstances, the PDD Director may approve the hiring of a family member to provide support services to the individual. The PDD Director will</p>			

Province and Programme	Eligibility	Entitlement	Financial management – payments and delivery of services	Outcomes	Act
		review the request to hire extended family members (excluding immediate family members) according to the following criteria: there are no other staffing resources available; and/or the individual has needs that require a unique blend of knowledge and skill that cannot be provided by other staff.			
<b>British Columbia</b>  Community Living British Columbia (CLBC)	Applicant must be: <ul style="list-style-type: none"> <li>– aged over 19 years;</li> <li>– have a developmental disability that started before he/she turned 18 years, or if he/she is over 19 years, has a diagnosis of foetal alcohol spectrum disorder or autism spectrum disorder and has a very hard time doing things on their own, such as shopping and managing money.</li> </ul> CLBC uses special tests to decide who may receive CLBC support.	CLBC pays for supports and services that include: <ul style="list-style-type: none"> <li>– learning new skills to help achieve goals;</li> <li>– support for work or other activities to enable the individual to be active in their community;</li> <li>– help for living in their community;</li> <li>– Connecting with special supports and services;</li> <li>– making friends and being a part of life in their community.</li> </ul> As of 31 March 2012, CLBC provides a range of support services for adults using either residential or family and day support services, or both.  IF is available for new supports or services or as an alternative to existing contracted services, but cannot be used to purchase spaces in existing group programmes or to	Individuals and families can select a combination of options, including direct funding, host agency funding and/or contracted services. Host agency funding is only available when the request for CLBC-funded supports is over \$6,000 per year.  The amount of individualised funding allocated to an individual by CLBC is based on the individual's disability-related needs, the estimated cost of the needed supports, and CLBC's financial resources. The types of supports and services funded by CLBC are described in the Catalogue of Services. When CLBC does not have funding available, requests for new or increased individualised funding will be managed and prioritised in accordance with the CLBC Request for Service Policy.  IF is available through direct funding or host agency funding payment options. The agent and/or Host	Communities where people with developmental disabilities have more choices about how they live, work and contribute.  Through IF, CLBC provides flexible, person-centred, self-directed payment options that allow individuals and families to arrange and manage the supports and services they require to meet disability-related needs.	CLBC, a Crown agency under the Ministry of Social Development and Social Innovation (MSDSI), is mandated under the Community Living Authority Act 2004 to fund supports and services in communities for adults with developmental disabilities.

Province and Programme	Eligibility	Entitlement	Financial management – payments and delivery of services	Outcomes	Act
		<p>expand existing group programmes that are already paid for by CLBC.</p> <p>(Based on Policy SE4.030 and Guide to IF)</p>	<p>Agency are responsible for ensuring that the supports and services purchased with these funds comply with CLBC policies and programme standards. The agent or Host Agency employs or contracts directly with all support workers or caregivers. Agents or Host Agencies cannot sub-contract with an agency or organisation to hire support workers on their behalf.</p> <p>Individual support planning policy (Community Living British Columbia, 2014, 8 August) linked to resource allocation policy in Chapter on financial sustainability</p> <p>Individual Financial Payment Policy (Community Living British Columbia, 2015, 1 April) clarifies the expectation that individuals make payments to the service provider, from their income, towards their shelter and support costs, when they are receiving a CLBC-funded residential service and the service provider provides the housing as part of their contract for service. The policy document provides information for staff to assist in determining the monthly amount an individual pays for shelter and support when this is required.</p> <p>CLBC offers two payment options for IF, Direct Funding and Host Agency</p>		<p>For fiscal year 2014/15, CLBC's budget was \$821 million, of which 93% was spent directly on services and programmes .</p>

Province and Programme	Eligibility	Entitlement	Financial management – payments and delivery of services	Outcomes	Act
			<p>Funding.</p> <p><b>Direct Funding</b>  Direct Funding enables individuals and their family members or representatives (agents) to arrange and manage the supports and services required to meet disability-related needs. Through Direct Funding, the individual or his/her agent receives money directly from CLBC to pay for the supports and services. A specific policy document outlines how CLBC contracts with and provides money directly to individuals or their agents for the purchase of supports and services. It explains eligibility for Direct Funding and how Direct Funding is requested. This document also describes the responsibilities that individuals or their agents and CLBC staff have in planning, implementing, monitoring and administering a Direct Funding agreement.</p> <p><b>Host Agency Funding</b>  Host Agency Funding enables an individual and his/her family or representative (agent) to use a host agency to administer funding allocated by CLBC to the individual. The host agency works with or on behalf of the individual and agent to arrange and manage the supports and services required to meet disability-related needs. A specific</p>		

Province and Programme	Eligibility	Entitlement	Financial management – payments and delivery of services	Outcomes	Act
			<p>policy document explains Host Agency Funding and describes how CLBC staff assist families to understand and access this payment option. It also outlines the roles and responsibilities for individuals, agents, host agencies and CLBC staff in developing and maintaining effective host agency arrangements.</p> <p>The types and amount of supports and services available to individuals and families through IF are consistent with what other individuals with similar levels of disability-related needs receive based on the Catalogue of Services. CLBC does not provide funds for supports or services that fall under the mandate of other government bodies or programmes such as health services or income assistance.</p> <p>Facilitators inform individuals and families who express an interest in Direct Funding of more than \$6,000 per year that their agent must be able to:</p> <ul style="list-style-type: none"> <li>– demonstrate his/her ability to fulfil the responsibilities of an agent including the ability to arrange and manage the individual's supports and services;</li> <li>– confirm his/her financial eligibility including completion of a credit check</li> </ul>		

Province and Programme	Eligibility	Entitlement	Financial management – payments and delivery of services	Outcomes	Act
			<p>by CLBC for funding amounts of over \$25,000 per year, and</p> <ul style="list-style-type: none"> <li>– submit a Representation Agreement or other documentation to show that they can legally act on behalf of the individual prior to the approval of Direct Funding requests of over \$6,000 per year. Individuals or families requesting information about Representation Agreements can be directed to the Nidus Personal Planning Resource Centre and Registry. (<a href="http://www.nidus.ca">www.nidus.ca</a>).</li> </ul>		
<b>Manitoba</b>  In the Company of Friends (ICOF)	A person must qualify as a ‘vulnerable person’ under the Act: an adult living with a mental disability who is in need of assistance to meet his or her basic needs with regard to personal care or management of his or her property (Section 1.1). A mental disability means significantly impaired intellectual functioning existing concurrently with impaired adaptive behaviour, and has manifested prior to the age of 18 years, but excludes mental disability due exclusively to a mental	<p>The Community Living disABILITY Services (CLDS) programme uses the Supports Intensity Scale (SIS) to assess the support needs of CLDS clients.</p> <p>In early 2014, the CLDS completed a pilot of the Supports Intensity Scale. Based on the success of the pilot, the CLDS programme has adopted the SIS as a standardised method of assessing the support needs of individuals across the Province receiving support from the CLDS programme. The SIS involves a detailed interview conducted by certified SIS facilitators with the CLDS</p>	Innovative LIFE Options Inc (LIFE) is a non-profit organisation that provides guidance, resources, training, and information to individuals receiving ICOF funding. Manitoba Family Services contracts LIFE to ensure that each person has a strong and functioning support network that supports his/her desires and autonomy.	Delivery of services is based on the goals that individuals living with an intellectual disability should have the opportunity to lead satisfying, productive lives in their communities, make their own decisions and direct their own lives (with support if needed), stay connected with their families, and develop friendships and other relationships in the community.	Vulnerable Persons Living with a Mental Disability Act 1993



Province and Programme	Eligibility	Entitlement	Financial management – payments and delivery of services	Outcomes	Act
	disorder as defined in section 1 of The Mental Health Act. A person must also be a Canadian citizen or legally entitled to remain and work in Canada on a permanent basis and be a resident of Manitoba.	participant and other individuals (family, support staff, etc.) who know the person well. The SIS is designed to measure the level of supports that a person with an intellectual disability needs in order to successfully participate in areas such as home living, community living, lifelong learning, employment, health and safety, and social activities.			
<b>Ontario</b>  Passport Program	A person is deemed to have a developmental disability for the purposes of the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act 2008 (SIPDDA), if the person has the prescribed significant limitations in cognitive functioning (intellectual capacity, including the capacity to reason, organise, plan, make judgements and identify consequences) and adaptive functioning (capacity to gain personal independence, based on the person's ability to learn and apply conceptual, social and practical skills in his or her everyday life) and those limitations originated before the person reached 18 years of age, are likely to be lifelong in nature, and affect areas of	<p>Passport Program funding can be used for the following services and supports:</p> <ul style="list-style-type: none"> <li>– community participation;</li> <li>– activities of daily living;</li> <li>– caregiver respite;</li> <li>– person-directed planning (up to \$2,500);</li> <li>– administration of Passport Program funding (up to 10% of Passport Program allocation).</li> </ul> <p>Services and supports may be purchased from the following types of service providers:</p> <ul style="list-style-type: none"> <li>– community service providers;</li> <li>– developmental services agencies;</li> <li>– private service and support providers;</li> <li>– adult education providers;</li> <li>– personal support workers;</li> <li>– neighbours, family members, friends.</li> </ul> <p>Passport Program funding may be</p>	<p>The Passport Program is designed to complement and work with other government programmes, resources and sources of funding to provide a wide range of supports.</p> <p>All Passport Program recipients sign a funding agreement with the Passport Agency, which works with individuals and families to arrange payments with their chosen service provider(s), if they would like to receive supports through a service agency rather than a direct payment.</p> <p>The maximum annual funding an individual can receive is \$35,000; there are no caps on the amount for each type of support apart from administration (up to 10% of allocation) and person-directed planning (\$2,500 annually).</p> <p>To promote a fair and equitable service system, all applicants are prioritised according to the</p>	The 'over-arching principle' underpinning the Passport Program is that people who have a developmental disability are members of the community. Services and supports funded under the Program are guided by the following principles: person-centred/directed; choice and flexibility; strong families and caregivers; fairness and equity; and accountability.	Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act 2008 (SIPDDA)

Province and Programme	Eligibility	Entitlement	Financial management – payments and delivery of services	Outcomes	Act
	major life activity, such as personal care, language skills, learning abilities, the capacity to live independently as an adult or any other prescribed activity (SIPDDA 2008, c. 14, s. 3 (1 and 2).	<p>used to compensate certain family members to provide services and supports, but it cannot be used to compensate primary caregiver(s) regardless of residence, the spouse of a person with a developmental disability regardless of residence, or a child under the age of 18 years. Definitions and examples of the types of services and supports and the types of providers are provided in the Guidelines. Passport Program funding may not be used to purchase the following types of services and supports:</p> <ul style="list-style-type: none"> <li>– indirect respite services and supports (e.g. cleaning, meal preparation, snow removal, care of other family members);</li> <li>– tuition for post-secondary education/degree programmes that are eligible for government student assistance programmes;</li> <li>– items for which the individual receives an allowance from the Ontario Disability Support Program (e.g. drug benefits, medical aids);</li> <li>– housing and home maintenance;</li> <li>– groceries, food, and restaurant meals for the individual with a developmental disability;</li> <li>– clothing;</li> <li>– household items and electronics;</li> </ul>	<p>individual's support needs and circumstances and available resources.</p> <p>The Guidelines discuss the roles and responsibilities of the recipients with regard to managing their direct funding, hiring a support worker, monitoring the quality of the services and supports they receive, budgeting, procedures for reimbursement and the misuse of funding.</p>		

Province and Programme	Eligibility	Entitlement	Financial management – payments and delivery of services	Outcomes	Act
		<ul style="list-style-type: none"> <li>– telephone/telecommunications;</li> <li>– holiday travel;</li> <li>– dental care and services;</li> <li>– fees for therapies/specialised services;</li> <li>– personal goods and services;</li> <li>– assistive devices and specialised equipment; and</li> <li>– vehicle purchase and/or modifications, leases and rentals.</li> </ul>			

This table has been compiled based on Spalding and colleagues (2006) and other more recent information retrieved from the following websites in July 2015:

Alberta: <http://humanservices.alberta.ca/disability-services/pdd.html>

British Columbia: <http://www.communitylivingbc.ca/about-us/policies/>

Manitoba: [http://www.gov.mb.ca/fs/pwd/pubs/spl\\_brochure.pdf](http://www.gov.mb.ca/fs/pwd/pubs/spl_brochure.pdf)

Ontario: <http://www.mcass.gov.on.ca/en/mcass/programs/developmental/servicesupport/passport.aspx>

**Table A2.3: People with a physical and/or developmental disability – disability support programmes**

Province and Programme	Eligibility	Entitlement	Finance and delivery of service	Outcomes
<b>New Brunswick</b>  Disability Support Program (DSP)	A person may qualify for this programme if they: <ul style="list-style-type: none"> <li>– are a resident of New Brunswick;</li> <li>– are aged 19 to 64 years;</li> <li>– have a long-term disability (this does not include a medical condition that does not result in long-term disability or services required to address drug, alcohol, nicotine or gambling addictions);</li> <li>– require disability-related supports in order to address unmet needs and to establish or maintain their living arrangements in the community, to assist or enhance the capacity of their natural support networks to provide support in the community, or to help them participate in the community, thereby helping to avoid long-term inactivity and stress on themselves or their caregivers.</li> </ul>	Disability supports that might be provided under this programme include: <ul style="list-style-type: none"> <li>– Home Support Worker;</li> <li>– respite;</li> <li>– personal supports and assistance within and outside the home;</li> <li>– supports for community involvement and participation;</li> <li>– personal living skills training;</li> <li>– transportation supports that are disability specific;</li> <li>– technical supports and assistive devices not covered under other programs;</li> <li>– residential facility services.</li> </ul>	–	Using a person-centred approach, the DSP provides personalised, flexible disability supports for persons with disabilities in the development of their personal disability support plans.
<b>Nova Scotia</b> Disability Support Program (DSP): <ul style="list-style-type: none"> <li>– Independent Living Support Program</li> <li>– Alternative Family Support Program</li> <li>– Direct</li> </ul>	<b>Disability Support Program (DSP)</b> The applicant must be diagnosed with one or more of the following: <ul style="list-style-type: none"> <li>– intellectual developmental disability;</li> <li>– long-term mental illness;</li> <li>– physical disability;</li> <li>– acquired brain injury.</li> </ul> They must be aged 19 years or older, reside lawfully in Nova Scotia, and have a valid NS Health Card.	<b>Independent Living Support (ILS) Program</b> Eligible individuals will have assessed unmet needs that can be addressed by the ILS Program, which provides up to 21 hours a week of supports and services to eligible individuals who are semi-independent and require minimum support in their own apartment or home, in order to: <ul style="list-style-type: none"> <li>– assist individuals to maintain and build connections and relationships with family,</li> </ul>	<b>Independent Living Support (ILS) Program</b> Individuals in the Independent Living Support (ILS) Program are eligible to receive funding to purchase hours of support. In addition, individuals are also eligible to receive funding for assessed unmet needs which may include shelter costs, food, clothing, household items, prescriptions, transportation, a comforts (personal use)	

Province and Programme	Eligibility	Entitlement	Finance and delivery of service	Outcomes
Family Support	<p><b><i>Independent Living Support (ILS) Program</i></b></p> <p>Eligibility for the ILS Program is determined by a functional and financial assessment. The applicant must meet the criteria for inclusion in the DSP, and also:</p> <ul style="list-style-type: none"> <li>– require no more than 21 hours of support a week;</li> <li>– be under the age of 65 years;</li> <li>– be able to access crisis support independently and be able to use an emergency response system;</li> <li>– be able to manage medication with minimal support and guidance;</li> <li>– be able to participate in decisions about their activities and needs;</li> <li>– be able to communicate these needs/preferences to others; and</li> <li>– be willing to participate in the Individual Support Planning process.</li> </ul> <p><b><i>Alternative Family Support (AFS) Program</i></b></p> <p>Residents are eligible to receive funding based on their need for items such as room and board, support and supervision, and respite. The applicant must meet the criteria for inclusion in the DSP, and also:</p> <ul style="list-style-type: none"> <li>– the applicant's assessed support needs can be successfully accommodated in an AFS setting;</li> <li>– appropriate supports identified through the assessment and</li> </ul>	<p>friends and other community members and resources;</p> <ul style="list-style-type: none"> <li>– assist individuals to maximise independence in instrumental activities of daily living such as: <ul style="list-style-type: none"> <li>▪ maintaining a household</li> <li>▪ laundry</li> <li>▪ shopping and banking</li> <li>▪ preparing meals;</li> <li>▪ transportation for community access</li> <li>▪ participating in leisure, volunteer, or work activities</li> </ul> </li> <li>– assist with the promotion and maintenance of health and wellness;</li> <li>– recognise the potential of individuals, and facilitate opportunities for continuing growth and personal development;</li> <li>– balance SPD resources and the eligible individual's expectations in a flexible and responsive manner in order to meet the assessed unmet needs of eligible individuals;</li> <li>– assist in the prevention of, and/or delay the need for, admission to a staffed residential support option.</li> </ul> <p><b><i>Alternative Family Support (AFS) Program</i></b></p> <p>The AFS Program supports persons with disabilities in an approved, private</p>	<p>allowance, and other approved items included in DSP policy and procedures.</p> <p>When the applicant has been determined eligible for the ILS Program, and if the ILS Program funding is not available in the fiscal year in which service is requested, the applicant's name is placed on a wait list, upon their request.</p> <p><b><i>Alternative Family Support (AFS) Program</i></b></p> <p>Funding is determined by a financial and functional assessment that complies with overall DSP policy, the Individual Support Planning process, and in accordance with approved Alternative Family Support (AFS) rates. In addition to an AFS monthly allowance for room and board, support and supervision, and respite, funding for other items identified as assessed unmet needs are available as outlined in SPD policy.</p> <p>If the AFS Program funding is not available in the fiscal year in which service is requested, the applicant's name is placed on a waiting list, upon their request. Funding is payable in advance at the beginning of the month to</p>	

Province and Programme	Eligibility	Entitlement	Finance and delivery of service	Outcomes
	<p>Individual Support Plan processes are available;</p> <ul style="list-style-type: none"> <li>– the applicant does not require long term or ongoing night awake support;</li> <li>– the placement is within approved funding levels and AFS Program resources; and-</li> <li>– the applicant or the person acting on their behalf have agreed that the available AFS placement is an appropriate residential program option.</li> </ul> <p><b>Direct Family Support (DFS) Program</b> Requirements include:</p> <ul style="list-style-type: none"> <li>– The family and child are permanent residents of Nova Scotia.</li> <li>– The child is under 19 years of age.</li> <li>– The child is living in the home of a family member/guardian of the child.</li> <li>– The child has been diagnosed as having a mild or moderate intellectual disability with a significant behavioural challenge, or has been diagnosed as having a severe intellectual disability, that has been documented within the past two years.</li> <li>– The child has a significant physical disability with ongoing functional limitations that are a result of the disability and seriously limit their capacity to perform age-appropriate</li> </ul>	<p>family home. Support and supervision is provided for up to two individuals unrelated to the AFS provider. The programme provides a family-like setting for individuals who may require varying levels of support and supervision, who may prefer living with a family, and who will benefit from the additional support a family environment can provide.</p> <p><b>Direct Family Support (DFS) Program</b> The Direct Family Support (DFS) Program provides funding for the purchase of respite services to assist with scheduled breaks for family caregivers and is not intended to provide for full-time in-home support, or to compensate caregivers for supporting their family member with a disability.</p>	<p>the:</p> <ul style="list-style-type: none"> <li>– AFS Provider – upon receipt of a monthly invoice detailing approved costs and expenditures submitted to the Care Coordinator;</li> <li>– AFS Resident – personal funds are paid in advance to the individual and/or the AFS Provider as identified in the Individual Support Plan.</li> </ul>	

Province and Programme	Eligibility	Entitlement	Finance and delivery of service	Outcomes
	<p>activities of daily living as determined by an approved clinician.</p> <ul style="list-style-type: none"> <li>– The family meets the <a href="#">DFSC Program income guidelines</a>.</li> <li>– The family agrees to participate in the assessment process.</li> </ul> <p><b>Direct Family Support for Adults (DFSA)</b></p> <p>To be eligible, the application and/or assessment process must identify and determine that the applicant/individual and their family meet the following criteria:</p> <ul style="list-style-type: none"> <li>– The applicant and their family are permanent residents of Nova Scotia.</li> <li>– The applicant is aged 19 years or over.</li> <li>– The applicant is residing in the home of a family member or guardian.</li> <li>– The applicant has a medical diagnosis of one or more of the following: intellectual disability, long-term mental illness, or physical disability.</li> <li>– The applicant and family have unmet needs as identified through the assessment process.</li> <li>– The applicant meets the financial eligibility criteria as outlined in SPD policy and procedures.</li> <li>– The applicant and their family agree to participate in the assessment process.</li> </ul>			

Province and Programme	Eligibility	Entitlement	Finance and delivery of service	Outcomes
<b>Prince Edward Island</b>  Disability Support Program (DSP)	<p>A person must:</p> <ul style="list-style-type: none"> <li>– have a disability (i.e. substantial physical, intellectual or neurological impairment that is continuous or recurrent for at least one year, and the direct and cumulative impact on the person's ability to attend to personal care, function in the community or function in a workplace results in a substantial restriction in one or more of these activities of daily living);</li> <li>– be a resident of Prince Edward Island;</li> <li>– be under age 65 years on day of application for disability supports;</li> <li>– reside outside an institution.</li> </ul> <p>To be eligible for disability supports, a person with a 'substantial intellectual impairment' must have an IQ score at or below 70.</p> <p>A person is eligible for employment and vocational supports if he/she is legally entitled to work in Canada; is 16 years or older; and has a substantial restriction to gainful employment resulting from his or her disability.</p>	<p>The Disability Support Program (DSP) focuses on the needs of the individual and/or family rather than entitlement. This allows for more flexible planning with individuals and families. The DSP will endeavour to ensure fairness and accountability in programmes that best respond to individual needs.</p> <p>Disability supports may only be provided to a person for the purpose of meeting an unmet need that is directly related to the eligible person's disability. Determination of unmet needs occurs during an eligible person's needs assessment. The needs assessment is conducted using an Assessment Guide, and includes a self-assessment and input by the applicant; input of family members and support personnel; and documentation from consultation with one or more healthcare practitioners, e.g. medical, educational and/or psychological. The applicant's level of functioning and maximum monthly funding is determined.</p> <p>On completion of needs assessment, the applicant is given a written report on the determination of the level of functioning; maximum monthly funding available; applicant's right to request a reconsideration; requirement to sign an Individual Support Agreement; the recipient contribution requirement;</p>	<p>The Individual Support Agreement (ISA) is the financial contract between the individual and/or their family and the Department. It sets out, by agreement, the dollar amount of the supports for which the Department will pay and the individual's and/or family's responsibility with respect to the support plan. Prior to entering into the ISA, the following steps must be taken:</p> <ul style="list-style-type: none"> <li>– a support plan must be developed, including costs;</li> <li>– the client contribution must be calculated;</li> <li>– the support plan and costs must be approved (this may be done by the Disability Support Worker, depending on signing authority and the costs of the plan).</li> </ul> <p>Once the ISA, with the support plan attached, has been agreed to and signed, the Disability Support Worker may set up the payments to the individual, parent/guardian, or agent. The Disability Support Worker will request that a cheque for the pre-determined amount be sent directly to the individual, parents/guardians or agent at the beginning of each month. The</p>	<p>The DSP was the first programme in Canada to distinguish between disability-specific support and income support. The purpose of the DSP is to assist with personal planning and to help meet needs related to an individual's disability. These supports are needs based, and are not intended to provide income. The Disability Support Program lists 13 'primary principles' that underpin the relationship between the individual and his/her family and the DSP worker. They include satisfactory quality of life and financial independence,</p>



Province and Programme	Eligibility	Entitlement	Finance and delivery of service	Outcomes
		<p>and ongoing eligibility requirements including reports and documentation related to expenses; and so on.</p> <p>Supports are provided in three main areas – child disability supports, adult disability supports, and employment and vocational supports. Supports can take a number of different forms, including respite care; community living and community participation supports; technical aids and other devices and family support programmes.</p> <p>Policies and procedures around provision of technical aids and assistive devices, including definitions, and categories of aids and devices, are detailed in a separate policy document.</p>	<p>individual, parents/guardians or agent will be responsible for paying all the funded expenses incurred as a result of the participant's special needs.</p> <p>Payments may be made to a third party if it is determined during the support planning process to be the most appropriate method, or if misappropriation of funds is suspected. In the case of technical aids and assistive devices, a once-off lump sum payment may be made towards the purchase of equipment according to client contribution policy.</p>	<p>recognition of the dignity and value of the person, and the importance of the family; and note the need for a support plan and goals, and, given resource limitations, for efficient programme management .</p> <p>Programme emphases include recognition of the uniqueness of every individual, and the importance of a person-centred approach.</p>

This table has been compiled based on Spalding and colleagues (2006) and information retrieved from the following websites in July 2015:

New Brunswick: [http://www2.gnb.ca/content/gnb/en/services/services\\_renderer.200972.Disability\\_Support\\_Program.html](http://www2.gnb.ca/content/gnb/en/services/services_renderer.200972.Disability_Support_Program.html)

Nova Scotia: <http://novascotia.ca/coms/disabilities/index.html> and <http://www.cdha.nshealth.ca/continuing-care/self-managed-care>

Prince Edward Island: [www.gov.pe.ca/ssd/disabilitysupports](http://www.gov.pe.ca/ssd/disabilitysupports)

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Community Living British Columbia (2009, 1 June) *Host agency funding*. Policy No. SE4.240

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[http://www.fin.gov.bc.ca/ocg/ias/pdf\\_docs/CLBC\\_Review\\_2011.pdf](http://www.fin.gov.bc.ca/ocg/ias/pdf_docs/CLBC_Review_2011.pdf)

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## Appendix 3 England

### Legislation and governance

The Care Act 2014, which came into force in April 2015, creates a single, consistent route to establishing an entitlement to public care and support for all adults with needs for care and support. It also creates the first-ever entitlement to support for carers.

- it sets out when a local authority has a responsibility to meet someone's care and support needs, and how it can do so even if it does not have to. Even when an assessment says that someone does not have needs that the local authority should meet, the local authority must advise people about what needs they do have, and how to meet them or prevent further needs from developing;
- it also sets out what must happen to help the person make decisions about how their needs should be met, and how local authorities must provide a care and support plan (or a support plan in the case of a carer);
- it provides people with a legal entitlement to a personal budget, unless a person is only receiving intermediate care or reablement support to meet their identified needs; and
- it establishes a legal entitlement to a direct payment to meet some or all of their needs. Provided that the direct payment is used to meet the needs identified in the plan, the person should have freedom over how the money is spent.

### Outcomes/Principles/Values

The Care Act 2014 (Sections 1–3) sets out the requirement for local authorities to 'promote individual well-being'. Section 2 defines 'well-being' as relating to any of the following:

- personal dignity (including treatment of the individual with respect);
- physical and mental health and emotional well-being;
- protection from abuse and neglect;
- control by the individual over day-to-day life (including over care and support, or support provided to the individual and the way in which it is provided);
- participation in work, education, training or recreation;
- social and economic well-being;
- domestic, family and personal relationships;
- suitability of living accommodation, or
- the individual's contribution to society.

To promote individual well-being, Section 3 requires a local authority to have regard to the following matters:

- recognition that the individual is best placed to judge the individual's well-being;
- respect for the individual's views, wishes, feelings and beliefs;
- preventing or delaying the development of needs for care and support or needs for support and the importance of reducing needs of either kind that already exist;
- ensuring that decisions about the individual are made having regard to all the individual's circumstances (and are not based only on the individual's age or appearance or any condition of the individual or aspect of the individual's behaviour which might lead others to make unjustified assumptions about the individual's well-being);
- the importance of the individual participating as fully as possible in decisions and being provided with the information and support necessary to enable the individual to participate;
- the importance of achieving a balance between the individual's well-being and that of any friends or relatives who are involved in caring for the individual;
- the need to protect people from abuse and neglect;
- the need to ensure that any restriction on the individual's rights or freedom of action that is involved in the exercise of the function is kept to the minimum necessary.

### **Eligibility – assessing ‘eligible needs’**

A needs assessment must be completed before eligibility for care and support can be determined. The Care Act 2014 (Sections 9–12) outlines how a local authority should assess an adult’s needs for care and support, and also situations in which an assessment may be refused. The *Care and Support (Assessment) Regulations 2014* spell out the rules regarding supported self-assessments, general requirements with regard to assessments, the need to assess the impact of an individual’s needs on their family and those caring for them, the training, expertise and consultations needed to carry out assessments appropriately, and any specialist expertise requirements, e.g. for assessing deaf-blind individuals.

An assessment must be provided to all people who appear to need care and support, regardless of their finances or whether the local authority thinks their needs will be eligible. It must assess the adult’s needs and how they impact on the person’s well-being and the outcomes they want to achieve, and it must be carried out with the involvement of the adult.

Chapter 6 of the *Statutory Guidance* on implementing the Care Act 2014 (Department of Health 2014) discusses in detail the assessment process, which may be face to face, a supported self-assessment, online or by phone, a joint assessment involving several different agencies, or a combined assessment including both an adult’s and a carer’s assessments. Assessments must be ‘appropriate and proportionate’, or ‘person centred’, i.e. tailored to what the person can do and to what the person expects/wants from the process. In undertaking an assessment, a local authority must also have regard to safeguarding the well-being of the adult, the possibility of fluctuating needs and how this might affect the assessment, and the strengths and capabilities of the adult, for example their own personal attributes and the presence of support from family, friends or the wider community. The local authority may also consider undertaking a ‘combined assessment’, including both the adult and his or her carer, or an ‘integrated assessment’ carried out jointly with another body such as children’s services, housing experts in the voluntary sector, relevant professionals in the criminal justice system, health or mental health professionals.

On the basis of the assessment, the local authority will be able to determine whether the person is eligible for care and support (Care Act 2013, Section 13). The *Care and Support (Eligibility Criteria) Regulations 2015* and the *Statutory Guidance* (pp. 96–99) outline the national minimum threshold for eligibility that applies across all local authorities in England. Under the national minimum threshold for eligibility, three interlinked conditions all have to be present:

1. The adult’s needs arise from, or are related to, physical or mental impairment or illness.
2. As a result of these needs, the adult is unable to achieve two or more of a list of specified outcomes, and
3. As a consequence, there is, or is likely to be, a significant impact on the adult’s well-being.

The specified outcomes are:

- managing and maintaining nutrition;
- maintaining personal hygiene;
- managing toilet needs;
- being appropriately clothed;
- being able to make use of the adult’s home safely;
- maintaining a habitable home environment;
- developing and maintaining family or other personal relationships;
- accessing and engaging in work, training, education or volunteering;
- making use of necessary facilities or services in the local community including public transport, and recreational facilities or services; and
- carrying out any caring responsibilities the adult has for a child.

An adult is regarded as being unable to achieve an outcome if he or she:

- is unable to achieve it without assistance;
- is able to achieve it without assistance, but doing so causes the adult significant pain, distress or anxiety;

- is able to achieve it without assistance, but doing so endangers or is likely to endanger the health or safety of the adult, or of others; or
- is able to achieve it without assistance, but takes significantly longer than would normally be expected.

The local authority must determine whether and how failure to achieve two or more of the specified outcomes impacts on the individual's well-being. Having made a determination, the local authority is required to meet the adult's needs for care and support which meet the eligibility criteria. According to *Factsheet 2* published by the Department of Health, *The Care Act – who is entitled to public care and support?*, the Care Act 2014 establishes that a person will be entitled to have their needs met when:

- the adult has 'eligible' needs;
- the adult is 'ordinarily resident' in the local authority area (i.e. their established home is there), and
- any one of five situations apply to them:
  - there is no charge for the type of care and support they need
  - the person cannot afford to pay the full cost of their care and support
  - the person asks the local authority to meet their needs
  - the adult does not have mental capacity and has no one else to arrange care for them, or
  - their care and support costs exceed the cap.

### **Carers**

The Care Act 2014 (Sections 10–12) outlines how a carer's needs for support are to be assessed and also situations in which an assessment may be refused. According to *Factsheet 8* published by the Department of Health, *The Care Act – the law for carers*, the Care Act relates mostly to adult carers – people aged over 18 years who are caring for another adult. This is because young carers (aged under 18) and adults who care for disabled children can be assessed and supported under children's law.

The Act gives local authorities a responsibility to assess a carer's needs for support, where the carer *appears* to have such needs. This replaces the existing law, which states that the carer must be providing 'a substantial amount of care on a regular basis' in order to qualify for an assessment. This means that more carers are able to have an assessment. The assessment will consider the impact of caring on the carer. It will also consider the things that a carer wants to achieve in their own day-to-day life. It must also consider other important issues, such as whether the carer is able or willing to carry on caring, whether they work or want to work, and whether they want to study or do more socially.

When the assessment is complete, the local authority must decide whether the carer's needs are 'eligible' for support from the local authority. This approach is similar to that used for adults with care and support needs. In the case of carers, eligibility depends on the carer's situation. The carer will be entitled to support if they are assessed as having needs that meet the eligibility criteria, and the person they care for lives in the local authority area.

### **Entitlements – 'meeting needs rather than providing services'**

In order to meet their statutory obligation under the Care Act 2014 to promote 'well-being', local authorities must consider 'how to meet each person's specific needs rather than simply considering what services they will fit into. The concept of meeting needs also recognises that modern care and support can be provided in any number of ways, with new models emerging all the time, rather than the previous legislation which focuses primarily on traditional models of residential and domiciliary care' (Department of Health 2014: p. 2).

### **Prevention**

Under Section 2 of the Care Act 2014, local authorities have a responsibility to provide services, facilities or resources that will help prevent or delay the development of care and support needs by people who do not have any current needs for care and support and by people with needs for care

and support, whether their needs are eligible and/or are met by the local authority or not. Chapter 2 of the *Statutory Guidance* accompanying the Care Act (Department 2014) details the types of prevention that may be provided:

- primary (universal) prevention aimed at people who have no particular health or care and support needs, which helps them avoid developing such needs by maintaining independence, health and well-being;
- secondary prevention (early intervention) aimed at people with increased risk of developing needs, where the provision of services, facilities or resources may slow down or reduce further deterioration; and
- tertiary prevention, which aims to minimise the effect of disability or deterioration for people with established or complex health conditions.

### ***Information and advice***

Under Section 4 of the Care Act 2014, local authorities are required to establish and maintain a service for providing people in their areas with information and advice relating to care and support for adults and for carers, regardless of whether they are eligible for care and support or not. Chapter 3 of the *Statutory Guidance* on the Act (Department of Health 2014) outlines the audiences for information and advice, what type of information and advice should be provided (including financial information and advice), when and how to deliver information and advice, proportionality and so on.

### ***Care and support planning***

Under Sections 24–30 of the Care Act 2014, once eligible need for care and support has been established, the local authority must undertake a planning process with the person who has the need, any carer they have, and any other person they ask the authority to involve (see *Factsheet 4* published by the Department of Health, *The Care Act – personalising care and support planning*, and Chapter 10 of *Statutory Guidance* published by the Department of Health, 2014). The care and support planning process considers what needs the person has, what they want to achieve, what they can do by themselves or with the support they already have, and what types of care and support might be available to help them in the local area. Section 8 of the Act gives examples of the types of care or support a local authority might provide in order to meet an adult's care and support needs:

- accommodation in a care home or in premises of some other type;
- care and support at home or in the community;
- counselling and other types of social work;
- goods and facilities, e.g. assistive technology in the home or equipment/adaptations, or
- information, advice and advocacy.

As part of the planning process, the local authority informs the person of the total personal budget that they will receive (Section 26). This is the amount of money that the local authority has worked out it will cost to arrange the necessary care and support for the person. It is the mechanism that, in conjunction with the care and support plan, enables the person to exercise greater choice and take control over how their care and support needs are met by:

- knowing, before care and support planning begins, an estimate of how much money will be available to meet a person's assessed needs and, with the final personal budget, having clear information about the total amount of the budget, including the proportion the local authority will pay, and what amount (if any) the person will pay;
- being able to choose from a range of options for how the money is managed, including:
  - direct payments, which allows the person to purchase their own care and support;
  - the local authority directly providing some type of support, for example by providing a reablement or short-term respite service;
  - the local authority managing the budget and a provider or third party managing the budget on the individual's behalf (an individual service fund); or
  - a combination of these approaches: for example, the local authority arranging a homecare service while also providing a direct payment to meet other needs;
- having a choice over who is involved in developing the care and support plan for how the personal budget will be spent, including from family or friends; and

- having greater choice and control over the way the personal budget is used to purchase care and support, and from whom.

The personal budget is an important tool that gives the person clear information regarding the money that has been allocated to meet the needs identified in the assessment and recorded in the plan. An indicative amount should be shared with the person, and anybody else involved, at the start of the care and support planning process, with the final amount of the personal budget confirmed as soon as possible. The detail of how the personal budget will be used is set out in the plan. At all times, the wishes of the person must be considered and respected. For example, the personal budget should not assume that people are forced to accept specific care options, such as moving into care homes, against their will because this is perceived to be the cheapest option.

According to Sections 31–33 of the Care Act 2014, a direct payment is a payment of money from the local authority, either to the person needing care and support or to someone else acting on their behalf, to pay for the cost of arranging all or part of their own support. The local authority must provide a direct payment to someone who meets the conditions in the Act and in the regulations. Schedule 1 of the *Care and Support (Direct Payments) Regulations 2014* lists categories of adults whose needs a local authority must not meet by making a direct payment; it includes those released from prison and those involved in drug and alcohol treatment or rehabilitation programmes.

### **Carers**

The local authority's responsibilities for prevention apply to carers, including those who may be about to take on a caring role or who do not currently have any needs for support, and those with needs for support that are not being met by the local authority or other organisation.

According to *Factsheet 8* published by the UK Department of Health, *The Care Bill – the law for carers*, a local authority and a carer will agree a support plan, which sets out how the carer's needs will be met. This might include help with housework, buying a laptop to keep in touch with family and friends, or becoming a member of a gym so that the carer can look after their own health. It may be that the best way to meet a carer's needs is to provide care and support directly to the person that they care for; for example, by providing replacement care to allow the carer to take a break.

Carers should receive a personal budget, which is a statement showing the cost of meeting their needs, as part of their support plan. It will include the amount the carer will pay, if any, and the amount the local authority is going to pay. Carers have a right to request that the local authority meets some or all of such needs by giving them a direct payment, which will give them control over how their support is provided.

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### **Useful website**

<http://www.nhs.uk/choiceintheNHS/Yourchoices/personal-health-budgets/Pages/about-personal-health-budgets.aspx>

## Appendix 4 The Netherlands

### 4.1 Legislative and governance frameworks

Following active promotion and campaigning by the patients' rights movement and the disability movement throughout the 1980s and 1990s, personal budgets (persoonsgebonden budget or PGB) were first introduced into the Dutch healthcare system in 1996 as a 'major innovation' of the Dutch welfare state, supported by both left-wing and right-wing parties (Kremer, 2006). Personal budgets were introduced as an alternative to care in kind. Access to personal budgets was controlled and regulated under long-term care legislation, specifically the 1968 Exceptional Medical Expenses Act (AWBZ). Following the creation of the 2007 Social Support Act (WMO), the responsibility for providing domestic care (and a personal budget to fund domestic care) to eligible individuals was transferred and decentralised to the municipalities and removed from the AWBZ. While the AWBZ is primarily focused on intramural care (hospital/institution-based care), the WMO is administered by the 441 municipalities and is mainly focused on providing extramural (community-based) support.

In 2012, following political pressure to reduce a consistent overspend in the national long-term care budget and as a response to allegations of fraudulent use of personal budgets, eligibility for personal budgets for AWBZ care was restricted to those whose impairments were severe enough to require residential care. This curtailment of eligibility pre-empted additional reform, much of which has been enacted since January 2015. These reforms came about for the following reasons:<sup>25</sup>

- The AWBZ was originally designed to cover exceptional medical expenses that would otherwise not be covered by traditional health insurance. Over time, additional care options have been added to AWBZ, increasing its total expenditure.
- Under the AWBZ, long-term care has become highly institutionalised, with more individuals residing in residential facilities with comprehensive care. The aim of reform is to keep people in their own homes longer, responding to their personal situation and determining what they can still do themselves or with help from their social network, when necessary with support from the municipality or care provided under a care insurance scheme.
- Since its enactment in 1968, the number of people receiving care under the AWBZ has grown substantially. In 1968, it was projected that 0.6% of the total population would require care under the AWBZ. In 2012, that proportion had risen to 5% of the total population. The number of individuals availing of personal budgets under the AWBZ grew substantially since their introduction, from 13,000 in 2002 to 130,000 budget holders in 2012. Expenditure on personal budgets during this time rose by an average of 23% annually (from €414 million in 2002 to €2.2 billion in 2012). By contrast, the expenditure on care in kind rose by 4% annually.<sup>90</sup>

As of 2015, under the reformed system, many entitlements that were that part of the AWBZ have been transferred to the following four Acts, depending on the nature of the entitlement. Together they aim to provide a coherent legal framework within which healthcare can be delivered 'according to the desires, capabilities and needs of individual people.'<sup>25</sup> A personal budget is available for care under all the following Acts:

- **The Long-term Care Act (WLZ)**  
Like the AWBZ, the WLZ is part of the social security system and all residents in the Netherlands are automatically insured, as are non-residents who work in the Netherlands. The insurance is financed through contributions. The new Act covers all forms of care for people with serious, long-term care needs who require intensive care or supervision at close hand 24 hours a day, including vulnerable old people and people with severe disabilities. The Act governs care in institutions and at home. Benefits may be in kind, on the basis of a personal budget, or be made up of a combination of the two. Care is granted on the basis of a care needs assessment. Just like the AWBZ, the WLZ provides a right to long-term care for individuals who qualify following a needs assessment by the CIZ. In other words, the WLZ remains a rights-based programme.

- **The Social Support Act (WMO 2015)**

The primary objective of WMO 2015 is to enable individuals to live independently for as long as possible in their own homes and to participate in society. The Dutch municipalities have responsibility for the implementation and policy making for this. WMO 2015 is not social insurance, but is instead part of the welfare legislation in the Netherlands. Examples of support that fall under WMO 2015 are support for participation, support for independent living, support in cleaning the house and support for informal care. Unlike the WLZ, the WMO is based on a provision-centred approach. While WMO 2015 provides a right to care, municipalities have significant discretion in choosing how they implement this Act. It is not stipulated in advance what kind of provisions can be applied for. The aim is to allow municipalities to ‘tailor’ the way care and support is provided for. When assessing whether someone should receive tailored care or support, the municipalities can review the overall situation of the individual. Municipalities can assess whether and to what extent an individual’s own social network or existing circumstances can suffice in enabling the individual to live independently and participate in society. Clients can appeal the decisions if they disagree.

- **The Youth Act (Jeugdwet 2015)**

All care that is provided because a person is suffering from a mental disorder – as well as mental health care, parenting support and social support provided to children under the age of 18 years – have been decentralised under the Jeugdwet 2015. Extension of the care provided under the Jeugdwet is possible up until the age of 23 years if there is no other Act that regulates the type of care provided. Most entitlements to care for disabled children and young people previously part of the AWBZ have been transferred to the Jeugdwet. In addition, entitlements to, and provisions for, youth-related care under the ZVW (see changes in the basket of care above) and the old WMO (social support and care provided by the municipalities) have been transferred to the Jeugdwet. Care that is covered by the WLZ or the ZVW is not part of the Jeugdwet. The Jeugdwet is also implemented by the municipalities and has similar aims – that children should be enabled to grow up in a healthy and safe way towards independency, self-reliance and participation in society; all dependent on their age and level of development.<sup>25</sup>

- **The Health Insurance Act (ZVW)**

In addition to the regular ‘basket of services’, several additional benefits in kind have been transferred to the Health Insurance Act (ZVW) as a result of the repeal of the AWBZ:

- Care related to sensory disabilities
- District nursing services (and a personal budget for district nursing services)
- The second and third year of treatment-focused intramural mental health care

District nursing services were transferred to the Health Insurance Act (ZVW) to centralise all district nursing services under one Act. The measure is aimed at allowing individuals to stay at home for as long as possible.

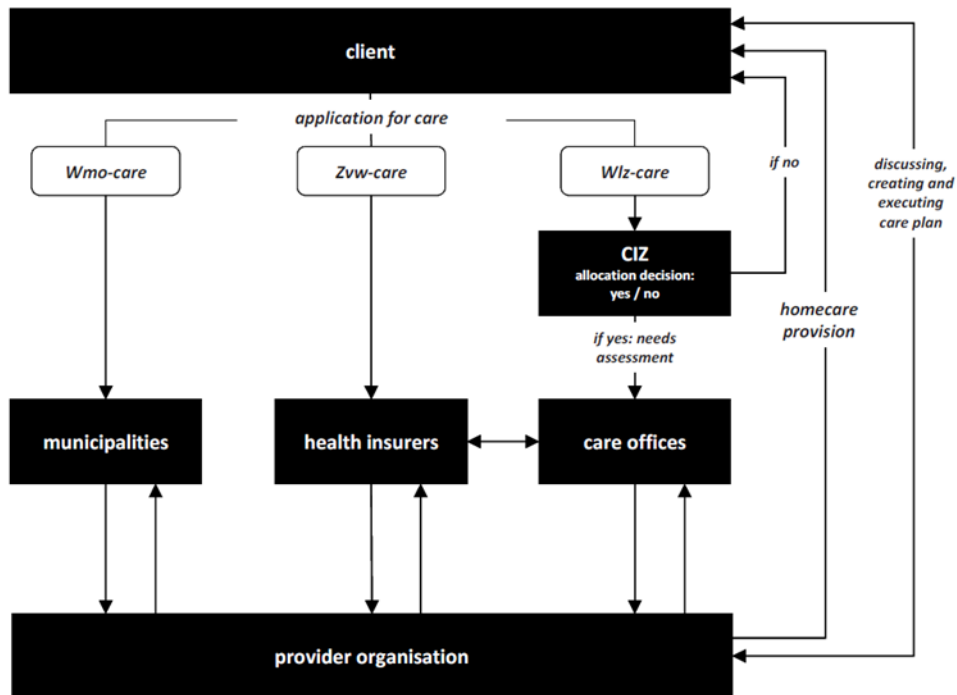


Figure A4.1 Long-term care provision in the Netherlands up to 2015  
Source: Peeters<sup>91</sup>

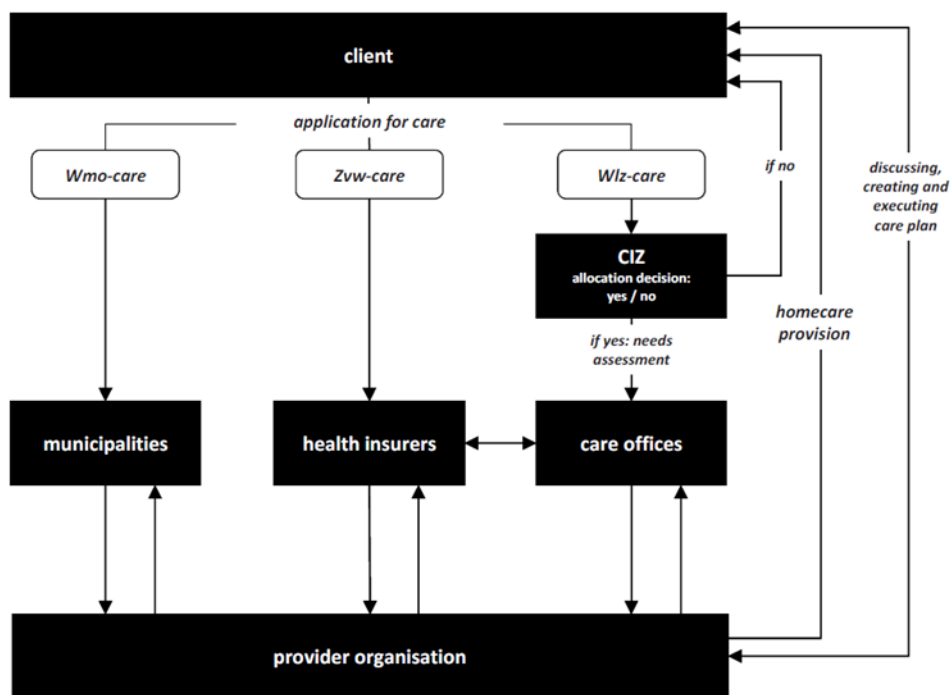


Figure A4.2 Long-term care provision in the Netherlands after 2015  
Source: Peeters<sup>91</sup>

#### 4.2 Primary motivation

With regard to people with disabilities, in June 2015 the Dutch government approved a plan of action for implementing the UN Convention on the Rights of Persons with Disabilities. The plan was

proposed by Martin van Rijn, State Secretary for Health, Welfare and Sport and will now be presented to parliament. The plan of action was drawn up jointly with parties in the field, such as the Alliance for implementing the UN Convention, the Association of Netherlands Municipalities (VNG), the Confederation of Netherlands Industry and Employers (VNO/NCW) and MKB-Nederland, who are keen to play a role in implementing the Convention. The Convention aims for all people to be able to participate fully in society, regardless of whether they have a disability. Ratification of the Convention was included in the second Rutte government's coalition agreement.<sup>92</sup>

In the past, the underlying philosophy of the Dutch long-term healthcare system has been one of state responsibility for the chronically ill, sick elderly and others who are in need of long-term care. In addition, informal care given by family and relatives has played a role. There is, however, no obligation to provide this care. The recent economic recession and doubts over the long-term sustainability of the long term care system has driven reform.

The general policy goal for long-term care was formulated in 2008 'to ensure that for persons with a long-term or chronic disorder of a physical, intellectual or psychological nature, care of good quality is available and that the cost level of this care is acceptable to society.'<sup>93</sup> The recent ideological shift to a 'participation society' has driven reform for long-term healthcare; as a result, the legislation and regulation of personal budgets is also changing. The aim of reform of long-term care is to keep people self-supported for as long as possible, and to ensure that long-term care is affordable, accessible and of good quality into the future. The new Long-term Care Act, which commenced in January 2015, forms 'the political realization of the participation society: people are expected to decrease their dependency on state provisions and instead become self-sufficient or dependent on family and community solidarity.'<sup>94</sup>

Kremer describes personal budgets, first introduced in 1996, as a 'major innovation' of the Dutch welfare state, which were initiated by the patients' rights movement and the disability movement and supported by left-wing and right-wing parties. Kremer asserts that the personal budget strengthens patients as consumers, and increases competition between providers, thus increasing efficiency.<sup>24</sup>

The 2015 long-term care policy reform aims to ensure future solidarity of the system and care and support for the most vulnerable people in society. The new long-term care system has been set up based on the following four principles:

1. Quality of life: the starting point of the new system is to focus on people's capabilities rather than disabilities.
2. Taking care of each other: when one needs support, one's own personal network and financial capabilities come first in providing support.
3. For those who do not have the (financial) capabilities to support themselves, care and social support is always provided.
4. Those who need care, assistance and supervision permanently are entitled to care under the WLZ.<sup>25</sup>

### **Governance**

The Ministry of Health, Welfare and Sports (VWS) is politically responsible for health and long-term care in the Netherlands. The Ministry is responsible for the WLZ, ZVW and WMO; it designs the governance schemes, decides on the coverage of WLZ expenses and entitlements and sets an annual total budget for WLZ expenditure. In order to implement and administer WLZ, the Ministry uses a number of government organisations:

- CIZ (Centrum Indicatiestelling Zorg), Centre for Care Assessment for assessing long-term care needs;
- CVZ (College voor Zorgverzekeringen), the Health Insurance Board for advice on Coverage package and financial consequences, and for overseeing Regional Care Offices that allocate care;
- NZa (Nederlandse Zorg Autoriteit), the Netherlands Healthcare Authority for monitoring conditions of competition among health insurers and setting tariffs;

- CAK (Central Administratie Kantoor), the Central Administration Office for financial administration and payments;
- IGZ (Inspectie voor de Gezondheidszorg), the Health Care Inspectorate for inspection of health and quality of care.<sup>95</sup>

The core of the WMO's philosophy is based on decentralised powers where the role of the Ministry of Health, Welfare and Sport is supervisory. Unlike care provided under the AWBZ and the WLZ, social support (WMO) is not a right. Municipalities are obliged to help people to participate in society and the community, but they are essentially free to design and implement WMO policy as they see fit, which can cause a variation in available services across the municipalities.<sup>51,96</sup> Underlying the WMO are the 'steering principles' that as much social support as possible should be given by third (private) parties and that those should be selected through market principles. In addition, the municipalities are legally bound to EU tendering legislation.

Although municipal offices are responsible for providing WMO support, they can outsource service provision, needs assessment and billing to other organisations:

- **De MO-zaak** is a commercial division of the CIZ, performing needs assessment for WMO support for many municipalities. If the client gives his or her consent, MO-zaak has access to AWBZ/WLZ data on previous and current needs assessment indications and care utilisation of the client.
- **Service providers.** Many municipalities establish contracts with commercial service providers on a yearly basis to ensure that providers remain efficient through competition. Service providers include volunteers, domiciliary care providers, taxi companies, companies providing instrumental aids (such as wheelchairs), and more.
- **Central Administration Office (CAK).** Municipalities often second the calculation of client contributions to the CAK.<sup>51</sup>

The responsibilities of the municipality under the WMO include:

- Setting the criteria for WMO eligibility, as well as the fees of clients' compulsory contributions. Eligibility criteria and client co-payment can vary widely by municipality.
- Needs assessment or adopting assessment provided by the CIZ or another qualified organisation. When the municipality takes responsibility for setting needs assessments, they must use the *International Classification of Functioning, Disability and Health* (ICF).
- Provision of services (provision of personal budgets and social support services in kind), or outsourcing service provision to a commercial service provider.
- Managing complaints and requests for assessment.
- Budget decisions: Municipalities receive money through municipal taxes and the municipal fund, administered by the national government.<sup>48</sup>

Putters *et al.* describe the WMO as 'framework legislation' that includes procedural and minimum requirements.<sup>26</sup> For example, it does not prescribe what the exact nature of the personal budget and personal contribution policy should be. However, boundaries or guidelines on which to base decisions have been put in place. In addition, the 'participation concept' has not been clearly defined, enabling municipalities to interpret this as they see fit.

Tjadens has noted that moving the responsibility for funding domestic care from the social insurance-based AWBZ to the municipalities involves a significant loss of entitlements, and access to domestic care is now entirely dependent on discretionary municipal budgets.<sup>97</sup> Moreover, locally devised and conducted assessments, previously only applicable to transport and home modifications, have now been extended to cover access to domestic care. As a result, local and regional variations in access arrangements may develop, reflecting individual municipal budgets and local political priorities. In addition, while in principle the WMO legislation allows municipalities to offer personal budgets for domestic help, most municipalities have concentrated on providing domestic help services in kind from contracted providers; only about a quarter of those receiving domestic help under the new WMO legislation receive this in the form of a personal budget.<sup>97</sup>

### 4.3 Eligibility and entitlements

#### **WLZ**

In order to be eligible for long-term care (WLZ) in the Netherlands, there are residency requirements, and individuals must take out the mandatory basic health insurance package (ZVW). In addition, residents are required to pay a WLZ premium – a fixed percentage of an individual's income. The premium is automatically deducted from wages or benefits. For individuals aged under 18 years, the government pays the premium on their behalf. In 2015, this premium was reduced to 9.65% of income. (In 2014 the premium paid under the AWBZ was 12.65% of income.) However, the decrease was offset by a 3% tax rate increase hike in the first and second income tax bracket.<sup>98</sup>

To determine eligibility for WLZ care, clients must request an indication or needs assessment from the CIZ. It is important to note that there are no eligibility requirements for the needs assessment itself. The CIZ carries out an objective, standardised investigation into personal circumstances and environment, which is checked against the following mandatory criteria:

- Is there continuous need for client monitoring or supervision?
- Is 24-hour care available in the neighbourhood?

An application for needs assessment can be made by a client, or on their behalf by a carer or companion. Consultation can also be arranged with a free independent client supporter. The CIZ, in principle, provides an outcome to the needs assessment within six weeks. The CIZ may invite clients to its offices, or may visit clients in their home, and may request additional information if necessary.<sup>42</sup>

Care under the Long-term Care Act (WLZ) may include:

- stay in an institution;
- care at home (if it is feasible and does not cost more than care in an institution);
- personal care and nursing;
- medical care (medical care which is necessary in connection with the illness, disability or disorder, as well as general medical care);
- tools that are necessary for the care provided by the institution;
- transportation to the place where the client receives counselling or treatment.

Possibilities for home care include:

- **Full home package (VPT)**  
With a complete package, clients get full care and support in the home, including meals, domestic help and outings. Rent or mortgage on the home remains the responsibility of the client.
- **Modular home package (MPT)**  
A client can receive care delivered by different providers. With MPT, no meals or household help is provided. Rent or mortgage on the home remains the responsibility of the client.
- **Personal budget (PGB)**  
With a personal budget, the client organises a contract for care with a carer of their choosing. The care must be of good quality, and the client must have the capability to manage their budget. The personal budget is deposited into an account in the State Bank, SVB, and the carer is paid from that account. (This measure was designed to prevent fraudulent use of the personal budget – an issue that has been highlighted in recent years.) The SVB offers this service and more to help administer and manage personal budgets for WLZ and WMO care. The personal budget for WLZ and WMO care is set at a rate of 66% of rates paid for services in kind.<sup>47</sup>

#### **WMO**

Municipalities have discretionary power with regard to conducting a needs assessment and providing for assessed needs. They can formulate their own criteria to determine who qualifies for publicly funded services (including personal budgets).

Generally, the municipality outsources the provision of social support services to commercial organisations. Each municipality decides whether client contributions are required, and if so, how they are calculated. Municipal workers can calculate and bill these contributions themselves, or these tasks can be outsourced to the CAK. Client contributions are usually required for domiciliary care, instrumental aids, home modifications and personal budgets.<sup>51</sup> Some municipalities use the CIZ process to conduct needs assessments and others have designed their own services. De Decken and Maarse note that this may lead to unequal access, where some municipalities pursue a generous policy and other municipalities may opt for a less generous policy.<sup>52</sup>

Individuals who wish to obtain WMO care must apply to their municipality, usually to a specific 'WMO Help Desk.' A care assessment is undertaken (by the municipality or the CIZ) taking into account:

- personal and family situation;
- client preferences;
- availability of additional care under different legislation.

Applicants have the right to be assisted by an independent client supporter during the assessment process, and the municipality must arrange this. There is no charge for this service. Municipalities are required to conduct the assessment within six weeks of application.

If the assessment shows that an individual is not sufficiently self-reliant to participate in society, and cannot receive such support from their social network, then the municipality is obliged to offer support by providing options of customised services and general services.<sup>43</sup>

### ***PGB (WLZ and WMO)***

Clients who receive an indication for care from the CIZ may opt for a personal budget. Applications for a WLZ personal budget is made to the Care Office, which arranges an interview to decide if the personal budget is the best solution. The main conditions are:

- Clients have a budget plan describing the care they are to purchase.
- Clients have a proper contract or care agreement with a carer.
- The SVB (the Dutch social insurance bank) manages payment of the caregiver (And SVB must approve the contract or care agreement).

**SVB (Sociale Verzekeringsbank)** is the organisation that implements national insurance schemes in the Netherlands. In addition, it provides services for WLZ and WMO personal budget holders called 'Betaling en overzicht' whereby people do not receive a personal budget directly but spend it through carers and care institutions. The SVB also offers the following services:

- advice on employment law, employers' obligations, sick pay and occupational health and safety services;
- model agreements covering various situations;
- collective liability insurance and legal assistance;
- help with salary administration;
- annual and quarterly reports on the SVB services provided.

The SVB's role in this is to assist a number of municipalities as cashier for the personal budget (PGB). The budget holder remains in control of how the budget is spent, but the budget is not paid into his or her bank account. The SVB pays carers and care institutions a monthly sum on behalf of the budget holder. Both the budget holder and the municipalities receive payment summaries showing what has been spent and how much is still left. These payment summaries can also be viewed online via My PGB. Because the SVB administers the budget and the budget holder no longer receives the money directly, the financial risks for the municipalities are greatly reduced. For example, municipalities will not have to reclaim a personal budget from a budget holder if only part of the budget has been used. The SVB will then pay the remaining amount back to the municipality at the end of the year.<sup>99</sup>



## **MEE**

Since 1 January 2015, any person who needs support can use an independent client support agency. Municipalities are obliged to make this available through the Social Support Act (WMO). Almost all municipalities have made agreements with MEE. **MEE** is an independent organisation that supports people with disabilities and their network in all areas of life and in all life stages, including:

- people with mental, physical, sensory or mental disability;
- people with chronic illness;
- the elderly;
- people with brain injury;
- people with autism.

MEE provides assistance helps with:

- education and development;
- learning and working;
- cohabitation and living;
- regulatory issues and funding.<sup>100</sup>

## **Per Saldo**

Per Saldo is an advocacy group for budget holders. Per Saldo also provides information and advice on the PGB.

## **CAK**

Every region in the Netherlands has a care office. Care offices contract healthcare providers to deliver the care that a client needs on the basis of the indication set by the CIZ. The Central Administration Office (CAK) pays the costs and is billed by the healthcare provider. The amounts paid by the CAK to healthcare providers are standardised amounts for every needs assessment.<sup>48</sup>

## **Financing**

### **WLZ**

The WLZ personal budget is paid from the WLZ scheme. Similar to its predecessor (AWBZ), but providing more limited cover, WLZ is a national mandatory, contribution-based insurance scheme. WLZ insurance premiums are calculated as a percentage of an employee's income. In 2013, the AWBZ premium was set at 12.65% of income and the maximum amount paid was approximately €4,270 per year. Long-term care services, including WLZ personal budgets, are funded from a central WLZ fund comprising WLZ premiums, government contributions and client contributions. In previous years, the breakdown for the AWBZ fund was as follows: AWBZ premiums (68%, via the national tax office), government contributions (24% paid on behalf of persons aged under 18 years who do not pay income tax) and user co-payments (8%).<sup>49,101</sup> It is not yet clear if the WLZ fund will have a similar breakdown.

In addition to paying insurance premiums via income-related deductions, clients are required to make a co-payment (frequently referred to in the Dutch literature as a contribution) depending on their income, age, marital status, and stage of care. In 2013, the co-payment paid during the first six months of care ranged from €152 to €798 per month. After six months, a higher payment is required, with a maximum monthly co-payment of €2,189. The amount of the contribution is determined by the CAK, which also collect the contribution.

Since 2013, 8% of an individual's private savings and assets (above a State-set threshold of €21,000) are accounted for in the calculation of the co-payment.<sup>101, 102</sup>

In 2015, the new WLZ premium was set at 9.65% of income. The WLZ contribution is 3% lower than the AWBZ contribution. However, this is offset by a 3% tax rate increase in the first and second income tax bracket (Deloitte 2015). In 2015, the maximum income amount subject to the contribution was €33,589 and the maximum monthly co-payment was €2,284.60 per month.<sup>98</sup>

## **WMO**

The WMO personal budget is paid from the WMO scheme. The WMO is a tax-funded scheme which is operated by the municipalities. Municipalities receive a State grant to implement the WMO and have discretionary power in its implementation.

Prior to the reform of the WMO, municipalities received funding from the national government through the Municipal Fund. Since 2007, additional funds were provided to cover the costs of new services outlined in the reformed Act (i.e. a personal budget for domestic assistance). This so-called 'integration payment' is adjusted each year, based on advice by the SCP (the Netherlands Institute for Social Research). The remainder of the budget is increased annually according to a standard growth rate.<sup>26</sup>

When the macro budget is determined, the division of funds for domestic assistance within the WMO is based on a newly developed 'objective model'. This model ended a situation in which historical figures determined the funding a community received; the division is now based on objective measures of the composition of the population of each respective community.<sup>26</sup>

The new objective model divides approximately €1.5 billion annually across the 413 municipalities. The budget is strictly limited and expenses that exceed the budget are not compensated, which means that the budget is fixed even when the exact demand is determined at a different level, i.e. at the municipalities' WMO offices, making the new objective model a typical risk-adjustment system. The division of means is determined for the forthcoming year and there is no ex-post recalculation. If individual municipalities either exceed or manage to stay within their budgets, there is no legitimate ground for compensation and/or other reclaims. The responsibility for whether or not to exceed the budget therefore lies with the municipality.<sup>26</sup>

### **Personal contribution WMO 2015**

Municipalities may ask for a personal contribution for the support they provide, and each municipality sets its own client contribution fees. The calculation and billing of the personal contribution may be undertaken by the municipality or outsourced to the CAK. If the CAK administers the client contributions, the required information on service usage is provided by the municipality or the service company, and information on income is provided by the tax office. Client contributions are usually required for domiciliary care, instrumental aids, home modifications and personal budgets.<sup>51</sup>

Note: PGB is not considered as income for budget holders. A recipient of a WLZ personal budget can apply for a WMO personal budget (or other benefits) and their WLZ personal budget will not impact on their eligibility.

## Appendix 5 New Zealand

### A5.1 Legislation and governance

Under the New Zealand Public Health and Disability Services Act 2000, disability support services include goods, services and facilities that are provided to people with disabilities for their care or support, or to promote their inclusion and participation in society, and independence, or for related or incidental purposes. In 2003, in order to create national consistency and reduce the risk of funding abuse, both of which had been problems with the previous incremental arrangements for 'discretionary funding' for goods and services for individuals with disabilities, the Ministry of Health piloted an 'individualised funding' (IF) programme. An evaluation of this pilot in 2008 found that although IF was producing positive benefits, the number of people receiving the funding was less than expected. Over the next two years the Ministry of Health opened up the eligibility criteria to include all individuals, rather than limiting it to high-cost/high-need packages, and increased the number of IF host providers. The intention was to substantially increase the number of people for whom IF was a valid alternative to traditional support services (Synergia 2011).

During the same period, the government's Social Services Select Committee was hearing submissions from disabled people, their families and service providers that they were generally unhappy with how services were being delivered. Services were uncoordinated and often difficult to access; existing services and support were inflexible; and there was little choice in how support was delivered (Social Services Select Committee 2009; NZ Government 2009). In response, the government adopted a new way of providing support, so that disabled people could have the life they aspired to like other New Zealanders (Cabinet Paper Office of the Associate Minister of Health, 2010). This 'new model for supporting disabled people' has four underpinning principles:

- *improved access to information and personal assistance* through introducing 'local area coordination';
- *allocation of funding not services*, including greater reliance on self-assessments and relevance to individual needs, but balanced by clearly defined rules about what funding can and cannot be used for;
- *more choice and control* for people over the support that can be purchased by means of individualised funding; and
- *stronger accountability* through concentrating on quality monitoring of whether people are living an 'everyday good life'.

Since 2011, the Ministry of Health has been rolling out projects demonstrating the various elements of this 'new model', and evaluating them on a rolling three-year cycle:

- [Local Area Coordinators](#) (LACs), to assist disabled people to plan for a good life, demonstration project launched in 2011 and two developmental evaluations completed (Evaluate Research 2012; Roorda *et al.*, 2014);
- [Choice in Community Living](#) (CiCL), an alternative to existing residential services, established as a demonstration project in 2012, and a developmental evaluation undertaken in 2013 (Evaluate Research 2014); and
- [Enhanced Individualised Funding](#) (EIF), to enable more choice and control over funding, piloted in 2013.

In August 2015, towards the end of the three-year demonstration of the 'New Model for Supporting Disabled People', a report was published assessing the extent to which the components of the 'new model' had contributed to increasing choice and control for disabled people over the way they live and the support they receive (Roorda *et al.*, 2015). This evaluation covers CiCL and EIF, and also considers whether CiCL and LACs can be implemented in a fiscally neutral way.

The Ministry of Health has overall policy responsibility for disability support services, including IF and EIF, whereas three categories of contracted non-governmental entities – Needs Assessment and Service Coordination (NASC) organisations, IF host providers, and local area coordinators – have responsibility for administration and service provision.

### ***Needs assessment and service coordination organisations (NASCs)***

NASCs are organisations contracted by the Ministry of Health to work with disabled people to:

- identify their strengths and support needs;
- outline what disability support services are available, and
- determine their eligibility for Ministry-funded support services.

In other words, the NASC:

- undertakes a needs assessment that looks at the individual's abilities, resources, goals and needs and works to identify which of these is most important. The goal of the needs assessment is to figure out how to maximise the person's independence and ability to participate as fully as possible in society;
- organises a package of services to best suit the disabled person. The NASC will take into account which needs and goals matter most to the disabled person and their family, whānau, aiga or carers (as determined during the needs assessment process); and
- figures out what support options are available. These might include both funded disability support services and support from people in the disabled person's networks or community.

The contract the Ministry has with NASCs requires three things:

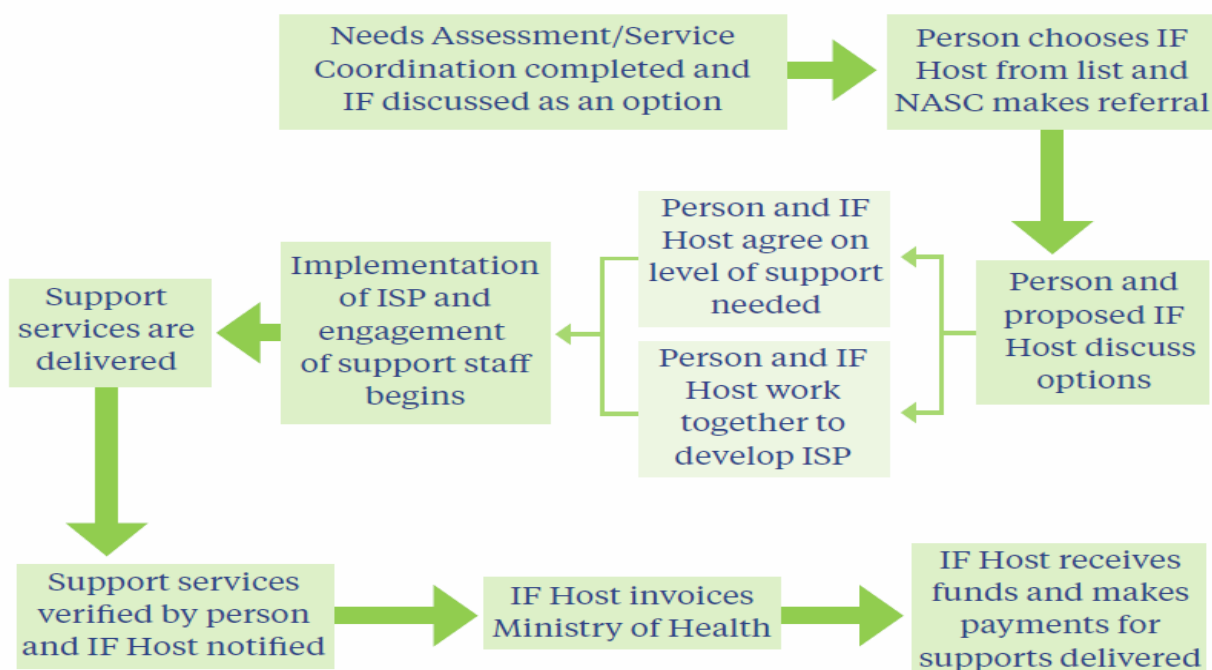
- facilitating the needs-assessment process;
- service coordination, which includes:
  - giving information about options
  - planning and coordinating the supports in a Support Plan
  - allocating some DSS-funded support services; and
- fair and cost-effective management of the Ministry-funded Disability Support Services.

The Needs Assessment and Service Coordination Association (NASCA) is a not-for-profit organisation for people who manage NASCs. Membership is voluntary, but all Ministry-contracted NASC managers are members.

### ***IF host provider***

The IF host provider is a (contracted) Ministry of Health provider who provides the IF scheme to disabled persons. The IF host provider meets with the disabled person to develop an Individual Service Plan (ISP), which implements the Support Plan and is designed to meet or contribute to the achievement of the disabled person's goals. Under IF, the host provider offers a menu of services, at three levels outlined below in Section 5.6, on Finance. Service level 1 is provided by the IF host to all disabled people who choose IF as a way to purchase their Home and Community Support Services (HCSS). IF host providers may offer additional service options (at additional costs) to suit individual needs.

## How IF works



Source: Ministry of Health (2012), p. 6

### Local Area Coordinators

Local Area Coordinators (LACs) are being trialled as part of the new model for support of disabled people.

LACs support disabled people and their families/whanau and/or family carers to strengthen connections with their communities and receive the support they need, and they engage with and support communities to become more welcoming and inclusive of disabled people by:

- building and maintaining effective relationships with disabled people, their families/whanau and their communities;
- providing accurate and timely information about local communities, supports and services;
- working with local communities, hapu and marae to ensure that disabled people are included and can contribute to their communities and
- assisting disabled people and their families/whanau to clarify their goals, strengths and needs and to plan for a good, everyday life;
- use local community networks to develop practical solutions to meet their goals and support needs
- access supports and services.

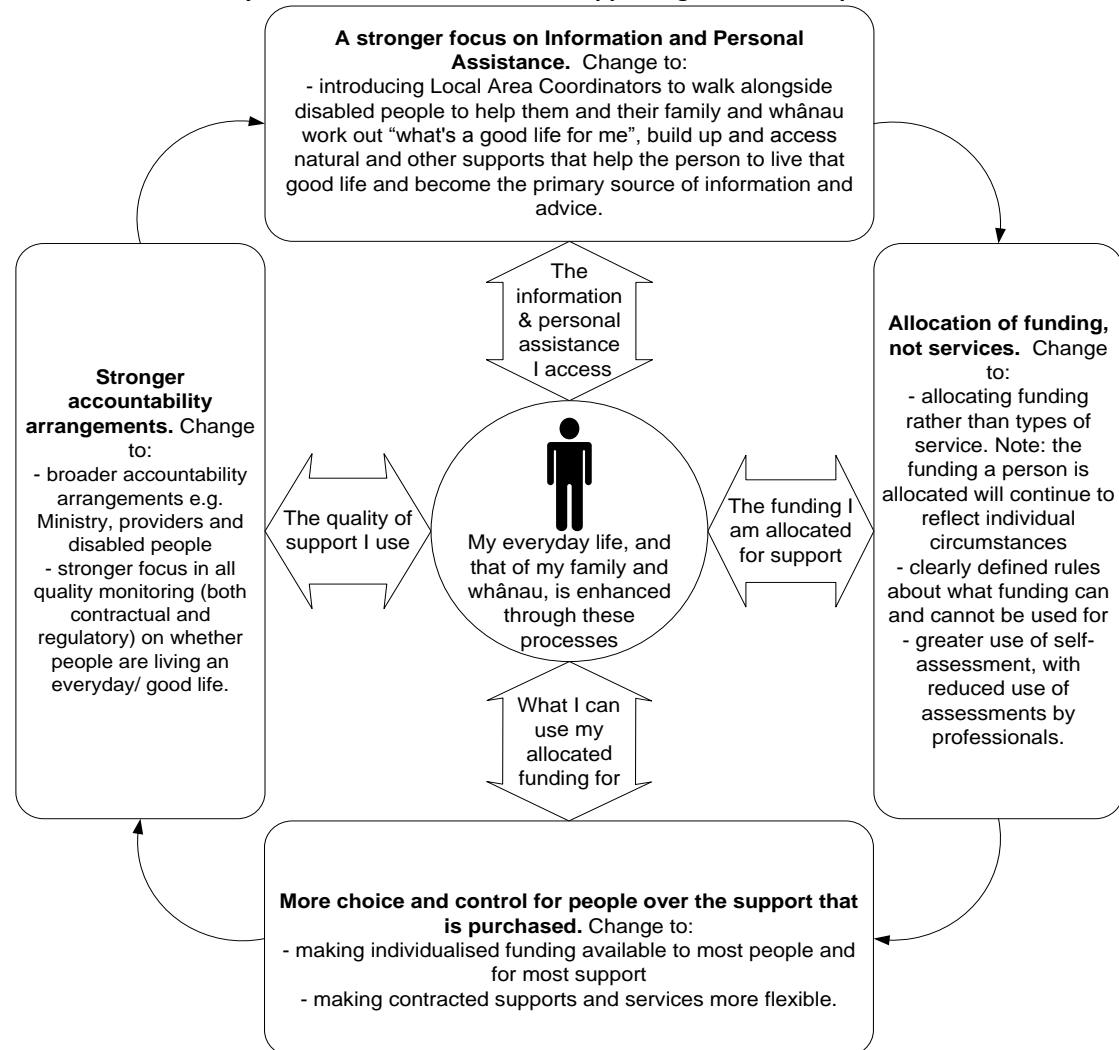
There are two levels of support:

- short-term support: sharing of information and initial assistance, and
- long-term support: in building networks and planning for a good, everyday life.

### A5.2 Outcomes/principles/values

The graphic below summarises the new model adopted by the New Zealand government for supporting people with disability, which includes their approach to individualised funding. This 'new model' is about people having more choice, control and flexibility, including over how they use their funding and the disability supports they buy with this funding.

## New Zealand Ministry of Health's 'New Model for Supporting Disabled People'



Source: Associate Minister of Health: Minister for Disability Issues (15 June 2010) *Cabinet Social Policy Committee Paper - Ministry of Health's New Model for Supporting Disabled People*. Downloaded on 16 July 2015 from <http://www.health.govt.nz/our-work/disability-services/new-model-supporting-disabled-people>

### 5.3 Eligibility

#### **Individualised funding (IF)**

Individualised funding (IF) is available for people who meet the Disability Support Services (DSS) group's definition of being disabled and have been allocated Home and Community Support Services (HCSS).

#### *Eligibility for assessment for Ministry-funded Disability Support Services (DSS)*

People are eligible for a needs assessment for disability support services if they have a physical, intellectual or sensory disability (or a combination of these), which is likely to continue for at least six months and limits their ability to function independently, to the extent that ongoing support is required. Those eligible are mainly younger people under the age of 65 years. The Ministry also funds DSS for people with some neurological conditions that result in permanent disabilities; some developmental disabilities in children and young people, such as autism; and physical, intellectual or sensory disability that coexists with a health condition and/or injury.

The Ministry of Health does not generally fund disability support services for people with personal health conditions such as diabetes or asthma; mental health and addiction conditions such as schizophrenia, severe depression or long-term addiction to alcohol and drugs; and conditions more commonly associated with ageing such as Alzheimer's disease. Disability support services are also not funded for most people with impairments such as paraplegia and brain injury caused by accident or injury: the Accident Compensation Corporation (ACC) has been responsible for funding these support services since 1974. In most cases, district health boards fund disability support services for older people, including people with disability aged 65 and over assessed as requiring aged residential care, and those with mental health needs.

#### *Eligibility for Home and Community Support Services (HCSS)*

Home and Community Support Services, comprising household management and personal care, are available for people who:

- are aged under 65 years;
- meet Disability Support Services' eligibility requirements, and
- have had a needs assessment confirming that they require home-based support services.

Household management is only available to people who have a Community Services Card, and to children under the age of 16 whose parents/caregivers have a Community Services Card.

For IF, the assessment process is as follows (Ministry of Health 2012):

1. the NASC undertakes a needs assessment and discusses IF as an option;
2. the applicant chooses an IF Host and the NASC makes the referral; and
3. the person and the IF Host discuss the options, agree the level of support needed, and work together to develop an ISP.

#### ***Enhanced individualised funding (EIF)***

The same eligibility requirements apply as for IF, but recipients of EIF are no longer restricted to receiving HCSS only. In Section 5.4 below, Entitlements, the expanded range of possible supports is described.

The process for assessing eligibility is as follows (Ministry of Health 2013):

1. The Local Area Coordinator (LAC) or Support Net (NASC) advises the person whether EIF is a relevant option. If it is, the person is encouraged to talk to their family and to people such as their LAC about the life he/she wants and the dreams he/she has. Together, the person and the various stakeholders create a document that outlines these goals, agrees on a plan on what needs to happen for the person to achieve his or her dreams.
2. The NASC helps the person through an assessment process to establish the amount of funding.
3. The person is then referred to a host organisation that will work with him or her to manage the budget.

### **5.4 Entitlements**

Starting in 2013, and as part of the 'new model for supporting disabled people', an 'enhanced individualised funding' (EIF) programme, enabling more choice and control over funding by the individual with a disability, has been piloted in two regions of New Zealand. In the account that follows, the features of both the original IF and the EIF programmes are described. The information has been taken from the Ministry of Health's website and from two publications – *Your guide to individualised funding* (Ministry of Health 2012) and *Purchasing guidelines for the new model for supporting disabled people* (Ministry of Health 2013).

#### ***Scope***

**IF** can be used to purchase HCSS provided by support workers (employees or contracted personnel or organisations), and to cover costs relating to the employment of support workers. HCSS help disabled people to live at home. They can provide help with household management and personal care. Household management may include help with:

- meal preparation;
- washing, drying or folding clothes, or
- house cleaning, vacuuming and tidying up.

Personal care may include help with:

- eating or drinking;
- getting dressed or undressed;
- getting up in the morning or getting ready for bed;
- showering or going to the toilet, or
- getting around the home.

Although other Ministry-funded disability support services can be allocated as part of a wider support package, IF cannot be used to manage services such as day and/or vocational services, rehabilitation services, supported living, or respite provided in Ministry-contracted facilities, carer support, residential services in Ministry-contracted facilities, information and advisory services, equipment or home modifications, child development services, or behaviour support services. These services will continue to be funded separately.

### **EIF**

Under EIF, people are allocated an amount of funding (a budget) and decide what disability supports to buy with that money, rather than having to spend it on a specific service as previously (i.e. HCSS). The individual is given an amount of funding for support and chooses how to use it, based on his or her plan. He or she can pay for support to achieve the goals in their plan, such as employing people to support them, and agree the hourly rates for the support received, or he or she can pay for support to help participate in community activities. Funding support for recreation activities is permitted if such activities are a disability support, contribute to the outcome identified in the individual's plan, and are within the scope of what the Ministry of Health can support.

To ensure that this money is used for its intended purpose, the New Zealand Ministry of Health has developed purchasing guidelines (2013). All uses of funding must meet the following three criteria:

1. The money is spent on disability supports (on things a disabled person needs that they wouldn't need if they didn't have a disability).
2. The disability supports contribute to an outcome in the person's plan.
3. The disability supports are within the scope of relevant Ministry of Health policies and responsibilities.

Each item or type of support a person wants to buy must meet all three criteria. For example, a person may want to buy something that is a disability support and contributes to an outcome in their plan. However, that disability support will not qualify if it is the responsibility of another agency or a district health board, or is not the responsibility of government, as it does not meet the third criterion.

Since 1 October 2013, the Ministry of Health has provided funding for some disabled people to pay a family member to provide personal care and household management. This Funded Family Care Operational Policy (2013) is authorised under Part 4A of the New Zealand Public Health and Disability Amendment Act 2000 (as inserted by section 4 of the New Zealand Public Health and Disability Amendment Act 2013), which came into force on 21 May 2013.

**Choice in Community Living (CiCL)** has been run as a demonstration project since mid-2012 (Evalua Research, 2013; Roorda *et al.*, 2015). Its aim is to 'support people to move out of a residential facility or family home and live independently in their own home in a fiscally neutral way'. The intention is that participants in CiCL should be entitled to the same housing choices as are available to other people (e.g. being an owner or a tenant) (NZ Government 2014). Roorda and colleagues (2015: 23–24) have reported that participants interviewed had moved from residential or family accommodation or some other unsustainable living arrangement into one of several alternative



arrangements, including private rented accommodation, social housing, units attached to their parents' homes, their own home or a house rented by an extended family member.

Entitlements under the CiCL programme are also governed by the Purchasing Guidelines (Ministry of Health, 2013), regarding which the reviewers of CiCL comment that they 'are not prescriptive, allowing interpretation on a person-by-person basis according to their individual circumstances and goals. This approach is intended to give effect to the principles of the New Model, namely, disabled people have increased flexibility, choice and control over the support they buy' (Roorda *et al.*, 2015: 28).

## Process

**EIF** is offered to disabled people who are perceived by the NASC assessor as able to manage a budget, or who have an agent to do so on their behalf (Roorda *et al.* 2015). The Ministry of Health contracts EIF host providers, who provide a mandatory level of service (level 1) which includes:

- working with the disabled person to develop an ISP, which details the use of funded supports;
- supporting the person with advice on the management of support staff and budgets;
- receiving information from the person that verifies the delivery of the support services (such as timesheets or expense claims);
- making sure that the person is fully informed about their entitlements (and any limitation on those entitlements);
- ensuring that all expenditure is within the Purchasing Guidelines;
- assisting and coaching the person in managing their funding budget, and ensuring that expenditure is within funding limits and that no over expenditure of allocated budget is incurred;
- reviewing at regular intervals how the person is managing with the support arrangements to ensure that the provision of the services meets the needs of the person, and
- ensuring that appropriate administrative processes are complied with and appropriate records are kept.

The disabled person decides the level of support they want from the EIF host provider. They can choose to self-manage (level 1) or to purchase additional supports from the EIF host, such as monthly statements, payroll services, completion of tax requirements (i.e. PAYE, Accident Compensation Corporation employer levies and KiwiSaver contributions), membership of the Employers' Association, additional budgeting tools, help with recruitment (levels 2 and 3).

The EIF demonstration project has included the trialling of two new processes – supported self-assessment, and local area coordinators (LACs).

Following a review of **self-assessment** models, practice and tools (MacDonald 2011), the Ministry of Health is trialling a supported self-assessment tool (Ministry of Health 2013b; Roorda *et al.* 2015). The person and whomever he/she chooses to work with, explore the following questions:

- What is the individual's disability and living situation?
- What does the individual want to achieve?
- How does the individual plan to reach his or her goals?
- What are the obstacles to achieving the goals?
- How does an individual's disability impact on their life?
- What supports does the individual receive, including those from family friends, community and agencies?

On the basis of the goals and needs identified through the self-assessment, an amount of funding is calculated, based on the unmet disability support needs. The person can then pay for support to achieve the goals in their plan, such as employing people to support them, and agree the hourly rates for the support received, or he/she can pay for support to help participate in community activities.

Recreation activities are permitted if they comply with the three criteria set out in the Ministry's purchasing guidelines, which were outlined above.

Following a review of **local area coordination**-type processes internationally (Bennett 2009), the Ministry of Health introduced local area coordinators (LACs) as part of the EIF demonstration project. As Table A5.1 illustrates, in comparison to NASCs and host providers, LACs are envisaged as primarily agents for transformative change for individual disabled people and their families.

Individuals may have an 'initial contact' (Level 1 support) with a LAC, during which they are provided with information and/or limited support, without any assessment or formal intake process. Anyone can contact a LAC for Level 1 support. People who meet the Ministry of Health's definition of 'disabled person' may choose to receive ongoing support from a LAC (Level 2), even if they are receiving any other support funded by Disability Support Services in the Ministry. While an evaluation of components of the 'new model' reports that there is as yet insufficient evidence to draw any firm conclusions (Roorda *et al.* 2015), the authors suggest that LACs have the potential to reduce people's need for disability services and support, and also ensure that people do not access higher costs and supports than necessary by:

- linking them to natural and/or community supports;
- supporting and encouraging them to plan and pursue job opportunities, set up their own business or study for a qualification;
- supporting and encouraging them to live as independently as possible, in their own home (p. 60).

**Table A5.1: Overview of roles and responsibilities of LAC, NASC and EIF Host Providers in delivery of Enhanced Individualised Funding (EIF)**

LAC	NASC	EIF Host
Support disabled people in their planning to identify personal goals and desired outcomes.	Support disabled people to do supported self-assessment.	Confirm how disabled people are going to use funding to meet their goals.
Work with disabled people to identify and develop natural supports to replace or complement paid supports.	Discuss indicative allocation with disabled people in light of their goals and desired outcomes.	Coach people how to manage their own support allocation.
If requested, assist with recruitment of support workers, e.g. job descriptions, suggesting recruitment options such as linking into community networks.	Confirm the allocation with disabled people.	Explain employer obligations and set up processes.
If requested, work with disabled people to problem solve and identify solutions for support issues.	Carry out annual reassessment and reviews.	Carry out annual reviews.
If requested, institute crisis management response when support arrangements fall down		Provide additional EIF-related services (e.g. payroll) as requested by the disabled person

Source: Roorda *et al.* 2015: 39

**Choice in Community Living (CiCL)** is also accessed through the NASC assessor, who works with the applicant and his or her family to see if CiCL is appropriate, and then helps the participant through an assessment process to determine the amount of funding he/she will receive. The NASC assessor supplies the participant with a list of support agencies that can help the individual develop a plan and facilitate their move into independent living. The intention is that people 'shop' around for a support agency that works best for them. Once the plan has been signed off by the NASC, the provider helps the participant to make their plan a reality. This includes finding the right accommodation and the right support so that he/she can move into his or her new home and achieve his or her goals. The provider and the participant's family can keep supporting the participant once he/she is in his or her own home, in order to make sure that the plan is working well and that the participant has the right support.

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#### **Useful website**

<http://www.health.govt.nz/our-work/disability-services>

## Appendix 6 Scotland

### 6.1. Legislative and governance frameworks

The **Social Care (Self-Directed Support) Scotland Act 2013 (SDS Act)** provides for individual choice over care and support. This legislation applies to all categories of persons in need of social assistance, including those with a disability, and carers. After a local authority has identified a person's needs – in collaboration with the adult, child/family or carer – it is required to offer four options in relation to the relevant support identified at the assessment stage:

- *Option 1:* The making of a direct payment by the local authority to the supported person for the provision of support.
- *Option 2:* The selection of support by the supported person, the making of arrangements for the provision of support by the local authority on behalf of the supported person and, where it is provided by someone other than the authority, the payment by the local authority of the relevant amount in respect of the cost of that provision.
- *Option 3:* The selection of support for the supported person by the local authority, the making of arrangements for the provision of it by the authority and, where it is provided by someone other than the authority, the payment by the authority of the relevant amount in respect of the cost of that provision.
- *Option 4:* The selection by the supported person of Option 1, 2 or 3 for each type of support and, where it is provided by someone other than the authority, the payment by the local authority of the relevant amount in respect of the cost of the support.

The implementation of the SDS Act depends on provisions in other legislation (Scottish Government 2014):

- the duty to assess an adult's need for care and support established by s.12A of the **Social Work (Scotland) Act 1968**;
- the legal basis for support to children established by ss.22 and 23 of the **Children (Scotland) Act 1995**, and
- the legal basis for the assessment of, and support for, carers established by s.12AA of the Social Work (Scotland) Act 1968, s.24 of the Children (Scotland) Act 1995 and s.3 of the SDS Act.

Legal duties in relation to the assessment of social care needs and the provision of healthcare support are broadly framed by the **Social Work (Scotland) Act 1968** and the **NHS (Scotland) Act 1978**. There is no definitive list of social care and healthcare interventions included in either piece of legislation. This provides a high degree of discretion to health and social care professionals and organisations (Scottish Government 2014: Section 13.7). Under the **Community Care (Joint Working etc.) (Scotland) Regulations 2002 (SSI 2002 No 533)**, an NHS board can transfer money to a council so that a person can receive a direct payment that includes funding from both the council and the NHS. However, there is no obligation on NHS boards to release funds to contribute to a direct payment. The SDS Act only places a duty on councils to offer the SDS options in relation to assessed social care needs. NHS boards only have the duty where councils have formally delegated responsibility for social care to the board (Audit Scotland 2014: 20).

The **Public Bodies (Joint Working) (Scotland) Act 2014** requires NHS boards and councils to establish new health and social care partnerships. Under these arrangements, NHS boards and councils are required, as a minimum, to combine their budgets for adult social care, adult primary healthcare and aspects of adult secondary healthcare. Although the SDS Act does not apply directly to health services, the SDS policy will have implications for health because NHS boards and councils will share money, staff and other resources under the new arrangements. For example, councils can charge people for some social care services, whereas NHS services are free at the point of contact (Audit Scotland 2014: 20).

The **Adult Support and Protection (Scotland) Act 2007** provides the legal framework for the protection of adults who are unable to safeguard their own interests. A local authority should ensure that there is an effective link established between their adult support and protection duties, child protection duties and their wider well-being, social care assessment and social welfare duties under the 1968, 1995 and 2013 Acts.

### **Local authorities**

Scotland's 32 local authorities have a statutory duty to assess people's need for social care and to make provision for community care services in their area. Under the SDS Act, they have a duty to offer the four options to supported persons whom they assess as requiring care and support. They also have a duty to provide information and assistance to individuals in order that they can make an informed choice about the options available.

### **Central government**

The Scottish government's Health and Social Care Directorates are responsible for the legal framework and the strategies and policies surrounding the implementation of SDS. It is part of a long-term aim to have more personalised health and social care in Scotland. In developing the strategy and drafting the legislation, the Scottish government consulted with and involved local councils, people who use services and their carers, organisations representing users, third sector and private sector providers and other relevant organisations. The Scottish government provides the funding for SDS through its annual local government finance settlement. The Scottish government is developing a monitoring and evaluation strategy to assess the impact of the SDS policy. It was due to start collecting national data starting in 2014 (Audit Scotland 2014: 19).

### **Care Inspectorate<sup>3</sup>**

The Care Inspectorate registers care providers and inspects services against national care standards. It also inspects how councils plan and deliver social care. The Care Inspectorate takes account of the SDS Act in the way it inspects councils' adult and children's services. The Audit Commission (2014) recommends that the Care Inspectorate should review the way it regulates individual care services. As SDS gives people more choices about their support and more control over how they use their budget, more people are likely to choose a combination of different services and support. They may purchase services from more than one provider, choose services not regulated by the Care Inspectorate (e.g., personal assistants or cleaning agencies), and use their budgets more creatively to purchase support other than existing services. The Audit Commission (2014) also notes that the national care standards are being reviewed to reflect the new emphasis on the impact that social care services have on people's lives, and not just their experience of the service quality.

With the introduction of the Public Bodies (Joint Working) (Scotland) Act, the Care Inspectorate is required to work with Healthcare Improvement Scotland to review joint strategic commissioning plans prepared by the new health and social care partnerships. These plans should set out how councils and NHS boards will jointly plan and deliver health and social care services, including SDS. The Care Inspectorate and Healthcare Improvement Scotland are considering how they will inspect councils' and NHS boards' health and social care services.

### **NHS**

#### *Section 13 of statutory guidance to SDS Act*

Social care and healthcare, particularly community healthcare, are closely related. It is not uncommon for a supported person to receive ongoing healthcare and social care support at the same time. A supported person's needs and outcomes will not always respect traditional boundaries between healthcare services and social care services.

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<sup>3</sup> The Care Inspectorate (or Social Care and Social Work Improvement Scotland [SCSWIS]) is the official body for inspecting standards of care in Scotland. An independent organisation with its own Board, it is funded by the registration and continuation fees it charges and by the Scottish Government. <http://www.scswis.com/>

A joint approach is not simply about the pooling or transfer of budgets. It should be a joint person-centred approach to assessment, support planning and review. It should recognise opportunities to pool expertise, share common approaches and combine resources at every stage in the supported person's pathway. This requires a solution-focused approach and a determination on the part of senior managers in health and social care to support the professionals they manage to adopt joint assessment, planning and review processes and take full advantage of the broad powers afforded them in legislation.

Health and social care staff may require additional training to facilitate the required collaboration and culture change at all levels.

The local authority and the Health Board responsible for any jointly funded packages of support should put in place the appropriate joint arrangements for the ongoing monitoring and review of the supported person's needs.

Where healthcare interventions are delegated to a non-NHS professional, the duty of care remains with the Health Board to ensure that these are delivered safely. It is vital that the NHS professional continues to bring their professional expertise to bear to ensure that the supported person's health needs are being met in a safe and appropriate way and by someone who is competent and trained to deliver those interventions.

At the organisational level, the local authority and the Health Board should develop effective arrangements around the corporate policies for the assessment and monitoring of all self-directed support packages where there is a healthcare component.

#### **Organisations representing users and carers, and individual users and carers**

Councils should plan and implement SDS working closely with people who need care and support, their carers and families, and organisations providing services. The national SDS strategy is about improving people's lives; it is not about delivering services more cheaply. However, like other public sector services, social care finances are under continuing pressure and councils have to find savings in some services as well as find ways to respond to increasing demand for social care. This creates a risk that communities may see SDS solely as an opportunity for councils to reduce spending rather than to improve the lives of people who need support. Councils should spend time working with communities, explaining the benefits of SDS and helping people to think creatively about what services would have the most positive impact on their lives. Without this, people may be less willing to think about alternative approaches to care because they may view alternatives simply as cost-saving measures.

#### **Organisations representing providers and with individual providers**

The SDS Act requires councils to take reasonable steps to promote a variety of providers and support so that people who use services have real choices. Councils should communicate and work with providers to do this successfully. It can be challenging to work closely with providers if a single council area such as a large city has a large number of such providers. For example, in certain circumstances providers may be business competitors, but nonetheless be expected to work collaboratively together. Larger providers often work with several councils. Councils also work with providers in different ways. In some cases, councils only provide information and may talk to providers through formal network meetings. In others, councils involve providers in their SDS implementation programmes by being represented on project boards and other forums, and they have a say in the council's approach. It is important to involve providers because they can contribute new and constructive ideas and experiences, and can help deliver the required changes. The *Commissioning social care* report recommends that councils establish and maintain good working relationships with providers in line with Scottish government guidance (Scottish Government 2010b).

Service providers need to change how they provide services. Third sector and private sector providers employ two-thirds of the social services workforce. To respond to the new statutory requirements, they need to consider options including:

- diversify the support they offer;  
be more flexible and responsive to people's choices;
- be able to manage people's budgets under option 2 of SDS;
- provide more detailed information about their services to councils and people who need support, and
- manage their funding and budgets differently to help them make these changes.

The Scottish government has allocated funding to third sector and private sector organisations to help them develop SDS. For example, it allocated funding to Scottish Care, the organisation representing private sector care organisations, to run a three-year programme 'People as Partners'. This programme helps providers understand the implications of SDS and develop their services.

Local councils should ensure that they have the right balance of services in their area to meet people's social care needs. To do this, they should develop a strategy that sets out the services people are likely to need in the future and where there are gaps in current services. This is known as a market-shaping strategy or market position statement. This helps both the council and providers to make decisions about the future. If councils do not have clear strategies and do not work closely with providers, they risk leaving gaps in the services available. This risk is higher in rural or remote areas where there may already be a lack of choice or a shortage of some types of services. The risk is also greater for specialised types of services that relatively few people need.

## 6.2 Primary motivation

The SDS Act specifies four statutory principles to help achieve the underlying aims or 'spirit' of the legislation. They apply to the initial assessment of need *and* to the provision of choice in order to meet those needs. The four principles are:

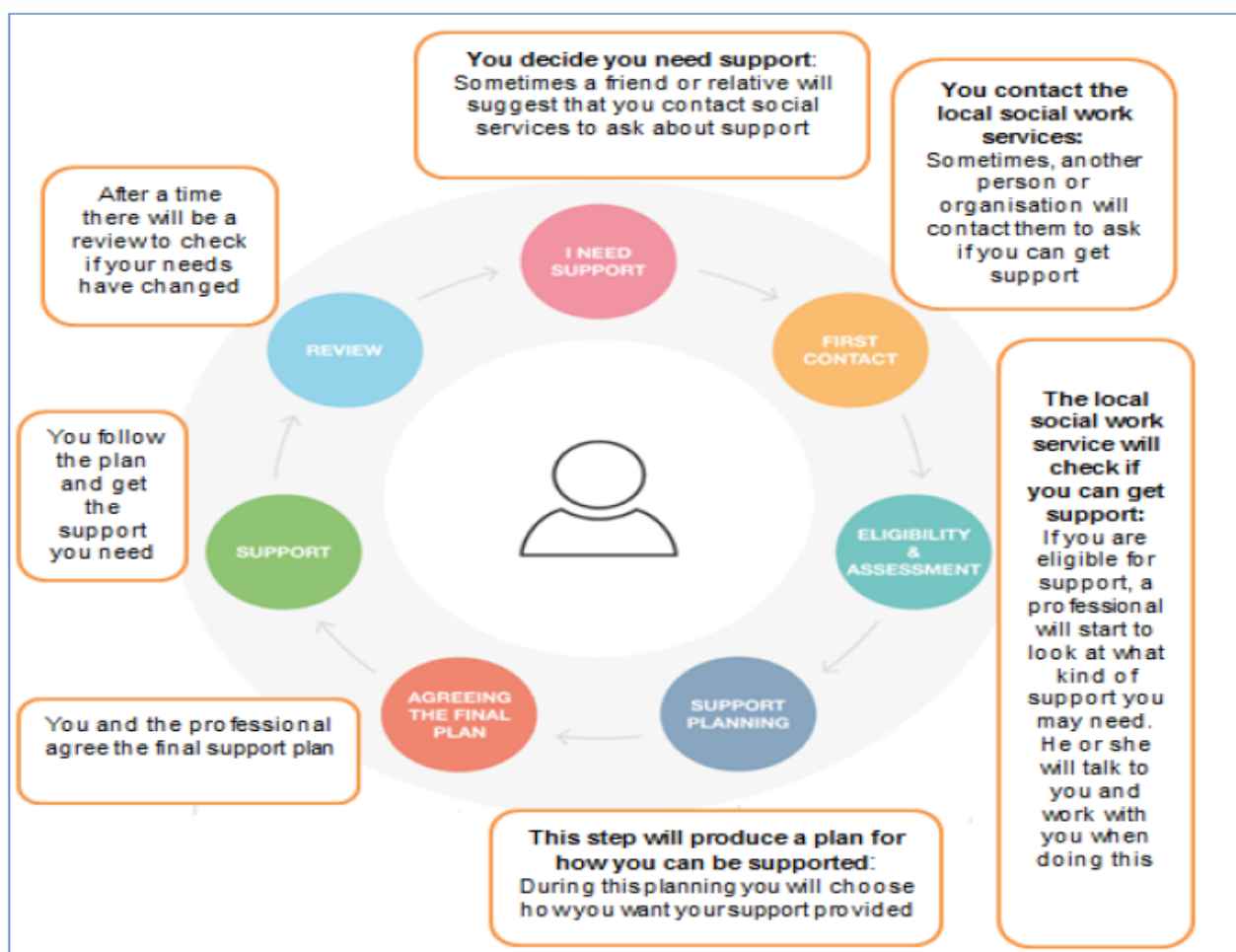
- *Participation and dignity*: the supported person should have the same freedom, choice, dignity and control as other citizens at home, at work and in the community.
- *Involvement*: the supported person must have as much involvement as he/she wishes in both the assessment and in the provision of support associated with that assessment.
- *Informed choice*: the supported person must be provided with any assistance that is reasonably required to enable him or her to express views about the options available to them and to make an informed choice about their options for support.
- *Collaboration*: the professional must collaborate with the supported person in relation to the assessment of the person's needs and in the provision of support or services to the person.

The intention is that these four statutory principles will ensure a human-rights-based approach to the assessment, support planning and support provision process, which in turn will improve outcomes and lead to person-centred and outcome-centred service delivery (Scottish Government 2014: 17–19). It will also influence the approach to assessing and determining eligibility and entitlement:

It involves a shift in the systems and processes surrounding assessment, moving away from a focus on deficits, and towards strengths and capacities. This is a significant system and culture change. It requires development opportunities and ongoing support for practitioners. This change, alongside the emphasis on choice, control and flexibility, should inform the authority's approach to assessment across adults, children and carers. (Scottish Government 2014: 32).

Figure A6.1 outlines the 'supported person's pathway', a graphic illustration of how the rights-based approach changes the approach to assessing eligibility and need.





**Figure A6.1: The ‘supported person’s pathway’, or process for assessing ‘eligibility’ and determining ‘entitlement’ under the SDS Act (Scottish Government 2014: 20)**

The steps in this ‘supported person’s pathway’ are as follows:

#### **Step 1: Inform**

The supported person decides that they need additional support. The supported person makes contact with social care services or community health services. There is an initial screening to determine if the person should progress to a formal decision on their eligibility for support. At this stage, the supported person should be provided with the relevant information and advice in relation to eligibility, assessment and support options.

#### **Step 2: Assess**

Initial decisions are made about the person’s eligibility for support under the various legal obligations:

- Section 12A of the 1968 Act (the assessment duty relating to adults);
- Section 22 of the 1995 Act (the duty relating to children in need);
- Section 12AA of the 1968 Act (the assessment duty relating to carer’s of adults), and
- Section 24 of the 1995 Act (the assessment duty relating to carers of children).

Following the initial determination of the person’s eligibility, the person’s needs are explored in detail. As part of this detailed assessment the two parties (the professional and the supported person) will begin to translate the initial needs into a more detailed exploration of the individual’s personal outcomes.

**Step 3: Plan**

Support planning covers a wide range of issues, but will tend to include a discussion of the choices available to the supported person; main risks and how the supported person and others can manage those risks; and resources that will help to deliver the person's support plan.

**Step 4: Choose**

This describes the stage where the supported person and the professional agree the support plan.

**Step 5: Support/Speak out**

This describes the provision of support to the person and the day-to-day decisions that will be made.

**Step 6: Review**

The update of the original assessment, review of the person's needs and consideration of any adjustments to reflect the changing needs or any changes in circumstances etc.

**6.3 Eligibility and entitlement – adults**

Underpinning the process of determining eligibility and entitlement to self-directed supports is a statutory requirement for local authorities to apply the principles already outlined in Section 6.2 above – participation and dignity, collaboration, involvement and informed choice. As a consequence, the terms 'eligibility' and 'entitlement' may not be accurate descriptors of how to access the supports: it is a more fluid process that is characterised in Sections 7–9 of the statutory guidance that accompanies the legislation as:

- determining eligible need;
- choosing option for accessing support, and
- support planning.

**6.3.1 Determining 'eligible need'**

The first step is to identify a person's needs with a view to determining whether the authority has an obligation to meet those needs, i.e. are they 'eligible needs'? In relation to adults, the person must be in need of support arising out of infirmity, youth or age, or require support arising from illness, mental disorder or disability. In relation to adults, it is up to the individual authority to determine its own approach to eligibility. Where the adult is over 65 years of age and eligible for personal care, or where the person is eligible for nursing care, the local authority must take account of the relevant joint Scottish government and Convention of Scottish Local Authorities (COSLA) guidance on eligibility criteria.

The statutory guidance gives an example of an eligibility framework for adults based on assessment of risk:

- *critical risk*: major risks to the person's independent living or health and well-being likely to require immediate or imminent provision of social care services (high priority);
- *substantial risk*: significant risks to the person's independence or health and well-being likely to require immediate or imminent provision of social care services (high priority);
- *moderate risk*: some risks to the person's independence or health and well-being, which may require some social care services to be managed and prioritised on an ongoing basis;
- *low risk*: some quality of life issues, but a low risk to the person's independence or health and well-being, with very limited, if any, requirement for the provision of social care services. There may be some need for alternative support or advice and appropriate arrangements.

The authority should have regard to the following when developing its approach to assessing eligibility:

- *take full account of how the person's needs and risks might change over time*. It should support the relevant professionals to consider the impact of failure to intervene, and whether this would lead to escalation of need in future. It should take a well-rounded approach, recognising that risks to participation in society (living an ordinary life, engaging

with others) are valid alongside risks to dignity (personal care, 'life and limb' support). It should recognise the potential hidden needs or highlighted in generic guidance documents. The relevant parties involved in assessment – the professional and the adult, child or carer – should be able to access information and advice about alternative sources of support with formal or funded social services.

- *take into account overall resources when determining eligibility criteria*: once the local authority has decided that a person's needs are 'eligible needs', it cannot refuse to meet those needs due to budgetary constraints.
- *take a strategic approach to the application of eligibility criteria*: in partnership with partners, including the health board, providers, user groups and carer groups, develop eligibility criteria within a broader framework of prevention, early intervention, support to carers and universal services. If a person does not meet a particular eligibility threshold, the authority should take steps to ensure that the appropriate arrangements are in place, providing an environment where the professional can direct that person to suitable alternative sources of support. The authority should also consider its strategy for investing in preventive and universal services – interventions which prevent or delay the need for formal social care and support.
- *develop policy in line with the four statutory principles*: in particular, the principles of involvement (of service users/carers), informed choice and collaboration. The authority should publish the eligibility criteria/framework.
- *continually review the person's needs*: this should include consideration of how urgently service provision is called for and what interim measures may be appropriate pending any long-term support.

#### ***Reablement and intermediate care***

Reablement services involve a short-term package of support provided over a six-week period, provided, for example, following a fall or discharge from hospital. The unique characteristic of reablement support is that it is *short-term* intensive support. There will be two possible outcomes: (a) the supported person may be eligible for long-term support, or (b) the reablement service will address the initial need and, as such, there will be no further 'stable' or long-term support. It would be sensible for a local authority to view reablement as a part of the assessment process – an early intervention which may or may not lead to more stable forms of ongoing support. However, where it is decided that the supported person will be provided with that stable ongoing support, the authority must offer the person the various choices set out in the SDS Act.

Intermediate care is an umbrella term describing a collection of services working to common, shared objectives and principles. It provides a set of 'bridges' at key points of transition in a person's life, in particular from hospital to home (and vice versa) and from illness or injury to recovery and independence. The purpose of intermediate care is to provide time-limited interventions at points of crisis in a person's life where this will restore or avoid a loss of independence and confidence, or reduce the risk of hospital admission (or a longer stay in hospital). Intermediate care can be viewed as an initial step, which can help determine a supported person's need, and inform any subsequent long-term support plan. Where it is decided that the supported person will be provided with stable ongoing support, the local authority must offer the supported person the choices set out in the SDS Act.

#### **6.3.2 Choosing option for accessing support**

Having determined the 'eligible needs', the local authority is required to identify the necessary supports, and offer the individual a choice of the four options for the provision of the support, as listed in Section 6.1 above. Situations where the SDS Act's duties to offer the four options do not apply are noted at the end of this section.

***Option 1 – Direct payment***: The local authority should take steps to ensure that the supported person can use their direct payment in *any way*, provided that the support purchased via the payment is in line with the assessment and support plan, that it meets the supported person's 'eligible need', and that it is within the criminal and civil law. Typically, direct payments have been

understood as a route to employing a personal assistant. However, a direct payment can also be used to purchase a wide range of services and other items. For example:

- a service from the local authority or from another local authority;
- a service from a provider organisation in either the voluntary or private sector;
- a product which can help to meet the supported person's needs;
- a short break or respite of one sort or another, or
- anything else that will help to meet the supported person's needs and the outcomes specified in the support plan.

This flexibility is supported by the legal meaning of the term 'services' as provided for in the core assessment and service duties. The Social Work (Scotland) Act 1968 uses the language of community care services, and the Children (Scotland) Act 1995 refers to a range and level of services. This can encompass any form of support that will meet the person's needs. It does not have to be restricted to the provision of a service in the form of a home care service or a day care service (although those are perfectly acceptable examples of a community care service). It can and should extend to any intervention or purchase that meets the needs and outcomes of the supported person.

**Option 2 – Directing the available support:** The local authority should make use of Option 2 to provide a route to greater choice and control for those who wish to take exert control over their day-to-day support, but are not willing, or do not feel ready or able, to choose the direct payment option. The local authority should not seek to limit flexibility beyond what is allowed under procurement law. The key limitation is that a person cannot use Option 2 in order to employ their own staff. Unlike the direct payment, there is no requirement for the funding to be provided directly to the supported person as a cash payment. The budget provided to the person should be operated as a virtual budget. The resource can remain with the local authority, or it can be delegated to a provider to hold and distribute under the supported person's direction.

The authority's arrangements may be operated as a formal framework agreement or other similar arrangements, although there is no requirement to do so within the 2013 Act. The arrangements should be flexible and inclusive: flexible – in that they should not seek to create or re-impose barriers to choice and control; inclusive – in that they should not seek to exclude particular types of service provision or particular providers from the full range of supports available to the person. For example, the arrangements should allow for flexibility in budgeting, allowing sufficient over-spends and under-spends within the individual's package of support (Scottish Government 2014: 51–52).

**Option 3 – the local authority arranges support for the supported person:** The local authority in collaboration with the supported person selects the appropriate support and then makes arrangements on the supported person's behalf. The supported person steps back somewhat, leaving many of the detailed decisions regarding the planning and controlling of how the available resources are used to the local authority. Nevertheless, the local authority, through its approach to commissioning and procurement of services, should seek to ensure that the services provided are as flexible as possible, are sufficiently personalised, and are ready to adapt to the desires of the individuals who use them. This should involve the necessary workforce education and development, ensuring that those who provide care and support do so in line with the general principles in the SDS Act (Scottish Government 2014: 52).

**Option 4 – mix and match:** Combining two or more of the above options, Option 4 recognises that some people will be content to take on some but not all of the control associated with one or other of the self-directed options. It ensures maximum flexibility in the options available, and may be attractive to people who would like to experiment with the direct payment or individual service fund for a small aspect of their support or for a small portion of their outcomes (Scottish Government 2014: 52).

#### **Discretion/restrictions in relation to offering the four options**

- Local authorities are not obliged to offer the four SDS options where the form of service is tied to a specific criminal justice order. This reflects the fact that the form of service will be,

by its very nature, prescriptive and controlled. These individuals may, however, be provided with a choice of the four options in relation to wider community care needs that they may have (Scottish Government 2014: 53).

- The four options are simply not available when the form of support deemed necessary is incapable of being delivered through one of the four options, i.e. it cannot be delivered through a self-directed option such as a direct payment or individual service fund. Examples include foster care (which cannot be purchased by means of a direct payment or converted into a single budget), and a social worker's intervention with a child/family to deal with a complex safeguarding situation (which cannot be converted into a direct payment or individual service fund).
- An authority is not permitted to offer a direct payment for provision of long-term residential or nursing care to persons of any age. An authority may offer the other three options under the SDS Act.
- An authority is not required to offer the option of a direct payment where it is likely to put the safety of the supported person at risk. Examples whereby the authority can use this 'duty of care' discretion include where a child's safety will be put at risk because it is clear that the money will not be used to buy the support the child needs, or where the assessment is conducted at an acute point of 'crisis' to the extent that the person's safety would be further jeopardised by a direct payment.

In exercising its discretion, however, a local authority should not depart from the intention and spirit of the SDS Act without good reason. For example, it would not be appropriate for an authority to:

- refuse a direct payment simply because the person's disability means it is a challenge (even a significant challenge) for them to manage the direct payment option;
- refuse to provide a direct payment simply because the person has dementia or a learning disability, or any other disability which may require extra support in order to make the direct payment option work; or
- develop internal policy guidance documents which define access to direct payments on the basis of general client group or disability alone.

### **6.3.3 Support planning**

The support plan should be developed in line with the statutory principles (see Section 4.2 above). The plan includes the personal outcomes which help to shape the plan, the resources (both financial and non-financial) which will help to meet those outcomes, the choices available to the supported person to arrange their support and all associated information. It will demonstrate a link between the supported person's eligible needs, their wider outcomes and the support required to meet those needs and outcomes. It should focus on what the person wants to achieve with the right help, rather than simply putting arrangements in place to stop things from getting any worse. It should be capable of acting as a reference point for the supported person, the local authority, the provider and, subject to the person's wishes, other important individuals in the person's life. The parties involved should be able to return to the plan, review the plan, add to the plan or make changes over time (Scottish Government 2014: Section 9).

### ***Determining appropriate level of funding***

Where the person is deemed to be eligible for support, the authority will consider a fair and transparent means by which to determine the appropriate level of funding (Scottish Government 2014: Section 7). Section 4 of the 2013 Act refers to a 'relevant amount', which is defined as an 'amount that the local authority considers is a reasonable estimate of the cost of securing the provision of support for the supported person'.

There is no single approach to resource allocation prescribed in the 2013 Act, nor any single method recommended by the Scottish government. The authority may wish to adopt an 'equivalence model', or a 'resource allocation system' (see Table A7.1). In addition, decisions about budgets may be made on a case-by-case basis.

**Table A6.1: Options for allocating resources**

**Equivalence model**

The local authority determines the cost of the service to be arranged and then provides the equivalent amount as a budget for the supported person to control.

**Resource allocation system**

The authority gathers information about the person's outcomes, allocates points to those outcomes and, on the back of this process, allocates a level of funding.

While systems and tools can be useful aids, on their own they are no substitute for the skilled judgement of a social worker or health professional in collaboration with the person. The local authority must ensure that the approach taken to the allocation of resources is both fair and transparent. It should take steps to involve user and carer groups in the development of any methodology used to define or determine budgets. Regardless of the specific approach to allocating resources, the authority should take steps to inform the person of the amount of support available under each of the options.

The local authority and the relevant professionals acting on its behalf should ensure that the nature and level of support meets the person's eligible needs. The local authority should ensure that professional expertise is brought to bear. The approach to defining the budget should be robust, rational and transparent. The level of resource identified in the final support plan should be sufficient to meet the needs identified as eligible in the assessment.

***Personal and nursing care***

Personal and nursing care is a form of social care and support. As such, it falls within the scope of the assessment and support planning processes described in this guidance. If the supported person has personal care needs, then the person should be provided with the full range of choices under the SDS Act.

***Housing support services***

Housing support is support other than care or housing management services to enable a person to establish or maintain occupancy of a dwelling. Housing support services are provided to help people live as independently as possible in their own homes. If the authority concludes that a particular form of housing service falls within the definition of community care services, then the SDS Act applies and the supported person should be provided with the full range of choices under the SDS Act.

***Equipment and adaptations (including home modifications)***

The local authority should have regard to the following key principles which represent good practice in home modifications: the supported person and their carer(s) should be placed at the centre of service provision and be in control; access to assessment and the adaptation itself should take account of need and be fair, consistent, reliable and reasonable, with a focus on prevention; assessment and access to financial and other non-financial supports for the adaptation should be equitable and fair; and the supported person should be able to understand the systems and rules, which should be uncomplicated and should maximise the ability of the supported person to make informed choices.

Options 1 and 2 in the SDS Act – the direct payment or the opportunity to direct the available support – may provide an opportunity to explore new or alternative ways to meet the person's outcomes. However, any additional costs or responsibilities that may be incurred by arranging the adaptation via a direct payment or individual service fund should be fully explained to the supported person. Consideration should be given as to how any ongoing costs will be met, and who will be responsible for these costs – for example providing additional top-ups to the direct payment to cover these fees.

### **Equipment/adaptations**

A key principle behind direct payments is that they can be used to purchase anything, provided that it meets the assessed needs of the supported person and is not illegal. This includes equipment and adaptations. A direct payment can be a useful way to provide additional flexibility and control to the supported person. However, as with any other form of support, the equipment/adaptation must meet the assessed needs of the person. In addition, it is a matter for the local authority to define the relevant amount of funding that is necessary to meet the assessed needs of the person.

A direct payment arrangement means that control and responsibility passes to the supported person. This means that ownership and responsibility for arranging the maintenance of the equipment or adaptation can pass to the supported person. In some instances it may make sense for responsibility for maintenance to rest with the local authority. The key priority should be to make use of the user/supported person agreement to discuss and clarify questions of maintenance, ownership and issues such as the donation of any equipment to the local authority, NHS, provider or fellow citizens after it is no longer required.

While there is no specific restriction on the use of direct payments to fund larger-scale adaptations, it is a matter for the authority to determine if the relevant support relates to community care support. A direct payment is an alternative means by which to meet assessed social care needs. It is not a substitute for housing improvement grants. When considering the funding of large-scale or particularly complex alterations, the local authority and the supported person should consider how additional responsibilities such as insurance, health and safety requirements and specialist support and expertise will be fulfilled.

### **Eligibility and entitlement – children and family members**

Under the Getting it Right approach (Scottish Government 2012), each child who requires support, whether from a single universal service or from several services or agencies, should have this support coordinated and recorded within a single plan. The local authority should seek to ensure that the assessment process is fully coordinated between adult and children's services, including any other relevant departments such as education.

Where an assessment takes place, an approach based on personal outcomes will help to draw out the child and their family's views on the things they want to achieve, the things they would like to do, and how they would like to do them. It will also help to ensure that the social care assessment can easily contribute to the Single Plan for the child.

Under the SDS Act, if the child is aged 16 years or older, then the child will have the right to make decisions about their own support and to choose how they wish to arrange this support. If the child is aged under 16 years, then the person with responsibility for the child, called the *appropriate person* in the 2013 Act, should make decisions about the child's support. The local authority should inform the appropriate person that they must, in so far as practicable and taking account of the maturity of the child, give the child an opportunity to indicate whether they want to express a view about their own support. The appropriate person should also have regard to the views of the child in making the key decisions about that child's support.

The authority should ensure that the child and their family – particularly where the child is approaching the transition to adult services – are fully informed of the legal routes available to them in order to ensure that the child's family have the opportunity to apply for the necessary powers to ensure that they continue to determine their support. Where the child or young person lacks capacity or may lack capacity in future, the local authority should make the child and their family aware of the Adults with Incapacity (Scotland) 2000 Act (the AWI Act).

For any young person, the process of growing up involves the gradual taking on of responsibility for themselves. Families with disabled children often face additional challenges that may delay or limit the young person's transition towards independence. The flexibility offered by self-directed options may offer advantages to the young person and their family. A direct payment or the opportunity to take control of their support may help the child/young person to take on greater responsibility right

across their life, to be more independent, and to have greater control over their future. Alternatively, the 'mix and match' approach may offer an opportunity to build the young supported person's confidence in managing their own support.

### **Eligibility and entitlement – carers**

A carer who provides a substantial amount of care on a regular basis has the right to request an assessment of their own needs. Under Section 12AA of the Social Work (Scotland) Act 1968 (relating to carers of adults) and Section 24 of the Children (Scotland) Act 1995 (relating to carers of children), the local authority must comply with any such request. In addition, the authority has an obligation to inform the carer of their right to request an assessment under section 12AB of the 1968 Act and section 24A of the 1995 Act.

An effective carer's assessment rests on an open and honest conversation between the professional and the carer, with a strong focus on personal outcomes. The characteristics of the carer are relevant when deciding whether they are providing a substantial amount of care on a regular basis. For example, they might be in poor health themselves or they may have other responsibilities such as school-age children. A carer's choice to provide care should also be taken into consideration. Preventive support is more cost-effective than support provided in a crisis or emergency, as well as being more suitable for the carer and the person they care for. Carers who do not meet the threshold for a carer's assessment can still benefit from low-level preventive support, and carers who feel confident enough to access low-level support are more likely to take up further support should their caring role increase in the future. In some cases, the carer may not wish to undertake a full assessment.

The SDS Act imposes a duty on an authority to consider the conclusions from the carer's assessment. In considering this aspect, the authority must consider whether the carer would benefit from some form of support to enable them to continue in their caring role. Section 3 of the SDS Act provides the legal basis for an authority to work with an adult carer in order to arrange some support for the carer. For young carers, the basis is Section 22 of the Children (Scotland) Act 1995, which will be replaced by the GIRFEC (Getting it right for every child) regulations outlined in the forthcoming Children and Young People (Scotland) Act 2014.

Support to a carer can mean access to universal services available in the community, referral to a known source of information and advice (for example, to a condition-specific organisation, or to a carers' centre) or the provision of further information in the form of booklets, websites, advice and guidance on coping with their caring role. Support in the form of information, advice, signposting, and other universal services is available to all carers whether or not a carer's assessment has taken place, and is available to all carers regardless of whether their caring role is regular or substantial.

Even without a formal assessment, carers may be offered support. Early preventive support helps to lessen any negative impact of a caring role. The aim is to support the carer in circumstances such as the early stages of a caring role, knowing that the caring will become more intensive in due course (for example, caring for a supported person just diagnosed with dementia) or while caring for someone whose condition is known to remain stable and low level, but where the impact of the caring role on the carer means they require some support. Preventive support may also mean arranging some form of funded services or support. Funded support to the carer can be of significant benefit to the carer and to the supported person, as when a carer is adequately supported in their caring role they may find it easier to continue to care. It can also lead to significant benefits to the statutory agencies responsible for care and support.

In deciding whether to provide funded services or support, the local authority should consider carefully the impact of their decision. Without the contribution of the carer, the local authority or other statutory agencies would have to step in with higher levels of support, which would be considerably more costly. Senior managers should encourage professionals to exercise their own judgement when considering the outcomes that carers wish to achieve and a preventive approach to supporting carers.



If as a result of the assessment the local authority decides to provide funded support, it must offer the carer choices as to how the carer wishes to receive that support. The local authority must offer the carer the four options within the 2013 Act, and it must give effect to the carer's choice. As with support to the disabled or older person, the authority must inform the carer of the amount of support available under each of the options. If the carer does not wish to make their own decision about how they will receive any support (and assuming that they still wish to receive support), then the local authority should continue to arrange support on their behalf.

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### Useful website

<http://www.selfdirectedsupportscotland.org.uk/>

[hrb.ie](http://hrb.ie)

