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Comparative analysis of budget utilisation in individualised funding models

Report C

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# Executive summary

The report was commissioned by the Australian Government’s Department of Social Services to inform mechanisms that will optimise utilisation of NDIS packages. The report examines schemes, nationally and internationally, with similar features to the NDIS in order to:

* Identify budget expenditure levels and influences on expenditure in other models
* Identify potential interventions to optimise budget utilisation to reflect needs and choices of NDIS participants
* Explore whether similar systems operate a benchmark level for individual budget utilisation and what an appropriate level might be.

In this report, a utilisation rate refers to a comparison of the monetary value of individual budgets allocated against the budget expended. The term *individualised funding* is used to describe models of funding deployed via direct payment to an individual or through an intermediary that allow an individual to make choices about expenditure to meet their needs.

The research that informs this report is based on a desktop review of relevant literature and interviews with national and international experts. The literature review involved a search of peer reviewed literature, as well as focussed reviews of grey literature and follow up contact with relevant organisations, where able, for additional data. Interviews were conducted with seven international experts exploring what utilisation rates different systems experience, whether targets are used around utilisation rates and how different systems have sought to shift utilisation rates.

This data identifies a range of different national and international individual funding schemes. Some of these have comparable features to the NDIS, but there are also some important differences meaning that we need to take care in drawing lessons from these.

Many individualised budget schemes differ from the NDIS in the sense that they are administered at a local or jurisdictional level, meaning there is a lack of comparable national data. Further, the data infrastructure for these schemes is often limited and utilisation rates are not always available.

A range of different factors drive utilisation rates and these vary across scale and time. Table A identifies some of the facilitators for budget spend and drivers of underutilisation.

**Table A: Drivers and facilitators of individualised budget spending**

|  |  |
| --- | --- |
| Drivers for underspend in individualised budget spending | Facilitators of individualised budget spending |
| Funding and service systems are unduly complex and individuals struggle to understand and complete administrative processes | Clear communication regarding eligibility and spending restrictions |
| Lack of information about how individualised funding operates and allowable budget spends | Provision of formal supports to participants |
| Lack of support in planning and implementing spending | Development of informal social networks to provide support to participants. |
| Lack of information about what services are available or their quality | Training of professional staff in individualised funding philosophy, and facilitating decision making and supporting people with a diverse range of needs. |
| Lack of providers or providers able to meet needs of individual needs available | Training to address cultural and linguistic needs when providing support and information. |
| Funding and service system lacks understanding of needs of CALD and Indigenous clients and services are culturally unsafe | Availability of advocacy within the community |
| Poor relationship between budget holder and funder/intermediary | Training and skill development for people with disability around decision making, creating a plan and responsibilities as employers |
| Being new to individualised funding | Professionals letting go of traditional power relations |
| Putting money aside for a rainy day | Availability of tools to identify what services are available locally and provision of some means to quality assess these. |
| Lack of appropriately trained workforce | Market stewardship tools to help identify where there are market gaps and to prevent market failure. |

For schemes with available figures on utilisation rates we find significant variation (between 42 and 99%) and disparities exists within schemes across geographical areas, system maturity and cultural group.

Overall, given the range of different factors that impact utilisation rates, the literature and interview respondents indicate these are not a good way to assess system effectiveness. Such a benchmark would be a blunt and ineffective indicator of scheme effectiveness. A key finding is that most respondents felt a 100% utilisation rate would generally indicate something is wrong with care planning or budget allocation processes. As many individuals do not go to the limit of their budgets in case an issue should arise, to use all of an allocation may indicate insufficient funding is available.

If utilisation rates are to be used as an indicator, the most effective way to use this might be to either have multiple figures for different groupings or to track these at an individual level over time.

1. Introduction

This report, by the Public Service Research Group, University of New South Wales, presents findings from a comparative analysis of individualised funding models for disability services. The report was commissioned by the Australian Government’s Department of Social Services to inform mechanisms that will optimise utilisation of NDIS packages. The report examines schemes, nationally and internationally, with similar features to the NDIS in order to:

* Identify budget expenditure levels and influences on expenditure in other models
* Identify potential interventions to optimise budget utilisation to reflect needs and choices of NDIS participants
* Explore whether similar systems operate a benchmark level for individual budget utilisation and what an appropriate level might be.

In this report, a utilisation rate refers to a comparison of the monetary value of individual budgets allocated against the budget expended. The term *individualised funding* is used to describe models of funding that are deployed via direct payment to an individual or through an intermediary that allow an individual to make choices about expenditure to meet their needs.

The research undertaken to inform this report was based on a desktop review of relevant literature and interviews with national and international experts. The literature review involved a search of peer reviewed literature as well as focussed reviews of grey literature and follow up contact with relevant organisations, where able, for additional data. Interviews were conducted with seven international experts exploring what utilisation rates different systems experience, whether targets are used around utilisation rates and how different systems have sought to shift utilisation rates.

The report begins by describing the methods used in this project in more detail. Following this, an overview is provided of the types of characteristics associates with individualised funding then by a summary of different national and international models. The next section describes the data found on individualised funding budget utilisation and areas of budget expenditure. Possible contributing factors to underutilisation and accompanying mechanisms to support utilisation are then outlined.

There were a limited number of evaluations found on individualised funding. There is a notable lack of high quality experimental studies, which means that strategic and policy decision on individualised funding are often based on local sources or anecdotal evidence (Fleming et al., 2019). Limited data were available on budget utilisation as many schemes are locally administered often with restricted data infrastructure surrounding them Further, exploring these issues at a jurisdictional level is not possible, because data infrastructure does not allow for this or these data are not available. A number of schemes encountered also have low budget caps and/or require personal contributions. Data, where available, indicates utilisation rates ranging from 42-99%. Common areas of expenditure are for personal assistance and support in the home, community based social or employment activities and equipment (where allowed). However, the data across schemes is not easily comparable due to varying restrictions on spending. The broader literature on individualised funding implementation indicates that access to information, support and having a trained workforce that can assist and adapt to a varying range of needs of people with disability are important enablers in participants understanding how to use their budget. It is likely these factors may also influence the effective utilisation of budgets, although there is little empirical evidence in this area. The report concludes by identifying gaps in our existing knowledge and where future research might fill these.

1. Methods

Research informing this report was gained primarily through literature review and interviews with national and international experts. This was supplemented with direct contact with agencies administering individualised funding schemes to obtain data, where possible. Ethical approval for this project was granted by UNSW Canberra (HREC Number HC200115).

The literature review involved searching published peer reviewed journal articles and grey literature, including government reports and formal evaluations of models. A search of databases (Cinaahl (EBSCO), Medline Ovid, Google scholar) and the search engine Google was undertaken using the terms ‘individualised funding’, ’personalization’, ‘personalised funding’, ‘self-directed support’, ‘direct payments’ and ‘acquittal’. This was followed by the use of snowballing techniques to identify relevant citations in both peer reviewed literature and grey literature. Literature obtained from the review processes was filtered to exclude further analysis of schemes that only provided participants with limited choice of their budget, for example where individuals were only able to direct attendant care services. These schemes have such significant differences to the NDIS that it means data generated from these are not informative for the purposes of this study. Figure 1 indicates the number of sources identified and screened through the literature review.

Figure 1: Literature Review

Grey literature identified through other sources (n=125)

Peer Reviewed literature identified through other sources (n= 27)

Peer Reviewed literature identified through database searching (n=163)

Total Records screened (n=315)

Once models of individualised funding were identified that had sufficiently similar features to the NDIS, we undertook another web-based search to identify further sources of information and contacts for agencies responsible for administering the various schemes. Where possible, contact was made directly with administering agencies to request data on individualised funding budget allocation and expenditure.

Semi-structured interviews were also undertaken with key informants in a number of jurisdictions to further examine issues faced within these settings. Interviews were undertaken via teleconference or video conferencing software and explored issues such as:

* What utilisation rates their system experiences and whether this is judged to be appropriate;
* What the drivers of utilisation rates are;
* Whether targets are set in relation to utilisation rates; and,
* Whether any initiatives had been put in place to change utilisation rates;

All interviews were audio recorded and verbatim transcripts produced. In total seven interviews were undertaken with international experts at the time of reporting. Table 1 indicates the organisations of the individuals interviewed. We have not identified their roles in order to maintain anonymity of sources in line with our ethical approval, but all respondents were or are senior leaders. Gaining access to informants has been significantly hampered by the global outbreak of the COVID-19 pandemic that emerged around the time this project commenced. Although Australia has fared relatively well through this process, other regions and countries that are of interest for this study have seen significant infection rates and in many cases disproportionate levels of death in disability populations (Kavanagh et al., 2020). At our request, where interviewees were not available, some services asked staff for written feedback around issues relating to underutilisation of budgets and efforts to help support individuals to spend their funds. Data from these interviews are reported alongside that from the literature in findings below, using direct quotes.

Table 1: Interviewees by country and organisational background

|  |  |  |
| --- | --- | --- |
| Country | Organisation | Number of respondents |
| US | Human Services Research Institute | 2 |
| Canada | Community Living BC | 2 |
| New Zealand | Manawanui | 2 |
| Australia | Former WA public servant | 1 |

All data were analysed via a thematic coding process to identify key features of the systems, evidence relating to utilisation rates and evidence relating to market stewardship.

Having provided an overview of the methods used in this research, the next section moves on to provide an overview of individualised funding and the various terminology and systems that comprise this topic.

1. Individualised Funding

Internationally we have seen a shift over the past few decades in the disability field towards different systems employing facets of individualised funding. Individualised funding describes a range of models and mechanisms aiming to provide greater choice and control for people using disability services. Various terms are used to describe these schemes including: self-management, personal budgets, direct payments, Cash and Counseling, personal assistance budgets and others. In this report we refer to this class of approaches as individualised funding schemes (IFs), unless referring to a particular scheme when its specific name is used.

Despite different approaches to naming these models they generally share key processes as part of the approach to individualised funding as shown in Figure 2.

Figure 2: Key processes in individualised funding

Aside from sharing these key facets there is significant variation between different models in relation to all processes of individualised funding including:

* *Eligibility*: Schemes may be targeted to people with long term disability or mental health problems or open more broadly to people experiencing difficulties in activities of daily living or who have experienced workplace or transport accidents.
* *Needs assessment*: This might be based on predetermined level of need, scoring via an assessment tool or professional assessment of need.
* *Budget allocation*: Some systems have a hard budget cap, or a predetermined budget according to level of assessed need or others a theoretically unlimited budget. Some models require the individual to contribute to costs.
* *Use of funds*: Models vary in restrictions on services and goods that can be purchased, including whether family members can be employed.
* *Brokerage*: Systems vary in terms of the provision of support to individuals in developing and implementing care plans, engaging providers to deliver services and employing support workers.
* *Budget deployment*: Within systems the funds may be held by different individuals, or variously by the client, service provider, financial intermediary or broker.
* *Accounting for funds*: Systems vary significantly in terms of the process and level of paperwork needed to account for spend of funds.

Broadly speaking there are two different categories of budget deployment available in individualised funding through either direct payment or a managed fund model. In direct payment models, funds are given directly to the individual who then manages the money to meet their needs in some cases supported by family or other carers. This model requires the individual to undertake a number of administrative tasks related to managing their budget and if appropriate to be responsible for activities such as employing staff. In the managed fund model, an intermediary is responsible for the budget administration on behalf of the participant. In some schemes the intermediary may also provide support and guidance to an individual in planning and managing their budget and care plans (Fleming et al., 2019). Some schemes allow a combination of these two methods. The range of mechanisms available for deployment of funds are outlined in Table 2.

Table 2: Mechanisms of individualised funding deployment

|  |  |
| --- | --- |
| Model | Description |
| Government management | Funder retains funds and pays providers on behalf of the individual |
| Service provider | Funding to a service provider who determines allocation to meet individuals needs |
| Financial intermediary | Intermediary pays for goods/services and responds to financial accountability requirements |
| Brokerage | Funding is allocated to an individual and held by broker. Broker arranges the purchase of service in consultation with individual or their representative |
| Direct payment | Funding is allocated to an individual or their representative who organise purchase of services and goods and are required to be accountable for expenditure |

The NDIS has no direct equivalent system nationally or internationally. While it shares some features with other systems there are a number of facets that make it unique. The key features of the NDIS can be characterised as being:

* A large scheme that will eventually cover around 475,000 participants;
* A nationally-funded scheme administered via the NDIA with broadly consistent national rules;
* Non-means tested. Entry to the scheme is determined by demonstration of permanent and significant disability;
* Individual budgets are based on what is reasonable and necessary and linked to goals;
* Includes three potential methods of budget deployment; self-managed, plan- managed funding and NDIA managed funding.

Several countries have national schemes (e.g. Sweden, Germany, Netherlands, Australia), with other countries having local or regional government schemes leading to local variation (e.g. Canada, USA). In the UK, while there are nationally legislated obligations under the Care Act for Local Authorities to provide personalised care, but these entities vary in their administration and implementation of schemes. Other countries are or have engaged in pilots or trials of individualised funding (e.g. New Zealand, US).

The relevance of lessons that might be drawn from other models of individualised funding depend on their design and key features. As indicated above, not all individualised funding systems are equal so we need to be careful when drawing lessons from one setting to another. Relevant scheme features include the presence of a budget that an individual can make choices about goods and services to be purchased from. Models with limited budgets are not usually associated with budget underutilisation and information is less readily available and useful (as in the Swedish Personal Assistance budget scheme). Similarly, models where there are severe restrictions on services that can be commissioned do not inform areas of expenditure.

The mechanisms used to account for budget expenditure vary considerably between schemes. Where governing budget expenditure is a responsibility of local regional authorities, data on individual budget utilisation was generally found to be unavailable in audited accounts and local evaluations. Where national government bodies have oversight of individual funding we were generally able to access information regarding the overall expenditure of the scheme and this was often compared to the budget available. This data reflects not only the overall expenditure on individual budgets, but the number of actual users and scheme administration costs. National government oversight of individual budget expenditure was often in the form of limited fraud checks to ensure expenditure was in line with permissible purchases. Several schemes permitted underspend and accrual of saved money for a short period to enable expenditure for one off or infrequent purchases, thus acquittal of budgets were reviewed over a longer period such as 6 months. For example, participants in the Victorian Individual Support Packages, that operated between 2008-2018, were required to able to carry forward unspent funds up to 5 per cent or $1500 of the total allocation (whichever is the greatest). Continued under-spend could result in a review of the support and funding plan (Australian Productivity Commission, 2011).

There are a number of countries that have well documented individualised funding models in the literature, but are less useful for the purposes of this report. Sweden is a good example of a country with a well-developed and regulated national individualised funding model that has been discussed widely in the literature. Swedish personal assistance budgets are limited to payments for assistance with personal care usually provided by private operators. While Sweden does record differences between budget allocated and spent, correspondence with the Health Department in Sweden indicates that underutilisation is unlikely as services are usually provided by for profit private providers. Similarly, the German care allowance does not cover the full cost of expenses and thus underutilisation is not an issue experienced in the scheme. Similarly, In Japan, service users pay 10% of the care cost, with the remainder paid by the social insurance fund (Forder and Fernandez, 2011).

The search of peer reviewed and grey literature revealed a range of individualised funding models either currently operating or evaluations on previously existing models or trials. The key features of these models are summarised in Table 3

Table 3: Features of individual funding models

| Country | Scheme name | Number of participants | Eligibility | Use of Budget | Budget Deployment | | Caps on Spending | Relevance to this project/NDIS |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| US (trial in 3 states 1998-2002) | Cash and Counseling Demonstration and Evaluation (CCDE) | 6583 (half to treatment receiving budget and half to control group) | Some variation between states but primarily adults with disabilities | Purchase of range of care related services and goods (Florida) and personal care services (Arkansas and New Jersey)  Purchase of counseling services to assist in budget spending and administration | | Direct payment | Yes | Medium- although two state schemes were only for personal care services |
|  |  |  |  |  |  | |  |  |
| Netherlands | Personal budgets or Persoonsgebonden Budget (PGB) | 44,000 (WLZ scheme 2019 participants source: Statistics Netherland) | WLZ scheme for those with long term care needs including people with disabilities, those with chronic illnesses and older people with high needs (also separate act for independent older person living) | Range of services including nursing, personal care, care that enables independence, respite and transport | Currently only payment via an intermediary (Gori and Luppi, 2019) | | No | Medium – limited range of services to purchase |
| Sweden | Personal Assistance Budgets | 434 (Dec 2019 personal communication) | People with Physical and intellectual disabilities and impairment under 65 years | Personal assistance | Direct payment or third-party intermediary | | No (LASS scheme) | Low – only personal care services |
| Germany | Long-term care Insurance cash benefit Pflegegeld (care allowance) |  | People with physical, psychological, or mental disease or disability and dementia | Informal personal assistance provided through family or neighbourhood | Direct payment | | Yes, capped at 3 predefined levels | Low – only personal care and does not meet full cost (Nadash et al., 2018) |
| France | Allocation personalisée d’autonomie (APA) or individual attendance allowance |  | Older adults (60+) with medium to high level of dependency | Personal care and assistance | Direct payment | | Yes, capped at 4 dependency levels | Low – only personal care and does not meet full cost (Forder and Fernandez, 2011) |
| Canada | Community Living British Columbia | 22,000 in 2018/19 | People 19 years or older with an IQ of 70 or under | Wide range of services including learning and skill development, support for work or other activities, community living assistance and social connectedness | Direct Payment or third-party intermediary or Microboard (incorporated entity, to receive and manage the funding for the individual) | | No – allocations based on support plan and available resources | High |
|  | Choice in Supports for Independent Living (CSIL)  British Columbia |  | Adults with physical disabilities and/or with developmental disabilities | personal assistance with activities of daily living, | Direct payment or third-party intermediary | | Yes - funds allocation based on CSIL Categories of Need Guidelines | High |
|  | Persons with Development al Disabilities (PDD) Program, Alberta | 12,000 people in 2017/18 (Sonpal-Valias, 2019) with 10% receiving through IF via family manager administrator (KPMG, 2010) | People 18 years or older with a significant limitation in intellectual capacity and adaptive skills (needs help with daily living activities) | Provides a range of community living, employment, community access supports | Family managed administrator who hires staff or service providers to provide the funded support | | No – allocations based on assessment of need | High |
| UK | Self-directed support (Scotland) | Direct payment 8390 people third party (individualised service fund) 7435 people | Open to anyone requiring assistance to live independently. This includes people with disabilities and older people and those with long term health conditions | Broad range of services | Direct payment or third-party intermediary or mixed budget and council services | | Yes - local authorities use various methods allocation including needs based or equivalent services cost | Moderate |
|  | Direct payment (Northern Ireland) | 65 in 2003 (Nolan and Regan, 2003) | People needing assistance from social care including disability and aged care | Personal social services providing support for everyday life | Direct payment | | Needs based assessment of hours required | Low –small scale and only personal assistance |
|  | Adult Social Care Personal Budgets (England) | in 2018/19 840,000 people | **Adults with physical, learning disability or mental impairment or illness needing assistance** | Range of in home, respite and community-based services and equipment | Direct payment, council managed or individual service fund (third party service provider) | | Low budgets and many people are expected to contribute towards costs | Moderate |
|  | Independent living fund (England, closed 2015) | ~21,000 | People with severe disability to maintain at home | Personal assistants | Direct payments | | Unable to determine | Low – only personal assistance |
|  | Individual Budget pilot  2005-6 (Glendenning) | 959 participants | For people with physical impairments and disability, learning disabilities, mental health and older people | Range of services including personal assistance and home care, transport equipment and leisure activities | Direct payment. Local authority control or independent agent control | | Overall budget cap from combined funding sources | Moderate – the English system includes older people |
|  | In Control Pilot sites evaluations 2003-5 | 1st trial 90 people  2nd trial 196 people | 1st trial people with learning disabilities, 2nd trial broader group including older people | Range of goods and services | Self-directed personal budget | |  | High |
| Australia | TAC individualised funding (Victoria) | ~200 | Severe permanent disabilities | Range of goods and services | Direct Payment | | Needs based assessment | High |
|  |
|  | Victorian Direct payments project (2006-2007) | 10 people | Adults with disability | Variety of services and goods to meet identified goals | Direct payment | |  | High |
|  | Victorian Individual Support Packages 2008-2018 | 7800 in 2011 | People with disability | A range of disability related supports including assistance with independent living and skill development and social participation | Direct payment, a financial intermediary or a registered disability provider | | Four main funding bands with 17 levels recognising low to high need | High |
|  | Western Australia Local Area Coordination (1988 –2017) LAC Direct Consumer Funding | In 2006 LACs support approximately 7500 people (Bartnik and Chalmers, 2007). In 2003 1,465 out of 6,981 people received direct funding | People with physical, sensory, neurological,  cognitive and/or intellectual disability who are under the age of 60 | Include family support, alternatives to employment and accommodation support | Direct payment available LAC Direct Consumer Funding | | Needs based allocation of direct funding | High |
| NZ | Enabling Good Lives Personal Budget Trial scheme 2012 to current (3 locations Mid Central District Health Board, Christchurch and Waikato) | 64 participants Waikato phase 1  Christchurch in 2015 175 participants | People with disabilities | Broad range of service housing, equipment, personal support skill development, employment and social connection | Via agency to manage funds or self-directed | | Pooled funding from person existing funding with option with additional funded support | Medium – trial with low participant numbers |
|  | Enhanced individualised funding trialled in Eastern and Western Bay of Plenty regions (discontinued) |  | People with disabilities | Personal assistance, respite, and funding for other supports such as social support or skill development | Administered through a contracted IF Host provider with varying levels of assistance provided | | Unclear | Moderate – administered through host |
|  | Manawanui self-directed funding | 7,062 in 2020 | People with disabilities | Purchase personal care and household management services (e.g. cleaning and meal preparation) from Ministry of Health Home and community services. Additional funding is available for respite care | Manawanui is the contracted IF host that either manages funds or assists client to self-manage | | Needs based allocation | Moderate – limited range of services to purchase |

,

Only a few models found internationally have sufficient budget, choice in expenditure and rigorous methods of financial accountability to inform budget utilisation and areas of spend. The individualised funding models presented in Table 3 meeting these criteria were examined for information regarding budget utilisation, areas of expenditure and mechanisms to support budget expenditure. These areas are expanded on in the following sections.

1. Budget utilisation

Data on budget utilisation was limited in the literature due to either restriction on budget size, meaning that most individuals expended all their budgets, or limited accountability for budget expenditure. A small number of individualised funding models were found that provided limited information on individualised funding allocation vs expenditure and are described in this section.

* 1. US Cash and Counseling

The Cash and Counseling Demonstration and Evaluation (CCDE) conducted in the US is one of the most often quoted sources of detailed information on an individualised funding model. The CCDE was a large-scale randomised policy experiment aiming to evaluate individualised funding to people with disabilities conducted from 1998-2002. The original program has since expanded and is referred to under a variety of state specific names such as self-directed care or participant direction. An inventory of participant-directed long-term services and supports conducted in 2016 shows 252 programs operating in the US  (Sciegaj et al., 2016).

In the CCDE Cash and Counseling demonstration, sites were established in Arkansas, Florida, and New Jersey. This model was characterised by:

* Individuals receiving a monthly allowance used to hire workers, and to purchase care-related services and goods;
* Individuals having the ability to designate representatives to assist with managing their care;
* The provision of counseling services to help plan and manage budgets and staff and provide advice on services; and,
* The provision of bookkeeping services to help consumers and their representatives manage their budgets and administrative responsibilities (Brown et al., 2007).

The characteristics of the model varied among the three states, with only Florida allowing purchase of a range of disability related goods and services. Arkansas and New Jersey provided participants with an allowance in lieu of the personal care services benefit in their respective Medicaid State Plans, which covered services such as help with eating, bathing, housekeeping, and shopping. Plan hours were capped at 16 per week in Arkansas, and at 25 per week in New Jersey (Dale and Brown, 2005, p.C1).

The CCDE provides limited data on utilisation rates measured both indirectly and directly. Indirect utilisation rates were examined in one state, New Jersey, through a comparison of reported hours of paid care to hours allocated in care plan. In this state the cash allowance was calculated by multiplying the number of hours of care allocated in consumers’ plans by an hourly rate. The comparison of reported hours paid and in the care plan is broadly indicative of budget utilisation as shown in Table 4.

Table 4: CCDE New Jersey reported budget utilisation at interview 9 months (Brown et al., 2007 modified from table A1 and A2)

|  |  |  |
| --- | --- | --- |
| Survey response | Use of hours in plan by treatment group (percentage) 18-64 years | Use of hours in plan by treatment group (percentage) 64 plus years |
| the same number of hours in plan | 41.2 | 51.2 |
| less hours than in plan | 19.1 | 14.9 |
| more hours than in plan | 22.9 | 17.4 |

As indicated in Table 4, 14.9% of participants aged 65 years and 19.1% of participants aged 18-64 indicated they used less hours than allocated in the plan. This measure as an indicator of utilisation rates has limitations as it is unknown the degree of underutilisation and whether one of the factors contributing to underutilisation of hours is greater than expected costs of workers or availability of workers. An additional limitation is that this figure only examines budget spent on direct care by workers, rather than counseling costs.

In a more detailed analysis of cost data from the CCDE, Dale et al (2004) examined the Arkansas demonstration site and compared the average personal care expenditure of cash and counseling recipients with actual incurred personal care expenditures at 2 and 12 months post enrolment (Dale et al., 2004). The utilisation rates are shown in Table 5.

Table 5: CCDE Arkansas direct budget utilisation rates

|  |  |  |  |
| --- | --- | --- | --- |
| Time post enrolment | Average anticipated monthly expenditure ($) | Average actual monthly expenditure ($) | Budget utilisation |
| 2 months | 509 | 456 | 89.6% |
| 12 months | 513 | 507 | 98.8% |
|  |  |  |  |

The increased utilisation rate at 12 months shown in Table 5 reflects a similar finding by Fleming et al that early assessments of program do not allow time for the intervention to be fully ‘put in place and to bed down appropriately’ (Fleming et al., 2019, p.56). The data from the CCDE provides evidence that budget underutilisation was experienced, but this largely resolved over time. Data was only available for state programs allowing commissioning of personal care services, rather than for Florida where a broad range of services were permitted to be purchased.

* 1. WLZ Long Term Care, the Netherlands

In the Netherlands there are a number of highly regulated individualised funding schemes for various grouping of people. The WLZ scheme provides individualised funding for people with long term care needs. This scheme includes, among other funding types, individualised funding in the form of a personal budget, which covers nursing, personal care, care than enables independence, respite and transport. Data obtained from Statistics Netherland outlines the average budget utilisation over the period 2009-2018 as shown in Table 6.

Table 6: Personal Budget (PGB): budget allocated and spent for long term care WLZ scheme (Statistics Netherlands)

|  |  |  |  |
| --- | --- | --- | --- |
| Year | PBG allocated (x1000 Euros) | PGB spent (x1000 Euros) | Budget utilisation (%) |
| 2009 | 2175516 | 1917298 | 88.1 |
| 2010 | 2397172 | 2156905 | 90 |
| 2011 | 2492956 | 2255459 | 90.5 |
| 2012 | 2747238 | 2458666 | 89.5 |
| 2013 | 2755000 | 2414866 | 87.7 |
| 2014 | 2746131 | 2410681 | 87.8 |
| 2015 | 1394541 | 1273918 | 91.4 |
| 2016 | 1784924 | 1566220 | 87.8 |
| 2017 | 1999849 | 1752707 | 87.6 |
| 2018 | 2184133 | 1874926 | 85.8 |

As Table 6 shows average budget utilisation varies from 85.8% to 91.4%. Figure 3 indicates a slow decline in utilisation rates over the 10-year period as shown via the dotted trend line.

Figure 3: Utilisation trend in Netherlands Personal Budget

The decline over time in budget utilisation shown in Figure 3 is occurring in a fully bedded down program. The data derived from a large number of Individuals receiving individualised funding over a long period of time provides robust and reliable data on average budget utilisation. Significant program reforms were made from 2012-2015 to reduce uptake and expenditure and restricted access to people with more complex needs. This saw the numbers of participants decline significantly (Alders and Schut, 2019), which may explain some of the under-utilisation but there is insufficient comment on this within the literature to fully explain this decline.

* 1. Victorian Direct Payments project (2006-2007)

A small pilot of direct payments involving 10 people with disability was undertaken by the then Victorian Department of Human Services in 2006-2007. The evaluation of the pilot examined underutilisation and found 6 of the participants reporting 8-45% underspend at the 6-month review from a total budget of $171,000 over that period, with two participants reporting overspend (Dimitriadis et al., 2007). The small number of participants and limited timeframe constrain the usefulness of this evaluation in providing robust evidence of underutilisation levels. However, this pilot, unlike any other evaluation encountered, did directly address reasons for budget underutilisation and these were reported as:

* Delays in receiving invoices
* Saving money to accrue for future activities (e.g. holidays)
* inability to access and recruit workers due to shortages
* Hospitalisation
* Cautiousness about spending

4.4 Victorian Individual Support Packages (2008-2018)

Prior to the NDIS, the Victorian government provided individual support packages (ISP) to people with disabilities. Budgets were provided either through direct payment, administered via a financial intermediary or provided directly to a registered disability provider. MOIRA Incorporated, a registered disability service provider, was contracted by DHHS to provide state-wide financial intermediary services at no additional cost to approximately 3000 clients with a disability. Data on budget utilisation from MOIRA is provided in Table 7 and in Figure 4.

Table 7: Victorian Individual Support Package financial intermediary data (MOIRA)

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Age Group | 2010/ 2011 | 2011/ 2012 | 2012/  2013 | 2013/  2014 | 2014/  2015 | 2015/  2016 | 2016/ 2017 | 2017/ 2018 | 2018/ 2019 | 2019/ 2020 |
| <20 | 40.59% | 49.63% | 33.84% | 46.95% | 42.08% | 39.19% | 34.77% | 38.99% | 29.99% | 27.26% |
| 21-40 | 50.32% | 42.32% | 42.43% | 40.24% | 38.47% | 38.30% | 40.42% | 37.63% | 30.26% | 25.02% |
| 41-60 | 51.92% | 48.98% | 48.17% | 49.81% | 51.81% | 49.53% | 49.48% | 48.31% | 43.96% | 48.06% |
| >60 | 56.55% | 49.96% | 43.48% | 39.13% | 44.49% | 47.09% | 48.51% | 47.23% | 47.22% | 17.99% |
| Total Percentage Utilisation | 49.22% | 46.32% | 42.99% | 44.28% | 43.76% | 42.46% | 42.14% | 41.78% | 35.43% | 27.68% |
| No. of Service Users | 2339 | 2399 | 2334 | 2636 | 2795 | 3327 | 3217 | 2637 | 1542 | 227 |
| Total of Allocated Grants | 41,887,712 | 50,305,886 | 52,652,592 | 55,328,220 | 62,801,873 | 80,041,878 | 93,158,836 | 77,998,721 | 42,552,559 | 7,062,512 |
| Utilisation per person | 8,815 | 9,714 | 9,699 | 9,294 | 9,834 | 10,215 | 12,203 | 12,358 | 9,777 | 8,612 |
| Under- Utilisation per person | 9,094 | 11,256 | 12,860 | 11,695 | 12,636 | 13,844 | 16,756 | 17,221 | 17,819 | 22,500 |

Figure 4: Victorian Individual Support Package financial intermediary budget utilisation (MOIRA)

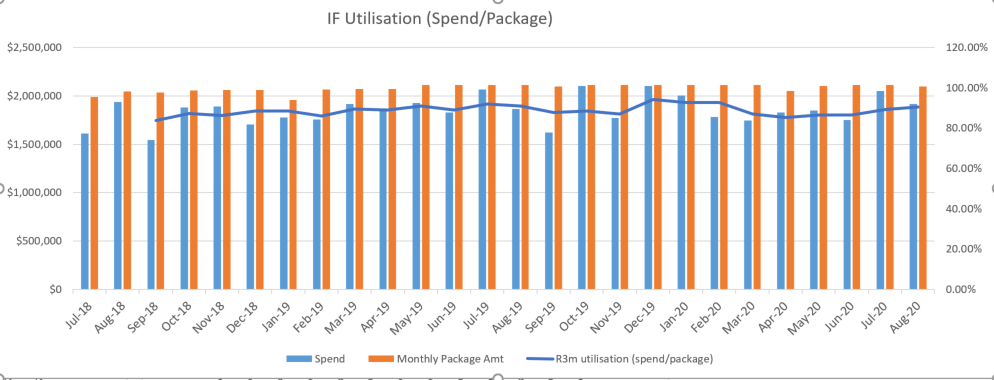
Table 7 and Figure 4 show a relatively low budget utilisation rate of between 42 and 50% between 2010/11 and 2017/2018. This utilisation rate drops further in the subsequent two years as clients begin the transition to the NDIS. MOIRA report that a large proportion of their financial intermediary clients in this later period concurrently received ISP and NDIS funds due to delays of up to 5 months in DHHS receiving advice that an NDIS plan had been approved. The concurrent receipt of both NDIS and DHHS funds resulted in further underspend in the ISP budget.

* 1. Victorian Transport Accident Commission

The Victorian Transport Accident Commission (TAC) provides individualised funding to approximately 200 people with severe injuries who are willing to manage their own funds independently, or with the assistance of a financial intermediary. TAC pays a monthly budget that can be used to purchase a broad range of approved attendant care, allied health, wellbeing and domestic services and equipment under $1000. Clients are able to carryover and accumulate a 20% surplus from the previous financial year in their account.

Data from July 2018 to August 2020 period shown in Figure 5 shows a summary of the aggregate monthly budget utilisation and indicates budget utilisation of approximately 93%.

Figure 5: TAC Individualised funding budget utilisation (TAC)



TAC attributes the relatively high utilisation rate to a long running and mature scheme with a narrow cohort of well-known clients. Clients have close and ongoing contact with TAC support coordinators and advice from individualised funding specialist who assist with service planning and budgeting.

* 1. Western Australia NDIS

Between 2014 and 2017, Western Australia operated the WA NDIS in a comparative trial of approaches to a nationally administered NDIS. These two schemes demonstrate a difference in utilization of around 23%, with the WA NDIS having a far higher utilization rate. Data from the WA sites and the NDIA operated sites demonstrate the structural differences between the schemes and factors that may have contributed to the differences in plan utilisation. The WA NDIS was based on local coordinators ‘assessing’ the needs of people with disability in the context of their existing supports and services, then applying the actuarial funding controls only once these aspects had been taken into account. This is reported to have resulted in a more targeted focus on the supports funded in each plan. The role of the local coordinator also included assisting the person to engage with service providers, thus ensuring the connection between funded plan supports and provided services occurred as quickly as possible. The second contributing element is that plan funds were committed to services providers in advance each quarter, with a requirement that unspent funds (for services not provided) were returned to the Disability Services Commission. This provided an incentive for service providers to ensure that their service provision was timely and comprehensive in relation to funded plan goals.

A joint comparative actuarial assessment was prepared by the scheme actuary for the NDIA operated NDIS and the scheme actuary employed by Western Australia for the WA NDIS. This assessment observed that:

“*The average annualised committed cost is $51,276 in the NDIA NDIS trial and $33,460 in the NDIA WA trial. However, the trial sites experience significantly different utilisation rates which need to be considered when comparing committed supports. The utilisation rate in the NDIA NDIS trial was modelled to be approximately 68%. Applying this 68% utilisation factor results in an average annualised cost per participant of $34,868. The utilisation rate in the WA NDIS trial was modelled to be approximately 85%. Applying this 85% utilisation factor results in an average annualised cost per participant of $28,441. The difference in utilisation of committed supports is driven by the intrinsic differences in the payment of providers between the sites. The WA NDIS trial pays providers quarterly in advance of support being provided following plan approval. Funding related to undelivered or under-delivered supports is refunded to DSC following an acquittal process. In the NDIA NDIS trial, providers receive payment after the support has been provided*.”

* 1. Manawanui, New Zealand

New Zealand has for over a decade developed and trialled new models of support for people with disabilities supported by individualised funding models of different types. Manawanui is a contracted IF Host provider, supporting over 7000 people with disability to manage their funds across New Zealand. Manawanui provides management support to all clients and additional payroll support to clients who do not want to manage timesheets and employee payments. Clients are designated self-managing or payroll clients depending on whether they receive the payroll service. Manawanui works with more than 15 different schemes across New Zealand in supporting individuals self-directing their care. Manawanui has comprehensive data on the use of IF budgets for their clients over the last 5 years as outlined in Table 8 and Figure 6.

Table 8: Manawanui: budget allocated and spent for self-directed care

|  |  |  |  |
| --- | --- | --- | --- |
| Year | Total Budget on client funding | Total Spend | Budget utilisation (%) |
| 2015 | $ 58,194,193.15 | $ 30,011,553.94 | 51.57 % |
| 2016 | $ 71,081,889.40 | $ 41,616,123.81 | 58.55 % |
| 2017 | $ 82,477,097.43 | $ 56,934,300.14 | 69.03 % |
| 2018 | $ 112,698,535.93 | $ 72,081,502.16 | 63.96 % |
| 2019 | $ 110,460,720.13 | $ 80,731,439.36 | 73.09 % |

The increasing utilisation rate over time demonstrated clearly in Figure 6 is consistent with previously discussed improved utilisation rates as IF programs mature. In interview, Manawanui described a range of reasons for this. Firstly, the data infrastructure is more effective so that spending and utilisation rates are tracked more accurately. Secondly, as the system has matured people are better able to use funding and there is more ability to spend allocated funds. As one interviewee explained, “people are better at it nowadays. As we get more familiar, as individualised budgets and self-direction get to be more of a standard way of doing things it gets easier and easier for people. It isn’t a weird and wild approach any more. And you have lots of organisations who are doing bits of it now, so offering up recruitment support and that sort of thing and employment advice.”

Figure 6: Utilisation trend in Manawanui budget allocation

Data from Manawanui indicates that 5% of client overspend with the remaining clients underspending. Interestingly, an analysis undertaken of spending by client type demonstrates that self-managing clients have larger underspends than those who have more contact with the organisation through payroll services as shown in Table 9. In interview it was explained that overspending tends to occur where plan assessors have been “a bit too frugal”. Working across fifteen different schemes it is reported that plan assessors tend to work in rather different ways and do not always allocate what is needed to support an individual. Overspending also occurs where a particular event occurs and this changes the need of the individual. For example, if a close family member of carer becomes ill and an individual therefore requires more support due to a reduction in informal support.

Table 9: Budget spend by client type (Statistics Netherlands)

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Service Type | Total Budget | Total Spent | Unique Clients | % Spending |
| Payroll | $ 359.127.250,23 | $ 239.981.104,24 | 5,311 | 66.84 % |
| Self-Managing | $ 100.589.937,10 | $ 59.814.870.72 | 1,751 | 59.44 % |

* 1. Other

Interviews by Martinez and Pritchard (2019) highlight that personal budgets often incentivise people to use public money wisely and found that budget holders frugally using their allocated funds to purchase products and services as defined by their care plans. The authors cite evidence from a pilot project offering personalised budgets to long-term rough sleepers in England found that participants spent less than they were allocated, only £794 on average out of the £3,000 budget. Further details on budget expenditure was not available.

1. Areas of expenditure

Areas of expenditure permitted within individualised funding vary widely between different models. Expenditure can range from a limited employment of personal assistance with activities of daily living and engagement with the community to the broader inclusion of expenditure relating to items such as equipment, household adaptations, transport, holidays and respite care. To understand areas of expenditure, models with both orientation towards people with disability and flexibility in use of the budget were examined. A key challenge in comparing areas of expenditure between individualised funding models is differences in permitted expenditure, which prevent comparing like with like.

* 1. Individual budgets pilot 2006-2008, England

In England the most significant research into individualised funding is an evaluation of individual budgets, undertaken by Glendinning et al (2008). The researchers examined 13 pilot sites where English local authorities with responsibilities for adult social care trialled individual budgets from 2006 to 2008. The 13 pilot projects involved 959 service users representing different groups of social care users receiving various combinations of funding streams that included funding for physical impairments and disability, learning disabilities, mental health and older people. Two of the 13 sites involved exclusively older people with the majority being people with physical/sensory and learning disabilities. The average annual gross cost of an individual budget was approximately £11,450 (Glendinning et al., 2008, p. 47). People were allocated into groups according to whether they were receiving individual budgets (via direct payment or a managed budget) or receiving standard services to compare the efficacy of these mechanisms. Table 10 outlines expenditure for the 285 people receiving individual budgets for which detailed records were kept (this includes 85 older people and the remainder with physical/sensory and learning disability and mental health users).

Table 10: Areas of budget expenditure in UK individual budgets (Glendinning et al., 2008 Table 5.6 modified)

|  |  |
| --- | --- |
| Type of expenditure | % (N=285) |
| Personal assistant | 59 |
| Home care (agency) | 22 |
| Home care (inhouse) | 5 |
| Meal services | 5 |
| Equipment –telecare | 2 |
| Equipment – other | 10 |
| Adaptations | 3 |
| Leisure activities | 37 |
| Planned short breaks | 22 |
| Childcare | 1 |
| Health and dental Services  (officially excluded but used by some) | 2 |
| Accommodation | 5 |

From Table 10 it can be seen that the key areas of expenditure were personal assistance and home care, leisure activities, planned short breaks and equipment.

* 1. Adult social care, England

Individual budgets are one mechanism that adults in England might use to receive social care through. Adult social care is provided to a range of eligible participants in England including those with physical and learning disabilities, mental health issues and older adults. Local authorities pay for care through a personal budget which may take several forms (National Audit Office, 2016):

* partially or fully as direct payments to an individual’s dedicated bank account or their nominee to be spent on outcomes agreed in a care plan. Prepayment Cards have been introduced by some local authorities to pay personal budgets to people who have been assessed as eligible for direct payments. The allocated funding is loaded onto a payment card.
* An account managed by the council. The authority commissions services for the user
* An account manager by a third party (individual service fund). The Individual Service Fund is where a provider “manages” a person’s personal budget in addition to providing the direct support.

A report by the National Audit Office (2016) on personalised commissioning in adult social care provides a breakdown of social care services to people with disabilities and mental health needs as shown in Table 11. However, this data does not provide a breakdown of service use according to budget deployment type.

Table 11: Social care expenditure by adults with physical and learning disabilities and mental health needs in England (National Audit Office, 2016)

|  |  |  |  |
| --- | --- | --- | --- |
| Type of expenditure | % for Adults 18-64 with learning disabilities (n=435) | % for Adults 18-64 with mental health needs (n=147) | % for Adults 18-64 with physical disabilities (n=325) |
| Care and support services | 56 | 67 | 55 |
| Personal assistants | 44 | 46 | 66 |
| Community or leisure services | 51 | 31 | 22 |
| Equipment | 3 | 8 | 6 |

As shown in Table 11, the main category of expenditure is for home support via an individual employing a personal assistant or via purchasing care and support services from an agency. This is followed by expenditure on community and leisure services and equipment.

* 1. Persons with Developmental Disabilities (PDD), Alberta, Canada

The Persons with Developmental Disabilities (PDD) Program runs in Alberta, Canada and provides a range of services to adults with developmental disabilities. Services can be received via funds provided to community service providers or family managed service administrators who then purchase services (10% of participants) or via direct government operations. PDD provides four main types of services and expenditure in these areas, via all funding mechanisms, as shown in Table 12.

Table 12: Areas of expenditure in PDD in 2017-18 (Government of Alberta, 2018 modified from data in Appendix A)

|  |  |  |
| --- | --- | --- |
| Type of expenditure | Description | % of total service delivery (19,383 total services provided)  (total n is not provided but 12,000 is approx. value) |
| Community Access Supports | helps promote community connection and social inclusion | 32.0% (6195 people) |
| Employment Supports | employment training and workplace support for maintaining paid employment | 15.6 % (3033) |
| Home Living Supports | support staff helps with living in home | 52.0% (10071) |
| Specialized Supports | helps caregivers and support staff, when additional support is required | 0.4% (84) |

As in the English model, home living supports and community access supports are the two major areas of expenditure, with employment supports being an additional category in this scheme.

* 1. Community Living British Columbia

The community living British Columbia (CLBC) program provides a wide range of services to people 19 years or older with an IQ of 70 or under. Services include learning and skill development, support for work or other activities, community living assistance and social connectedness. Participants can access services via direct payment or third-party intermediary/host agency or a microboard (incorporated entity, to receive and manage the funding for the individual). The main areas of expenditure in the scheme for the year 2010 is shown in Table 13.

Table 13: Areas of expenditure for CLBC (Stainton et al., 2013 modified from Table 9, 7, 23 and 29)

|  |  |  |  |
| --- | --- | --- | --- |
| Type of expenditure | % expenditure for Host agency funding  (n=100) | % expenditure for Microboard  (n=262) | % for Direct funding (n=101) |
| Respite | 9.2 (21) | 12.2 (46) | 34.4% (56 people) |
| Community based services | 24.0 (55) | 25.1 (95) | 25.8 (42) |
| Behavioural consultations |  | 0.3 (1) | 0.6 (1) |
| Direct family support | 6.1 (14) | 0.5 (2) | 4.3 (7) |
| Employment | 1.7 (4) | 0.5 (2) | 3.1 (5) |
| Employment services – individual placement |  |  | 1.2 (2) |
| Home based |  | 2.6 (10) |  |
| Home sharing\* | 7.0 (16) | 9.3 (35) | 4.3 (7) |
| Host agency coordination fee | 35.4 (81) |  |  |
| Individual services | 0.4 (1) | 8.2 (31) |  |
| Homemaker services\* |  | 0.8 (3) | 2.5 (4) |
| Live in support\* | 0.9 (2) | 6.6 (25) | 8.0 (13) |
| Outreach support\* | 5.7 (13) | 9.3 (35) | 3.1 (5) |
| Skill development | 7.0 (16) | 16.4 (62) | 9.8 (16) |
| Supports to home sharing/live in support\* | 2.2 (5) | 1.9 (7) | 3.1 (5) |
| Staffed residential |  | 5.8 (22) |  |

The expenditure categories are not fully explained in the source document, however the report by a group examining CLBC (Queenswood Consulting Group, 2011) and the CLBC website provides more in-depth understanding of these areas. Community based services in this model refers to services operating outside the individual participant’s home that enable them to engage in with their community for vocational and/or social or recreational reasons (Queenswood Consulting Group, 2011). There are four types of these community inclusion support services including employment, skill development, community-based (support to participate in community activities outside a participant’s home) and home-based (activities for mainly group residential settings). This model has a number of categories to describe in home residential supports to daily living including:

### [Supported Living (Outreach / Cluster)](https://www.communitylivingbc.ca/what-support-is-available/residential-supports/supported-living/) which are support with activities of daily living in the individual’s home

* Home sharing and live in support, where the primary residence is shared by the support person contracted by CLBC and the individual being supported
* Residential support in group homes

There are also a range of other services for individuals and families including behavioural consultations with a psychologist or qualified counsellor and home‐maker services, which provide individuals with basic housekeeping services or temporary personal care to successfully live in the community.

When the categories of outreach support, live in support, supports to home sharing/live in support, homemaker services, home sharing are combined as a single entity under home living supports they represent the major areas of spend for microboards and the secondary areas of spending for host agency and direct funding. As Table 13 demonstrates the other most common areas of expenditure in order of highest spend are community-based services, respite care, and skill development.

* 1. Victorian Transport Accident Commission

The Victorian TAC allows expenditure in a broad range of preapproved services and goods outlined in Table 14. Expenditure on items such as home and vehicle modifications and high cost equipment are handled through a separate process for capital requests.

Table 14: TAC expenditure types

|  |  |  |
| --- | --- | --- |
| Type of expenditure | Description | |
| Services | Acupuncture  Attendant care  Audiology  Child care (if eligible)  Chiropractic  Community group programs  Dietetics  Exercise physiology  Gym and swimming programs  Nursing | Occupational therapy  Osteopathy  Physiotherapy  Podiatry  Psychology  Respite  Social work  Speech pathology  Specialist disability laundry services |
| Equipment | Continence equipment  Other equipment under $1000 |  |

TAC calculates that 80% of the funds allocated are spent on attendant care, with 16% on allied health services and the remaining 4% on equipment under $1000.

## 5.6. Summary

Reviewing the data provided on the five schemes described in this section indicates the main area of expenditure is personal assistance and support in the home for daily living activities. This is followed by community based social or employment activities and equipment (where included) being an area of minor expenditure. This is consistent with the US CCDE demonstration trial that found consumers used their allowances mainly to hire workers and few used them to modify homes or cars (Brown et al., 2007). This may be a reflection of the amounts allocated in these budgets and that these only allow a limited amount of support for individuals around need priorities in terms of daily living activities.

1. Mechanisms to support expenditure

Ensuring individualised funding participants’ assessed needs are being met according to planned care underlies the drive for budget utilisation. Establishing appropriate mechanisms to support budget utilisation requires an understanding of the factors contributing to ability to spend. Most fiscal policy initiatives encountered within the literature on individualised funding are aimed at overall cost containment, rather than increasing individual utilisation. Given the literature on budget underutilisation is extremely limited in terms of quantitative data, broader qualitative studies examining the implementation of individualised funding models were reviewed to understand factors that may influence individual expenditure and these are augmented with findings from interviews undertaken for this research.

As the sections below demonstrate, there are a wide range of different factors that impact on utilisation rates. As one New Zealand based interviewee explained: “It is really difficult to attribute changes in utilisation rates to one specific thing. There are a whole lot of things that go on and can have an impact on these. The care planner has an impact and also if government restricts things can be bought and have fewer options then utilisation goes up”. An interviewee in the US also concurred with this sentiment, stating “there are so many idiosyncratic reasons why utilisation rates are high or low”. Utilisation rates are impacted by a range of issues between systems, but even within the same system individuals will experience various barriers and enablers to spend. As the sections below demonstrate, we see issues on both the demand and supply side that impact on ability to spend. On the demand side, inabilities to operate a complex system and lack of information and support can impact an individual’s abilities to spend funds. On the supply side, unavailability of services or inappropriate services can prevent individuals from securing services even where they have funds available.

* 1. Drivers for underspend of budgets

A number of studies examined challenges associated with implementing individualised funding. Drivers associated with underspend of budgets identified in the literature and interviews are described in this section.

* + 1. Complexity

In a recent systematic review of 73 largely qualitative studies of individualised funding interventions for people with disability in Europe, the US, Canada and Australia, Fleming et al (2019) identified several implementation challenges among the 9000 people captured in the studies. Individualised funding models that deploy direct payments to people with disabilities, or their advocates, require recipients to have administrative skills not previously required in former traditional direct service provision models. Some people may need extensive support in accessing individualised funding, managing a budget, accounting for expenditure, accessing required services and employing and managing staff (rostering, disciplining and training). This poses a greater challenge for people with intellectual or developmental disabilities and has seen the creation of brokerage models and microboards, in some schemes, to provide support to people in managing their budget. The degree of assistance provided by a third-party intermediary can be limited to financial assistance, a fiscal intermediary, or as in the case of the broker may include developing and implementing care plans (Fleming et al., 2019).

Fleming et al (2019) found challenges experienced navigating complex bureaucracy and accountability requirements of individualised funding were especially prominent in the early stages of program implementation. This finding echoes the lower budget utilisation rates seen in the first few months of implementation in the CCDE Arkansas presented in Section 4.1. Participants report feeling less burdened with the requirements of the program once they had settled into programs and developed skills to manage their budgets (Fleming et al., 2019, Piccenna et al., 2015) .

In interview, Canadian respondents explained they had higher utilisation rates in schemes at the start, but these had reduced as the system had matured. This was because the system became more restrictive over time, so individuals could not spend on money on things they had before and that had been identified as priorities to them (e.g. specialised swimming classes). As the scheme matured they found that more people were handing back money at the end of the year. As one interviewee explained “sometimes the design is well intentioned but the structures and the accountabilities become so prohibitive”. There is an important message in this experience as criteria for spending became so restrictive those accessing the scheme felt like little had changed. As another interviewee describes: “If all you can do with your individualised funding is use it to pay for services that were there before then it isn’t much of a change.”

* + 1. Access to Information and Support

Lack of assistance with managing a budget was a key challenge identified in a survey of almost 2600 personal budget holders in England in 2014. The survey found that people experienced problems getting support (21.2%), choosing support (19.5%) and planning support (19.5%), where support in this context equates to services as per their support plan (Waters and Hatton, 2014). This survey identified that access to information was a key issue. 24% of people experienced problems with obtaining information and advice and understanding restrictions on budget spending (Waters and Hatton 2014).

Problems with accessing information have been widely reported elsewhere in the literature (see for example Spalding et al., 2006, Dimitriadis et al., 2007, Laragy and Ottmann, 2011, Pike et al., 2016). A study of Australian individualised funding conducted in 2008 found that only half of service providers reported that people with disabilities and their families had good levels of awareness of the rules and systems of individual funding (Fisher et al., 2010). Similarly, the Auditor General’s review of Victorian individualised funding for disability (Victorian Auditor-General, 2011) identified challenges for people with disability accessing information in relation to how funds could be used was related to poor quality supports from support staff, reflecting inconsistent training. This was particularly notable for people who had communication difficulties or did not have supporters who understood or were able to assist in decision making. Fleming et al (2019) report misinformation and mixed messages are also key challenges for schemes internationally.

As part of the research process we collected information from staff at Moira Youth, Disability and Family, a Victorian based organisation that provided financial intermediary services for clients receiving individualised funding though a Victorian DHHS trial. These staff told us that poorly communicated plans by plan coordinators was a key barrier identified in funding being used effectively. Staff reported clients being unclear what funding was for and how to locate and purchase services. These communication breakdowns were more evident in clients from Culturally and Linguistically Diverse (CALD) communities, see section 6.1.5 for more on this issue. As colleagues from the US note, provision of information is important not just for the individuals who hold these budgets, but also for family members. As one interviewee noted, “In IDD it isn’t really about self-direction it is about family self-direction”. This individual noted that it is important to not only provide accessible information to individuals who hold budgets, but also to other family members or friends who might be supporting this process.

In a longitudinal study of user experience of direct payments conducted between 2007 and 2009 in England, Arksey and Baxter (2012) found that insufficient contact over time between service users and local authorities left individuals feeling uncertain about the use of budgets. They report cases with no follow up after early contact resulting in large individual budget underspends. Moira Youth, Disability and Family staff report clients unhappy with current services are often unaware they can request alternative providers and had limited knowledge of other service options. This situation typically results in underspends due to individuals simply disengaging with services. Similarly, users whose circumstances changed in the short term, as with hospitalisations or short-term illnesses, did not engage with activities normally budgeted for leading to underspends.

Changing circumstances can clearly lead to increased or decreased support needs and thus changes in spending. Users of individualised funding need assistance to manage these periods. Glendinning et al (2008) demonstrated that regular monitoring of people with individual budgets stopped between six weeks and six months after initial review and ongoing support was often lacking. Arksey and Baxter (2012) suggest, in the English context of direct payments /personal budgets, perceived insufficient continuing support may be due to local authorities prioritising meeting targets to increase the level of uptake of direct payments by new recipients over continuing involvement with those people already receiving them.

Poor working relationships have been identified by a number of studies as undermining the effectiveness of support received by program participants (Fleming et al., 2019). Martinez (2019) describes factors that may undermine effective working relationship including poor communication, reluctance of staff to embrace new ways of working with clients under individualised funding and challenges experienced by participants and their carers in fully engaging with organisations to design and implement their care. Interestingly, Fleming et al (2019) in their systematic review, found staff and organisations identified another often reported challenge in the form of individuals expressing guilt and not wanting to be a burden on the system resulting in modest requests for assistance. In other words, individuals did not feel able to approach services to request information or a change in their services due to a concern that they might be an annoyance to a service.

* + 1. Workforce

The successful use of individualised funding is dependent on the availability of providers that individuals can obtain services from. Evaluations consistently identify difficulties recruiting, developing, and retaining appropriate staff as a key challenge in individualised funding (Lord, 2000, Anand et al., 2012, Davey et al., 2007, Scottish Government, 2018, PDD Review Panel, 2019), . Inability to obtain staff may lead to underspends in budgets. In a review of individualised funding literature in Canada, the US, Australia and the UK, Chopin and Findlay (2010) found participants identified problems with staffing including low wages contributing to high turnover and leading to difficulties hiring appropriately trained staff. High expectations on staff, the lure of better employment options, demanding working conditions and burnout are factors contributing to staff turnover (Blackman, 2007), (Sonpal-Valias, 2019). Limited availability of staff leads to competition among agencies and program participants. This can be worse in rural areas (Spalding et al., 2006). Chopin and Findlay (2010) report inequities in the ability of participants to top up staff wages in some individualised funding programs can result in socioeconomic differences in clients’ abilities to locate quality staff.

These findings from the literature were also reflected in comments from interviewees. As one Canadian respondents described, “The primary reasons funds would be underutilised is issues around recruitment and retention. At least up until COVID struck the economy has been so hot in British Columbia and broadly people’s salaries are not that competitive. So, whether you are a service provider or whether you have individualised funding, finding staff to work for the funding available is a challenge. If you can’t find people to work, then you can’t spend your money”. The same respondent reported that governments had largely invested money in recruitment and retention within the sector via larger providers. However, they had more recently invested in microboards and also created a website called Support Workers Central to try and match support workers with families who might want these. This is similar in nature to Australia’s HireUp site.

In the US similar sorts of issues were experiences. Respondents explained that individualised funding systems find it difficult to recruit workers when the unemployment rate is low. As one respondent explains:

“the unemployment rate in the US was extremely low so in facility based programmes or home based programmes it was extremely difficult, almost impossible to find staff. Even if you had money in the budget to find staff. But in self-direction programmes where people can employ family member, friends or neighbours, certainly my experience is that employment rates are higher and you don’t face the sort of factor of high unemployment rates. But there’s down sides to that too. We see families who rely almost exclusively on that income stream and perhaps are isolating individuals in their own homes or cutting them off from communities. Some states in the US are very opposed to employing family members, but by and large it solves much of the workforce problem and of course you have people who you know rather than strangers providing a very intimate form of care”.

This respondent went on to note that family members are sometimes more willing to work for lower wages. Which raises the question about “the best way to support families to take care of one another”. The NDIS does not make provision to pay family members to deliver care and has tighter regulatory frameworks in terms of who might be paid to provide support work. But certainly in North America we heard a number of times that utilisation rates often depend on broader employment rates within the economy.

* + 1. Geographical location

A number of respondents indicated that they experience underutilisation in some areas due to geographical factors such as rurality and remoteness. In these case respondents explained in these areas the population level is typically lower and this means that there are fewer potential buyers, particularly of highly specialised services in an area. As a consequence, these areas may be unattractive to providers reducing availability for buyers. As a New Zealand-based respondent commented, “We know some of our rural customers find it really difficult to get support workers, getting staff and keeping them for an extended period…the lack of services that are accessible also in rural areas”. Similar issues were reported in Canada and the US. Respondents largely indicated that their experience is that local factors are highly influential in terms of drivers of utilisation rates.

* + 1. Culture and background

In interviews a number of respondents commented that they believe there needs to be somewhat of a culture shift before individuals are able to effectively operate in an individualised funding system. Respondents reported that individuals were not used to being asked what they wanted in terms of services and they required somewhat of a change in mindset before they are able to engage in processes of purchasing services in an effective way. As one Canadian respondent explained:

*“We did a little bit of research to try and understand why uptake wasn’t as high as it was – because individual funding is the ideal. One thing that came to light was a real cultural element. Those who used it had been told about it and encouraged by other families. So we need to get more of those families using it and happy about it to talk to other families. The bureaucracy isn’t very good at selling it. Over $6000 there is an onerous reporting structure. It is a real commitment, you have to hire people, find others if they cancel at short notice and other things and we don’t fund those costs. There was a proposal for brokers to help this, but in the end this didn’t get taken up by the government”.*

There is a real learning curve involved for those who have operated within traditional systems in order to understand that they are able to truly direct their own services.

For those from culturally and linguistically diverse backgrounds, interviewees from all systems also reported difficulties in accessing and operating purchasing systems. In the US one respondent described that “We also saw in our surveys of case managers here of people who are self-directing…lower income people, people whose first language isn’t English. It basically was a service for middle class and upper middle class people who had the time, the capacity and the sophistication to do the various things that had to be done from accounting to hiring to whatever. And that’s unfortunate, but that’s the case”. As this respondent indicates those from lower socio-economic or non-English speaking background tended to fare worse within these systems and found it more difficult to spend funds.

In terms of First People’s groups, in Canada it was reported that these groups also tend to find it more challenging to access IF systems and to spend budgets. In New Zealand these issues were also felt through Maori and Pacific Islander populations. In this case one respondent explained that issues tend to compound in the sense that this group is over represented in terms of numbers of individuals from socio-economically disadvantaged backgrounds.

* + 1. Saving for a rainy day

Interview respondents in all systems explained that they found individuals not spending their total budget allocation just in case something happened and they found they urgently needed supports. It is well established in the literature that people with disability are more likely to be socio-economically disadvantaged and less likely to be in work (Kavanagh et al., 2013, Milner et al., 2014). As such individuals may be less likely to have resources to fall back on in the event of a crisis or an unpredicted event. Many systems do not allow individuals to overspend and so people will leave money in their budget “People will sit on a bit of money and save it just in case” (New Zealand respondent). This was also reflected in the Canadian experience, one respondent explained: “People often err on the side of caution with budgets – you save a bit in case something happens and you need more. Then you are often penalised for this as you are seen as not needing this. This could encourage waste – people spend the money just because they have to or they lose it”. Here they are reflecting on the fact that even in this system where unspent funds are usually taken out of the budget in the following year, individuals still operate in this way because the penalties for overspending are so much more significant than underspending.

* 1. Facilitators of budget spend

Strategies to address common challenges in implementing individualised funding that may have an impact on budget utilisation were examined in the literature. Strategies found include the provision of information, support and training. These potential budget utilisation facilitators are described in more detail in this section.

* + 1. Information provision and access

Access to high-quality, timely and ongoing information is a key factor identified cited in the literature as ensuring individualised funding recipients can make informed decision and realise anticipated benefits (Dew et al., 2013, Martinez and Pritchard, 2019). Laragy and Ottmann (2011) found that clear guidelines defining what is allowed and what is not, while maximizing flexibility and creativity are important along with understanding the amount of money allocated, the monthly balance and services available. Information must be tailored to meet the needs of individuals and encompass diverse cultural and linguistic needs (Laragy and Ottmann, 2011). While some information can be provided digitally, users with cognitive impairments or technological impediments (including lack of access to the internet) must be able to access information (Martinez and Pritchard, 2019). A Social Care Institute for Excellence report highlights that whilst social care personal budget users ‘valued having written information, it was usually the time spent discussing personal budgets with their social worker, community psychiatric nurse, or support provider organisation that helped them the most’ (Newbronner et al., 2011, p.5).

One of the assumptions built into individualised funding systems is that management costs will be lower as many of these activities shift from a public body on to the individual navigating the system (Spandler, 2004). This experience is borne out in the evidence. For example, English studies found that while care packages were not more expensive for those with personal budgets, their care management costs were higher (Glendinning et al., 2008, Jones et al., 2012). Counterintuitively, care managers spent longer on assessments of people with individual budgets (Jones et al.2012). Costs for individual funding systems are often underestimated and host agencies are required to work unrealistic schedules (Fisher et al., 2010, Laragy and Ottmann, 2011).

The role of frontline staff and advisors with direct contact with people with disability are essential in assisting access to information. Dew et al (2013) describe research undertaken in individualised funding in Western Australia that highlights the role and ongoing relationship between a support workers and carers in accessing information. Targeting training to frontline staff is important as they work directly with the budget recipient and are often involved in the assessment and decision making processes (Carr and Robbins, 2009, Martinez and Pritchard, 2019). Users of the NDIS report specialist knowledge of conditions in their support coordinators, age specific knowledge and a good understanding of community, mainstream and informal networks is valued (Peters, 2020)

In a number of systems it was reported that budget holders do not know what services are available or have any judgement about their quality. As such, a number of systems have invested in technological applications that provide online directories so that individuals can get a sense of what services are available in their locality or to help link individuals up with, for example, support workers. The issue of quality is also problematic, with a number of interviewees explaining that service users lacked a way to get a sense of whether services are effective or would work for them. In several countries different actors have created websites that allow service users to provide a review or rate services according to how effective they found them to be (the Australian equivalent would be Clickability).

* + 1. Support and advocacy systems

The development of adequate supports for a person with disability in making decisions is widely acknowledged as an important facilitator of effective individualised funding in the literature (Spalding et al., 2006). Fleming et al (2019) found that a network of support, whether it be family and friends or a broker were integral in the person with disability managing their individualised funding. Indeed, many of the respondents we interviewed reported having mechanisms for this within their systems. As one respondent in the US explained: “Supported decision making and service brokers are a helpful thing in driving up utilisation rates”. The main types of supports needed by people using individualised funding include supports with managing money, budgeting and accounting, accessing required service and employing and managing staff (Carr and Robbins, 2009). The need to ensure individuals are supported in planning and implementing plans is also a common finding (see for example Chopin and Findlay, 2010, Laragy and Ottmann, 2011, Riddell et al., 2006). A support network, with good communication and facilitation skills, that can guide a person in exploring their goals and implementation strategies are highly valued (Fleming et al., 2019).

Supports come in various forms, including those provided by the formal individualised funding workforce (i.e. funders, providers or from an independent body) and those provided by informal social networks. The local area coordination approach undertaken in Western Australia (WA) had a focus on building the relationship between the coordinator and the person with disability. The WA Disability Service Commission employed local areas coordinators who provided personalised and flexible support to plan and implement care for between 50 and 65 people with disability, including, in some cases, individualised funding. Significant time was devoted to coordinators getting to know people’s strengths and needs (Lord and Hutchison, 2003). Evaluations of the program found that the programme was as good as the individual local areas coordinator that each person had (Bartnik, 2010). Indigenous and CALD groups had a less positive view of the scheme and evaluations found the need for more culturally sensitive responses (Vincent, 2010). One way to do this would be to increase the numbers of individuals from these backgrounds working within these schemes. A review of the WA scheme stated;

In relation to both these groups, a need was identified for active strategies to increase the number of Indigenous and CALD people working as LACs, and to provide appropriate cultural awareness training to assist other LACs to understand the added complexities of disability in an Indigenous or CALD family setting (Disability Services Commissioner, 2003)

Individualised funding programs need to offer varying levels of support to people with disability appropriate to their cognitive, physical, social and cultural needs so they can be active participants in developing and implementing their plans. People also need easy access to on-going advice and support as their situations and needs change. Arksey and Baxter (2012) argue that regular contact with direct payments or personal budget recipients can facilitate appropriate use of funds, avoid large under-spends and provide a supportive environment in which users of direct payments ask for advice. This is echoed by Chopin and Findlay (2010) who found informants in their study mentioned periodic reviews as being important to the success of individualised funding.

The use of independent organisations for advice and support provide an important alternative to support provided by funders and providers. Several pilot personal budget schemes in England have shown that key to improving outcomes is utilising a combination of both trained frontline and administrative staff and ensuring there are sufficient independent organisations to provide support to users (Martinez and Pritchard, 2019). Lord and Hutchinson (2003), in a review of ten of the most promising individualised funding disability initiatives worldwide, found nine of the most successful were identified with infrastructure supports, providing support for planning and administrative tasks, that were separate from service providers and funders. Similarly, an evaluation of the Canadian Individualised Quality of Life project, which provided 150 individuals with learning difficulties and their families in Ontario with personalised planning, support and funding from 1997, found that it was the independence of the planning support that made it especially valued and effective (Carr and Robbins, 2009). A review of the literature of UK self-directed support scheme enablers and barriers conducted by Manthorpe et al (2011) reiterates that brokers and advocates are most effective when independent of funders and as such funders should pay for advocacy where individuals or their representatives cannot undertake this role. Arksey and Baxter (2012, p.156) suggest English local authorities might benefit from recruiting ‘expert direct payments recipients’ who could share their experiences, outcomes and learning with others potential users and workers in the system. While user-led independent support services are seen as particularly useful, studies have demonstrated limited use of these services by users (Carr and Robbins, 2009).

For vulnerable and/or people who communicate in non-traditional ways, the successful use of individualised funding requires a support system or network to assist the individual (Blackman, 2007). Family members, relatives, friends, trusted advisors or advocates are important supports to these individuals and problems can be encountered when there is a lack of support people available and/or capable of providing this support. Blackman et al (2007) describe similar difficulties amongst families and/or other supporters with limited personal resources or finances and/or those for whom English is a second language*.* Willams et al (2003)found that parents provided strong support to people with intellectual disabilities in managing direct payment and only acted as barriers when they did not have enough information. The provision of fiscal intermediary support services to informal support networks has been suggested as an effective strategy to assist families and friends with managing the burden of administration and accountability (Powers et al., 2006).

The role of formal supports in developing the informal support system has been identified as important in the literature*.* Lord and Hutchinson (2003) make a clear distinction between case management and the role of a broker or support coordinator. Whereas the case manager role was described as being more limited with larger caseloads, brokers or support coordinators were seen as facilitators and important in building relationships between people with disability, their family networks and the community. Facilitation could include helping an individual build social support networks, assisting their support networks to undertake care planning and assisting people to find, purchase and create supports (Lord and Hutchison, 2003).

To be effective facilitation requires strong relationships between facilitators and the person with disability. Fleming et al (2019) found strong trusting and collaborative relationships between the person with disability and their support network, formal or informal, were integral to the success of individualised funding. Martinez and Pritchard (2019) describe this relationship in terms of co-production where the ‘lived experience of service users must be given equal footing to professional expertise’. Strong, open and collaborative relationship in individualised funding programs require a cultural shift in the way that workers and participants have previously worked. Lord and Hutchinson (2003) emphasise the focus of facilitation is on supporting the person with disability to manage their own arrangements not to manage it for them*.* This approach to facilitation enables people to exercise control and choice as well as developing skills in managing budgets, which may be an important enabler of improved budget utilisation observed over time. A number of studies reported the development of skills in managing individualised funding improving over time. Arksey and Baxter, in their 2 year longitudinal study of direct payments found examples of users becoming ‘expert direct payment recipients’ (2012, p.156). People developed skills in core financial and human resources administrative tasks as well as interpersonal skills and decision making.

Data on plan utilisation provided in the NDIS discussion paper on support coordination (National Disability Insurance Agency, 2020) provides some interesting comparative data on plan utilisation for participants with and without funding for support coordination. People with funding for support coordination utilise 66% of the funded plan compared with 67% for those not funded for support co-ordination. On face value this does not strengthen the argument for support coordination in assisting budget utilisation, however as Naufal (2020) explains the interpretation of this data is complex. The comparison between those with and without funding for support coordination is not straight forward given that only 69% of funds allocated for support coordination are used. This means the group allocated funding for support coordination is likely made up of many people who either receive no support coordination or low levels. This makes the comparison with those not funded less robust. The other key issues that Naufal highlights is that the group allocated funding for support coordination are generally more complex and will experience more barriers to accessing services and thus potentially have lower budget utilisation rates. Given this, support coordination may be enabling those with complex needs to achieve budget utilisation on parity with those not funded for support coordination. More data is needed to understand this issue fully including data on budget utilisation according to the level of support coordination actually received.

* + 1. Training

Training is a key theme identified in the literature as key to successful individualised funding implementation. Training is important not only for workers in the system but also for participants. There is strong evidence to support the training of frontline staff and first-line manager in the effective implementation of individual budget schemes particularly where direct payments are made (see for example Glendinning et al., 2008, Laragy and Ottmann, 2011), . The role of frontline workers, as discussed earlier, is essential in ensuring users get the information they need. However, evidence from a number of schemes indicates that the knowledge of frontline workers or their ability to disseminate this information is often limited (Martinez and Pritchard, 2019). This may be due to inexperience, capacity issues due to overwork or cultural resistance to individualised funding models. Frontline workers need adequate training to effectively enact their role in information provision and support. Workers also need training to accommodate and support people with a wide range of diverse needs and differing levels of experience and expectations (PDD Review Panel, 2019, Fleming et al., 2019).

Fleming et al (2019), in their systematic review of the literature, found training of practitioners and coordinator/brokers was important in improving knowledge and understanding of individualised funding. The shift to a consumer-driven system can be challenging and stressful for workers accustomed to having more control (Laragy and Ottmann, 2011). Changing worker attitudes can play an important role in the success of individualised funding programs (Laragy and Ottmann, 2011, Stainton, 2002). Workers with a more detailed understanding of the background and philosophy of individualised funding were highly valued by participants. Workers with this knowledge were found to provide useful information and guidance to participants (Fleming et al., 2019).

Similarly, training people with disability and their representatives in staff recruitment and administrative skills was often cited as a facilitator (Fleming et al., 2019, Manthorpe et al., 2011, Chopin and Findlay, 2010). This training was important given that a key barrier to spend is accessing clear consistent information from professionals about basic aspects of individualised funding implementation such as entitlements, the range of services and supports available and how to access them. Several jurisdictions and models, such as in Scotland, New Zealand and the USA, have requirements to ensure that training, guidance and support is provided to participants and their advocates in the role of employers.

* + 1. Workforce

There is little in the literature regarding strategies to deal with workforce shortages. Fisher et al (2010) note the development of successful working relationships between support workers and clients or their families, together with ongoing support and training by providers, are key features leading to support worker development and retention. Workforce retention issues were generally recognised as ‘ongoing and stressful’ (Alberta Council of Disability Services, 2018, p.10) given that some of the drivers of this are not related just to disability services, but also to the broader economy as we see in the North American cases.

* + 1. Market stewardship

Many individualised funding systems are reliant on purchasing services from a disability market. Just as Australia has seen the creation of a disability market with the introduction of the NDIS, other systems also have markets where individual budget holders purchase service from a range of private, public and not-for-profit providers. The assumption within markets is that providers will compete to deliver services wherever demand arises. But, as noted in Section 5, gaps have opened up in some areas, most notably, although not restricted to, rural and remote areas or relation to highly specialised services.

It is widely agreed that public service markets are not ‘conventional’ markets, but rationing systems. Conventional markets are based on a supply and demand relationship, where some individuals miss out on, or receive lower quality of a product or a service. In a conventional market, changes in price provides information on supply and demand. Traditional market economics places a heavy emphasis on the ability of price variations to ‘signal’ needed changes in supply and demand for particular goods (Hayek, 1945) This is how markets can coordinate an efficient allocation of limited resources. In contrast, in a quasi-market, prices for the most part do not change according to purchases between providers and participants. Consumers require services regardless of price. Further, unlike conventional markets, change in price does not provide information about variations in supply and demand. Information about supply has to be gathered and distributed in some other way. Within quasi-markets governments play a role in attempting to balance considerations of efficiency and equity (Bartlett and Le Grand, 1993). In this sense there is a crucial role for market stewardship within quasi-markets in order to guard against market failure.

Market stewardship denotes a more active role for government in the management of markets than found in conventional ‘free’ markets. Where market regulation involves ‘light touch’ approaches such the removal of fraudulent service providers, market stewardship comprises oversight actions – such as price regulation - by governments, deliberate market shaping activities and active support for innovation and take up of best practice (Carey et al., 2018). Market stewardship is most effective when localized, policy specific and both formal and informal (Brown and Potoski, 2004). While there are theoretical and conceptual discussions of market stewardship, a recent review into the empirical evidence base for market stewardship actions revealed limited empirically tested research in the academic and grey literatures on what market stewards can do in the face of quasi-market failure (Carey et al., 2020). There is a clear need for tools that can help identify where market gaps might emerge and to intervene to prevent market failure.

* 1. Summary

The studies presented in this section identify a number of the barriers and facilitators of spending in individualised funding systems. These are summarised in Table 15. Many of these drivers and facilitators of individual funding spending will be present within the same system and impact differently on various groups depending on their characteristics. It is only at the local level where it becomes apparent which of these have an impact and what might therefore help.

Table 15: Drivers and facilitators of spending in individualised funding systems

|  |  |
| --- | --- |
| Drivers for underspend in individualised budget spending | Facilitators of individualised budget spending |
| Funding and service systems are unduly complex and individuals struggle to understand and complete administrative processes | Clear communication regarding eligibility and spending restrictions |
| Lack of information about how individualised funding operates and allowable budget spends | Provision of formal supports to participants |
| Lack of support in planning and implementing spending | Development of informal social networks to provide support to participants. |
| Lack of information about what services are available or their quality | Training of professional staff in individualised funding philosophy, and facilitating decision making and supporting people with a diverse range of needs. |
| Lack of providers or providers able to meet needs of individual needs available | Training to address cultural and linguistic needs when providing support and information. |
| Funding and service system lacks understanding of needs of CALD and Indigenous clients and services are culturally unsafe | Availability of advocacy within the community |
| Poor relationship between budget holder and funder/intermediary | Training and skill development for people with disability around decision making, creating a plan and responsibilities as employers |
| Being new to individualised funding | Professionals letting go of traditional power relations |
| Putting money aside for a rainy day | Availability of tools to identify what services are available locally and provision of some means to quality assess these. |
| Lack of appropriately trained workforce | Market stewardship tools to help identify where there are market gaps and to prevent market failure. |

1. Benchmarking

As outlined in the introduction, one of the research aims for this project was also to explore whether similar individual funding systems operate a benchmark level for individual budget utilisation and what an appropriate level might be. The literature review did not find evidence of such a process operating in other systems. In interviews most respondents said that utilisation rates are not something that they routinely collect and analyse. Having said this, some said they would occasionally monitor this to ensure that it does not reach particular levels as they would see this as indicative of a problem. As a New Zealand interviewee explained: “if our utilisation rates were tracking at 100% I would be suspicious that people were being underfunded. There should always be some wriggle room in those budgets”. There was general agreement from respondents that 100% utilisation rate would be indicative of a problem and typically it is illustrative of insufficient funds being made available within a plan.

Manawanui did, however, report routinely using utilisation rates as an indicator in the early days of their operation and at a time when not all funders were fully supportive of individualised funding systems yet. As an interviewee explained:

*“We used to use the utilisation rate to demonstrate that people are better at managing the money themselves…A typical provider will send someone in at 8 o’clock in the morning and 8 o’clock at night and that is what everyone gets whether they want it or not or need it or not. With self-direction the person themselves can say I don’t want it tonight I’m doing this, this and this or don’t come at that time. They’re just better at managing their budget. We used to use utilisation rates as an example of that. Utilisation rates in IF are generally about 5% less than the traditional system”.*

In this case it is possible to overspend in some of the different New Zealand individualised funding system. Utilisation rates were used to demonstrate to funders that individuals were not overspending and in fact most were spending less than they had done on traditional services. The utilisation rate is part of a suite of different data points that Manawanui used to demonstrate that they are transparent and accountable in their operations. But having established this trust, this figure is less of a concern.

What these findings suggest is that utilisation rates are a relatively blunt measure of the effectiveness of a scheme. There are so many different factors that might contribute to utilisation rate levels that this is not necessarily an indication of one issue. What does seem clear from the findings is that 100% utilisation is generally seen to be an indication that something is wrong with care planning/budget allocation processes. Many people in receipt of individualised budgets are careful in their use of these allocations and often reserve some in the event that their circumstances change or an unforeseen issue arise. If people are using 100% of these budgets it could suggest there is insufficient allocation in the first place. Establishing a benchmark also opens up the system to potential gaming of this value.

If utilisation rate is to be used as some sort of barometer of system effectiveness, rather than setting one utilisation rate, some respondents suggested establishing different utilisation rates according to different groups. Or instead, monitoring the utilisation rate of an individual over time and, for example, using this in planning processes to explore whether there are issues in accessing necessary services. So utilisation rate might be more helpful at a local level than at a jurisdictional or national level.

1. Limitations

There are a number of limitations to the literature and data reviewed as part of this report. As outlined earlier, a key limitation in the study is the lack of comparability of different individualised funding models due to different implementation features. This combined with the small number of programs from which data about budget utilisation and areas of expenditure were obtained limit the robustness of the findings. Webber et al. (2014) undertook a review of the literature in relation to individualized funding and found that studies often lacked detail about funding mechanisms, and in some cases found it difficult to distinguish between processes and outcomes. Along with a number of ‘methodological shortcomings’, the team found they were limited in the extent to which they could interpret findings. In addition some of the evidence on individualised funding has come from pilot programs which may have received additional resources, training and financial incentives to support their implementation (Martinez and Pritchard, 2019). Manthorpe et al. (2015: p. 44) concur, describing studies found in their scoping review as ‘often small-scale and/or characterized by small sample sizes; they may be reliant on pilot activities, with little or no long-term follow up’. These resources are not necessarily available when scaling up programs and therefore caution must be exercised when interpreting the outcomes of pilot projects.

In addition to the challenges posed by the quality and availability of data, the COVID-19 also had an impact on our ability to collect data. Data collection processes started just prior to the World Health Organisation declaring a global pandemic. It is well evidenced that people with disability are more vulnerable within health emergencies (Dickinson et al., 2020). This is not necessarily because of individual’s impairments, but as a result of the discrimination they face through service systems and broader society. The implication of this is that many policy makers, service providers and experts were actively engaged in pandemic response processes and we struggled to engage as many respondents as originally anticipated as a result.

1. Areas for future research

As this report has demonstrated, aside from some notable exceptions, most number of systems do not collect data on utilisation rates at a national level. One potential avenue for future research could be in collating figures regarding utilisation from different local governments/states/provinces across a country and use this to interrogate and compare national figures. As Section 6 illustrates there are a large number of data gaps in relation to different mechanisms to help individuals to spend their budgets. Notable amongst these are: how to provide to CALD and Indigenous groups and in culturally sensitive ways; how to increase an appropriately skilled workforce; and, how to identify market gaps and prevent market failure.

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