# A narrative review of self-directed disability budget management

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## Acknowledgements

The NDIA acknowledges the Traditional Owners and Custodians throughout Australia and their continuing connection to the many lands, seas and communities. The NDIA pays respect to Elders past and present and extends this acknowledgement and respect to any Aboriginal and Torres Strait Islander people who may be reading this report.

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# Abbreviations

| | |
|---|---|
| CRPD | Convention on the Rights of People with Disability |
| DVD | Digital Versatile Disc |
| FACS | Fair Access to Care |
| NDIA | National Disability Insurance Agency |
| NDIS | National Disability Insurance Scheme |
| OECD | Organisation for Economic Co-operation and Development |
| ULO | User led organisation |
| UK | United Kingdom |
| UN | United Nations |
| USA | United States of America |

# Glossary

**Agency managed funding** in the literature typically refers to the funding of services and supports directly from disability or social care budgets (e.g., "block funding" of services) and not through individualised self-directed budgets.

**Circles of Support** comprise family, friends or volunteers from the network of a person with disability who are committed to an individual's well-being provide support (Gridley, Brooks, & Glendinning, 2014a).

**Citizen advocates** can be any citizen (including family) to support a person to express their wishes, or to protect their rights.

**Person Centred Planning** is not a single intervention, but is an umbrella term defined by five key features: (1) the person is the focus; (2) family, friends or other people from a circle of support may be partners in the planning process; (3) the plan captures what is important to the person at the centre, their capacity, and their support needs; (4) the plan generates actions focused on life and not just the services or resources that are needed or available; and (5) the plan involves ongoing learning, listening and opportunities for action (Ratti et al., 2016).

**Peer advocates** have a similar experience of living with disability as the person for who they are supporting to express their wishes, or to protect their rights.

**Self advocates** can speak for themselves, express their wishes, and defend their own rights.

**Self-direction** of disability funding is when a person is allocated a budget for their disability-related supports, and they choose how their funding is spent. They may receive the funding directly, or a third party may manage it on their behalf.

**Self-management** of disability funding is when a person is allocated a budget for their disability-related supports, and the funds are paid directly to the budget holder or a nominee to pay for their support needs.

**Social Capital** is defined as the resources that one can access through their social connections.

**Statutory advocate** is a paid professional whose role as defined in law. They must protect the person's procedural rights, and support them to assert those rights (Flynn, 2013).

# Executive summary

The information included in this review aims to inform the development of an effective [Self-Management Policy](#) for the NDIA, as well as any considerations that may be relevant to the development of guidance, tools or processes once the policy has been developed. This review focused on the design, context and outcomes from countries that are most similar to Australia and that provide individualised funding to people with disability that they can self-direct or self-manage. In this executive summary we briefly summarise the key findings. More detailed summaries are provided at the beginning of each key section.

## Methods

The review uses systematic review methods to identify relevant literature that was narratively synthesised to address the key questions outlined in the a-priori protocol developed in consultation with the NDIA's Agency Policy team.

## Key findings

This review identified insights on the following key aspects of self-direction of disability funding around the world:

- the purpose and design of self-directed funding schemes;
- the social, environmental and political contexts of self-direction of disability funding;
- who can and does self-manage or self-direct their funding;
- safeguarding and risk management processes;
- facilitators and barriers of self-direction and self-management, including processes relating to recruitment and employment of support workers; and
- outcomes and cost-effectiveness of self-directed funding schemes.

Self-management initiatives typically focus on promoting social justice and the protection of the human rights of people with disability by supporting their choice and control over how they live their lives, including where and how they access supports. The key objectives of self-management in many countries have been to reduce the cost of residential and other traditional services. The neoliberal political philosophy is commonly cited as underpinning self-managed individualised funding with the focus on reducing government power and control over services and increasing consumer choice and control to stimulate the development and competitiveness of the social services market.

There are four main fund management options within self-directed programs, each of which represent variations of two of the plan management options available to NDIS participants: plan management and self-management. All four options were included in this review for consistency with the international literature that focuses on self-direction of individualised funding. In the **open or user-led** option the budget holder receives cash payments that they

can spend in ways that support their needs (consistent with *NDIS self-management*). In a **planned, budgeted and managed** option payments are made to a provider (e.g., agency, cooperative or disability representative organisation) who makes purchases on behalf of the budget holder (consistent with *NDIS plan managed funds management*, where the participant chooses a plan management provider to assist them to manage their funds, such as purchasing and paying for supports, or providing capacity building support). **Brokerage**, involves a third-party organisation is responsible for overseeing administrative tasks and supports budget holders to plan, arrange and manage their services and supports (consistent with *NDIS plan managed funds management*). Finally, many countries use a **hybrid model** whereby people can use elements of the open, planned and brokerage model (consistent with the NDIS, where participants can use a combination of self-management, and agency or plan management).

It is generally recognised that people with any type of disability can self-manage as long as they have the support of family, a circle of support, or an independent representative, agency or broker if they have limited capacity. Safeguarding and risk assessment and management processes should be integrated throughout all aspects of self-management. While financial risks are often the focus of safeguarding strategies, fraud and financial exploitation is rare. The most common safeguarding issues are physical abuse or neglect; however, the risks are not higher than for people accessing traditional agency managed supports or services, or for those who are not self-managing their budget. More intensive safeguarding practices should be targeted towards people with the greatest risk of harm, abuse or financial exploitation. Budget holders and their family may need training, support and advice about safeguarding both before commencing to self-manage their supports, and over time in a way that empowers them to recognise safeguarding risks and to mitigate them.

In line with the social model of disability, the review identified a range of facilitators and barriers, including mechanisms needed in scheme design, the disability sector and workforce to enable people with disability to successfully access and use their self-managed budget (Section 3.5 & 3.6), including recruitment and employment of support workers (Section 3.7). We also summarise the processes and supports needed by people with disability to make an informed decision about whether they want to self-manage, and to enable them to successfully self-manage their supports.

Self-management has been found to lead to beneficial outcomes for the budget holder and their families. These include higher satisfaction with access to needs-led supports and improved quality of life, health, social and community participation, choice and control, empowerment, independence, and relationship quality. Family members also report increased participation in paid work. Moreover, fewer adverse events have been reported. However, the positive effects of self-management are only realised when people are able to creatively and flexibly use their funding, and they have timely access to appropriate information, supports and tools to manage the administrative aspects of self-management. While cost-effectiveness evaluations are limited and evidence is weak, most studies have found that self-management and self-direction of individualised funding cost less and are more cost-effective compared

with accessing services through agency-managed funding (e.g., "block" funded services that are not paid for by an individualised self-directed budget). Costs to the funding scheme are typically higher when supporting people to initially start to self-manage; however, ongoing auditing costs can be contained if budget holders are using financial or bookkeeping services to support payroll or accounting.

In summary, we have identified many potential benefits of self-direction and self-management of funding for people with disability, their family and support networks, and for governments. To maximise the effectiveness of self-management, it is important that facilitators are optimised, particularly providing people with accurate and timely information, support, training and tools, so that they can manage the operational, administrative and reporting requirements. While safety and risks have not generally been found to be increased for people who are self-managing their funding, this is likely because most schemes have taken a cautious and proactive approach to risk containment.

# 1.  Introduction

The purpose of this document is to summarise literature on self-direction of disability support funding, particularly through self-management of a disability budget. The literature discussed in this review aims to inform the development of an effective [Self-Management Policy](#) for the NDIA. The NDIA recognises that having control over personalised budgets can give participants the ability to choose the supports that will best meet their needs. It provides flexibility so they can change supports as their needs, abilities, or preferences change, or if they find something better. It creates empowered consumers invested in understanding their budget and using it optimally. This is expected to generate better value and outcomes for participants and the NDIS, greater linkages with community and mainstream supports, and forced growth of better quality, innovative supports across the sector. Self-management of funding by NDIS participants is expected to be a key lever in ensuring participants realise the full benefits of the visionary social reform provided by the NDIS.

## 1.1  Research Questions

The following questions guided the scope and structure of the review:

1. How effective is self-management and self-direction of disability funding for supporting people living with disability to achieve desired outcomes (e.g., quality of life, participation, health, safety, satisfaction)?
2. Do environmental factors impact on the success of self-management, including:
    a. The presence and distribution of educative supports (e.g., via peer support, courses/sessions, or printed / online guides),
    b. Models of ecosystems that facilitate greater adoption (e.g., Disabled People's Organisations, government or other bodies mandated to provide helplines, online chat / fora, etc.)?
3. Are there any lessons as to more efficacious models, as well as how any of these have links back into policy renewal and process improvements?
4. Are there quality systems or processes that facilitate self-management (e.g., data availability & transparency), and how do jurisdictional approaches contribute to creating informed consumers (e.g., factors such as price per unit, adherence to audits, individual outcomes, using registered providers, managing legal or ethical breaches?)
    a. What facilitates the successful implementation and uptake of self-management?
    b. What are the issues and barriers to the successful implementation or use of self-management in disability support schemes for the person with disability, their family/guardian, support worker/service or the scheme?
5. How do the acceptability, effectiveness and benefits of self-management vary for different participant cohorts?
6. How are mistakes or misuse of funding monitored, identified, and handled? How do the schemes balance deterring people from doing the wrong thing with allowing them to learn

from mistakes, and build their capacity? How common is it for people to misuse their funds for inappropriate, ineligible, or fraudulent purposes?

7. What is the cost effectiveness of self-management versus scheme or administrator management of disability funding? Where in the process of scheme administration and the purchase of supports are savings realised (e.g., reduced scheme administration costs, better value purchases, and broader influences on market to drive costs down as participants start to access more diverse support options and competition grows).

# 2.  Method

To identify relevant evidence and insights from the literature, the following databases were searched, including Campbell Collaboration; Specify, Embase, Emcare and MEDLINE via OVID, and the Cumulative Index of Nursing and Allied Health Literature (CINAHL) database via EBSCO., We sought to identify literature individualised funding and budgets for people with disability (Fleming et al., 2019). The search strategy sought to identify relevant literature for all disability cohorts; however, it was designed to ensure that literature was identified that discussed self-management for people who may face additional barriers to self-management due to intellectual, cognitive or psychosocial disabilities.

All search results were screened for relevance in Covidence by one author, and full text articles were obtained for records that appeared to be relevant. We prioritised information from existing high quality systematic reviews and empirical studies. Relevant sources were also identified from hand searching reference lists of included publications; however due to limited time it was not possible to source all cited papers. Where this is the case, the citing paper has been noted in the relevant citation. Supplementary searches for grey literature and journal articles were undertaken to identify further information.

The evidence was summarised in a narrative synthesis, guided by the key research questions established in the review protocol.

# 3.  Narrative literature synthesis

After removing duplicates, 2,757 records were screened for relevance of which 269 records were relevant, and 77 additional records were sourced from reference lists and grey literature. Most literature focused on implementation, evaluation and experiences of self-management and self-direction of funding in the UK and USA given their extended history with the independent living movement, personalisation, self-directed care and direct payments.

Self-direction of disability funding is defined as the allocation of a level of funding through a personal budget that the budget recipient can use to purchase social services or supports directly, or through a third-party agency or broker, to meet their disability and social care needs. The terminology, design, implementation, and use of self-direction and self-management varies from country to country (Verhaeghe, 2020), as outlined in Table 1.

Terminology commonly employed within the literature included personalisation (used to characterise the policy change), individualised funding (the funding model) and self-management (the funding options within the model), Figure 1.



**FIGURE 1: COMMON TERMINOLOGY**

In most settings budget holders have the opportunity to fully or partially self-manage their funding through direct payments, consistent with the process by which NDIS participants can self-manage their funding. Therefore, we refer to the approaches used around the world as reflecting *self-management*, but highlight, where relevant, key differences in scheme design, implementation, or uptake between countries. This review provides overviews of the following key topics to support the NDIA policy and guidance on self-management:

- A brief overview of the **history and different funds management options within individualised funding systems**;
- **Who can self-manage**, including eligibility and assessment practices and supports required to enable self-management;
- **Risk assessment** and **safeguarding** processes;
- The role of **social and environmental factors in self-management**, including politics, the service environment; advocacy, user-led organisations and peer support networks; and family and circles of support;
- **Facilitators, barriers** and **challenges** of self-management, including information access and training needs;
- **Outcomes of self-management** for people with disability and their support networks, including factors that influence those outcomes; and
- **Cost-effectiveness of self-management**

## 3.1 Overview of self-management implementation globally

### 3.1.1 A brief overview of the history of personal budgets and self-management

Increased focus on personalisation in the past 20-40 years has led to wide implementation of personal budgets and the opportunity to self-manage social and disability care around the world (Verhaeghe, 2020). Personalisation involves considering what is important in the life of someone living with disability, both now and in future, and allows people to tailor their supports and services to meet their needs rather than fitting into existing service models (Sims & Cabrita Gulyurtlu, 2014; Tarrant, 2020). The pathway towards personalisation and self-management emerged following the independent living movement in the 1960s in California, United States of America (USA), before widespread lobbying by people with disabilities who sought to take more control over their lives and services (DeJong, 1979). The right to be included in society was most recently being endorsed in Article 19 of the United Nations Convention on the Rights of People with Disability (CRPD) (United Nations (UN) Department of Economic and Social Affairs Disability, 2006), including the supports that people may need to be included.

**Table 1**. Key terms for personal budget and social care self-management

| Self-management scheme or term | Country |
|---|---|
| Assistance allowance | Sweden |
| Cash and counselling | United States of America |
| Cash for care/ 'allocation personaliseé a l'autonomie' | France |
| Cash for care | Scotland |
| Cash payments | Austria |
| Cash payments (Independent Living Fund) | England |
| Cash payments for care | Germany |
| Consumer directed care | Australia |
| Consumer directed Family Support | USA |
| Direct payment | England |
| Direct payment/ direct funding | Canada, British Columbia |
| Direct Payment Vouchers | Italy |
| Home care service vouchers | Finland |
| Household aid and attendance allowance | United States of America |
| Independent Support broker | Ireland |
| Individual budget (comprising funds from multiple streams) | England |
| Individualized funding | Canada |
| Medicaid Waiver | United States of America |
| Personal assistance budget | Belgium |

| Self-management scheme or term | Country |
|---|---|
| Personal budget (local authority funds for social care) | England |
| Personal budget | Germany |
| Personal budget/ 'Persoonsgebonden budget' (PGB) | The Netherlands |
| Personal Health Budget (integrated for health and social care) | Italy |
| Person-Centred Budget | Netherlands |
| Planned individualized funding | New Zealand |
| Self-determination programs | United States of America |
| Self-Directed Care/Supports | United States of America |
| Self management model | Ireland |
| Special services at home | Canada |
| Support for interdependent living | Canada |
| User-controlled personal assistance | Norway |

*Notes*: other terms used in self-management include indicative allocation, individual service fund, managed account, managed budget, notional budget, personalised care, pooled budget, virtual budget (Camoni, Picardi, & Venerosi, 2020; Fleming et al., 2019)

Self-management initiatives typically focus on promoting social justice and the protection of the rights of people with disability (Carr, 2011a; Hamilton, Mesa, et al., 2017), while also using person-centred processes to enhance quality of life, wellbeing, autonomy, self-determination, empowerment choice and control of people living with disability (Benoot et al., 2021; Carey, Crammond, & Malbon, 2019; Fleming, McGilloway, & Barry, 2016; Fleming et al., 2019; Richards, 2020; Verhaeghe, 2020). Self-management programs have also aimed to improve the family's capacity to care for a family member with a disability (Tarrant, 2020; The Health Foundation, 2010). In some settings, self-management involves the co-production of services (Dursin, 2021; Webber et al., 2014).

The implementation of self-management has generally resulted in a radical redistribution of public, or government, funding from institutionalised services and agencies to the service user and their family (Benoot et al., 2021). Most countries approached self-management as a means to reduce the cost of social and disability service provision (Carr, 2011b; Dickinson, 2017; Laragy, 2010; Verhaeghe, 2020). However, successful self-management requires that budget holders, or their support networks, are able to know and articulate their needs, negotiate the market, and purchase and monitor their support services (Carey, Crammond, & Malbon, 2019; Sims & Cabrita Gulyurtlu, 2014).

### 3.1.2  Fund management options within self-directed programs

Self-management and personalisation has been described as varying along a continuum, with 'deep' processes where budget holders self-organise and/or co-produce their own services through to relatively 'shallow' processes, such as service users having input into the services that they access (Dursin, 2021). Around the world, there are four main fund management options within self-directed programs, each of which are consistent with variations of the plan management options available to NDIS participants. All four options were included in this review for consistency with the focus in the international literature on self-direction of individualised funding. The four main ways that people can practice self-management include:

1. **Open or user-led**: aligns with the independent living philosophy whereby the budget holder is allocated cash payments and they have freedom to spend it as they wish to support their needs, often with few accounting mechanisms to monitor spending; although regular reviews are used to ensure that there is adequate care (e.g., Austria, Germany, Finland) (Dickinson, 2017; Nally, Moore, & Gowran, 2021; Verhaeghe, 2020). However, Fleming et al. (2019) highlighted that open models tend to place more administrative duties on the person with a disability in light of auditing funding use, and are therefore predominantly taken up by people with a physical or sensory disability. This model is most consistent with *NDIS self-managed funds management*.

2. **Planned, budgeted and managed**: involves payment of a budget to a provider (e.g., agency, cooperative or disability representative organisation) who makes purchases on behalf of the budget holder for items that align with the predefined needs as outlined in the plan of the budget holder (Dickinson, 2017), and further limitations may be imposed on the types of goods and services that can be purchased (Verhaeghe, 2020). This model is most consistent with *NDIS plan managed funds management*.

3. **Brokerage**: a third-party organisation takes responsibility for overseeing administrative tasks and providing support, guidance or information to budget holders so that they can plan, arrange and manage their services and supports (Fleming et al., 2019). The broker may help the budget holder to develop their plan, establish a circle of support, negotiate costs with service providers, or commission bespoke services if none are available (Fleming et al., 2019). In some parts of Canada, the USA and the Netherlands people must use an independent support broker. Some brokerage agencies use aggressive marketing strategies, which can be problematic for budget holders (Verhaeghe, 2020). This model is most consistent with *NDIS plan managed funds management* with additional support to create and coordinate services in thin markets or to address unique needs.

4. **Hybrid**: In most countries people can choose to use elements of open, planned and brokerage options (Verhaeghe, 2020), such as management of their support workers but delegation of administrative and financial responsibilities to a cooperative (Laragy, Sanders, & Brophy, 2015). This model is consistent with the option for NDIS

participants can use a combination of self-management, and agency or plan management.

Key ways in which some countries have designed and delivered different individualised funding systems are described below:

- **USA**: The design of each scheme varies from state to state, and have included "consumer-directed", "self-directed" or "participant directed" care programs since the 1970s (Camoni, Picardi, & Venerosi, 2020). People may receive their budget through direct payments, waivers or vouchers to pay for their support needs (The Health Foundation, 2010; Verhaeghe, 2020). In some situations people can pay their own family members to provide care (Singer, Biegel, & Ethridge, 2010), especially if there are shortages in the availability of long-term care staff (The Health Foundation, 2010). People are generally not allowed to employ their spouse as a caregiver (Laragy, Sanders, & Brophy, 2015)

- **Canada**: self-managed budgets have been available for at least two decades in most provinces in Canada (Camoni, Picardi, & Venerosi, 2020); however, the way that each scheme operates differs between jurisdictions. The schemes have traditionally focused more on children and young people, and people with higher support needs (The Health Foundation, 2010).

- **United Kingdom** and **Ireland:** Personal budgets can be taken through direct payments, managed funds held within the local authority, and/or through traditional service use (Carr, 2011b; Manji, 2018). Direct payments are means tested, and many people are required to contribute to the cost of their own care (The Health Foundation, 2010). In England, personal budgets and direct payments are predominantly funded from central taxation (Carr, 2011b), but each local authority manages their own individualised funding programs (Laragy, Sanders, & Brophy, 2015).

- **Europe**: The scoping review by Nally, Moore, and Gowran (2021) reported that direct payments are available in nine European countries (i.e., Croatia, Sweden, France, Germany, Netherlands, Norway, Slovakia, Spain, Sweden, and Switzerland), and on a limited basis in seven other countries (i.e., Belgium/Flanders, Estonia, Ireland, Italy, Latvia and Romania).
  - **Sweden**: the highly regulated scheme has focused on three groups of people: people with severe intellectual disability or autism, people with acquired brain injury and people with permanent physical or mental impairments that are not linked to normal ageing (Laragy, 2010). Sweden embraces the social and relational view of disability (i.e., that both individual impairments and social/physical environments contribute to disability), so a high number of citizens are recognised as having a disability and are entitled to self-management (Lindqvist & Lamichhane, 2019).
  - **Denmark**: personal budgets are designed to reduce bureaucracy and to enhance the quality and quantity of time that social workers or planners can spend with people using services (Carr, 2011b). Budget holders can choose

their services, or choose supports that will be paid for directly by the local authority (Eriksson, 2014).

- o **Norway** and **Finland**: The Municipality evaluates eligibility, and budget holders become the employer and manager or their own supports with or without assistance from the municipality or from cooperatives (Camoni, Picardi, & Venerosi, 2020; Christensen, 2012).
- o **Austria**: self-managed funds are relatively unregulated, and can be used flexibly (Carr, 2011b; Leece, 2004).
- o **Germany**: personal budgets are heavily regulated and can be received through in-kind services or cash payments (The Health Foundation, 2010). It is typically expected that the budget will be managed by carers (Moran et al., 2012).
- o **France**: The system is heavily regulated and includes a case management, signposting and supportive counselling to help people get the most out of their personal budgets (Carr, 2011b; The Health Foundation, 2010).
- o **Belgium:** personal budgets are available as cash payments, vouchers, or a combination of both cash and vouchers (Verhaeghe, 2020).
- o **Netherlands**: the scheme is highly regulated, but allows for the employment of relatives (Leece, 2004). Funds can be paid directly to services, or as direct cash payments to the budget holder, or through a combination of both options (The Health Foundation, 2010).
- o **Italy**: self-managed funds are relatively unregulated, and can be used flexibly (Carr, 2011b; Leece, 2004) to improve quality of life and restore or improve social functioning (Camoni, Picardi, & Venerosi, 2020).

### 3.1.3 What can typically be purchased with a self-managed budget?

The types of items and services that people can purchase with self-managed funding predominantly focus on personal assistance and daily living, support and transportation (Arksey & Baxter, 2012; Camoni, Picardi, & Venerosi, 2020; Laragy, Sanders, & Brophy, 2015; Larsen et al., 2015; Slasberg & Beresford, 2015; Verhaeghe, 2020), which accounted for 67% of "low-need" budget and 76% of "high-need" budgets in one study (Wilkinson-Meyers et al., 2015). People may also be able to use their funds for participation in social activities, equipment or technology (Laragy, 2010; Moriarty, Manthorpe, & Harris, 2019), and respite services (McNeill & Wilson, 2017). In the USA and Italy, people can also purchase health care services (e.g., nursing, rehabilitation) with the expectation that this will support wellbeing and reduce need for residential or hospital-based care (Camoni, Picardi, & Venerosi, 2020; Carr, 2011b; Verhaeghe, 2020). Similarly, the study by Whitaker (2015) found that often a 'preventive' family-oriented approach was taken whereby a child's personal budget was used to cover the cost of items to prevented larger scale costs for a child at risk of requiring foster care (e.g., counselling for a parent, or purchasing nursery items). Once needs have been identified and a plan has been created supports or items can typically be purchased from existing traditional social services, the private sector, the volunteer sector, user-led organisations, community groups, or family and friends (Carr, 2011b). In some countries, such

as in Germany, any service or support can be purchased as long as it is within the budget and contributes to achieving agreed goals (Junne & Huber, 2014)**.**

### 3.1.4   Governance, regulation and quality assurance

According to the Academic Network of Disability Experts, the mechanisms for scheme regulation vary around the world, and can include the use of independent inspectors, government inspectors, accreditation from a regulatory body, quality management systems, regulations, standards, guidelines, a quality committee within the organisation, complaint mechanisms, or the Committee on the Rights of Persons with Disabilities (Nally, Moore, & Gowran, 2021). The scoping review by Nally, Moore, and Gowran (2021) highlighted several other quality assurance mechanisms used around the world. For instance, in Sweden staff must complete a quality management course, and have a duty to monitor service quality and to report violations. In America, all states must have a quality management strategy, quality assurance plan, and quality improvement plan that outlines system performance measures, outcome measures and budget holder satisfaction measures.

## 3.2   Who can and does self-manage?

**Key points from the literature**

i.   Staff often assume that people with some disabilities cannot self-manage leading to their official (e.g., via eligibility criteria) or unofficial exclusion (e.g., via 'gatekeepers' who oversee who is offered funding).

ii.   Overall, however, it is generally recognised that people with limited capacity to self-manage may be able to self-manage as long as they have the support of family, a circle of support, or an independent representative, agency or broker.

When self-management schemes were initially introduced, such as Direct Payments in the UK, people with some types of disability, such as learning disabilities, were often excluded as it was assumed they would not be able to manage to self-direct or to oversee the administrative processes (Harkes, Brown, & Horsburgh, 2014b). Even when eligibility was broadened, people working in the disability sector often remained confused about who was eligible (Leece, 2000), and acted as informal gatekeepers by only offering self-management to people they considered to be the "*right sort of person*" who could benefit from and administer self-management (p.414; Ellis, 2007). Considerations that influenced these biases included the perceived ability of the individual to manage their own money, and their risk of exploitation or harm (for an overview, see systematic and scoping reviews by Harkes, Brown, & Horsburgh, 2014a, 2014b; Sims & Cabrita Gulyurtlu, 2014). For instance, in a mixed methods study with staff working on safeguarding issues in the UK one senior manager commented that "*you'll be aware that really we have to offer a Direct Payment, unless there's a safeguarding reason not to*" (p.8; Stevens et al., 2018). More recently, however, it has been recognised that people with limited capacity to self-manage may nonetheless be able to do so if they have access to support of family members, a circle of support (Fleming et al., 2019), or

a welfare guardian who can act in the best interests of the person with disability (Harkes, Brown, & Horsburgh, 2014b). Alternatively, a third party or professional may enable them to self-manage if there is no suitable representative available from informal networks, or if they are at risk of exploitation by family members (Alakeson et al., 2016).

In their systematic review on self-direction of services and supports Lakhani, McDonald, and Zeeman (2018) reiterate that the literature points to the need for service providers to avoid the assumption that people with disabilities cannot arrange their own services, and instead empower them to self-direct their supports.

Key insights into who self-manages are influenced by how schemes determine access to self-managed funding; and the processes for identifying a "suitable person" for budget holders who have limited capacity. Furthermore, insights into levels of uptake over time highlight the reality of who chooses to self-manage, is offered the option to self-manage, or is able to effectively self-manage. Each of these points are summarised below.

### 3.2.1 Self-management eligibility and how access is determined

> **Key points from the literature**
>
> i.  In England, Northern Ireland and Ontario Canada eligibility is restricted to people who can manage their funding independently or with assistance from a nominee.
> ii.  Many countries do not specify eligibility in terms of self-management capacity, and instead focus on eligible needs, age, disability type or severity, or means-testing.
> iii.  Eligibility and budgets are typically determined from a professional-led needs assessment, although there is growing emphasis on the importance of self-assessment.
> iv.  The information presented in this section reflects the information available in the literature.

**Eligibility for self-management**

The scoping review by Nally, Moore, and Gowran (2021) highlighted that eligibility criteria for self-management schemes for personal assistance vary across countries, and can include: age limits (e.g., Belgium/Flanders, Denmark, Ireland, Italy, Norway, Serbia, Slovakia, Slovenia, Sweden, Switzerland), specific disabilities (e.g., France, Italy, Serbia, Slovenia, Switzerland), disability severity (e.g., Bulgaria, Netherlands, Norway, Slovenia, Spain). In some countries access is also means-tested (e.g., Belgium/Wallonia, France, Germany, Italy, Netherlands, Norway, Spain, United Kingdom). Some examples of how eligibility and access are determined in countries where the ability to self-manage is specified include:

- **Ontario, Canada**: Access to self-managed funding is available for people with physical disabilities needing support for daily activities (e.g., eating, bathing, or dressing) who *can demonstrate their ability to 'self-direct'* (Hande & Kelly, 2015).
- **England/United Kingdom**: Local authorities have had discretionary power to provide self-managed funds (through direct payments) to people who appear **'…***to be capable*

*of managing a direct payment by himself or with assistance*' (Hyslop et al., 2020); however, eligibility criteria vary across countries in the UK, and local authorities within countries (Carr, 2011b). For instance, some local authorities impose their own eligibility criteria to restrict self-managed budgets to people are assessed to be "*needy enough*" (p.96; Harkes, Brown, & Horsburgh, 2014b). For instance, people with mild to moderate learning disabilities were often assessed as ineligible (Harkes, Brown, & Horsburgh, 2014b). To determine eligibility and budget allocation, people must have a needs assessment consistent with the Fair Access to Care (FACS) criteria for prioritising eligibility for care and support (Barnes, 2011).

- **Northern Ireland**: self-managed funding (Personal Social Services through Direct Payments) can be provided to service users where they are *satisfied that the recipient has the capacity to manage it*, either independently or with assistance (Department of Health and Social Services, 1996 as cited in McNeill & Wilson, 2017).

- **Germany**: Self-managed funding is available for "*persons with physical, psychological or mental disease or handicap that are expected to need a substantial amount of help to carry out the routine activities of everyday life for approximately six month or more*" (p.27; Gibson & Redfoot, 2007). Access is determined through a budget conference where their needs are assessed, the development of targets and agreeing to how these targets will be achieved (Junne & Huber, 2014)**.** While eligibility is *not legally based on capacity*, in reality people are often denied access if they have no capacity to manage a budget (Benoot et al., 2021):

  > '*The administration thinks it is written that somebody can be refused access to a personal budget, because they lack capacity. But that is not written in the law, instead, if you are not able then you have to get an assistant… The answer should not be "you don't get it because you cannot do it", but it should be "we pay you also to help to do it if you really want to do it"*' (Practitioner 11, p. 784).

Changes in eligibility criteria that restricted the type of people who could access self-managed funding were thought to primarily reflect concerns that personalisation increases demand for the social care system, particularly of people who previously never used social services applied for funding (Henwood & Hudson, 2008). Moreover, growing pressure on available resources has meant that several countries have had to reduce budgets or change eligibility criteria (see Section 3.8.3 on austerity measures).


**Person-centred planning tools**

In most settings in order to access self-managed funding the disabled person must undergo an assessment to define, measure and prioritise their needs (Leece, 2004). The systematic review by Fleming, McGilloway, and Thomas (2021) concluded that a formal assessment could both facilitate and inhibit the success of individualized funding. Three types of assessments are considered important when identifying support needs: **essential lifestyle plans** (e.g., where to live and with whom, what to do day-to-day, routines and preferred

characteristics of those providing support); **mapping** of the individual's life history and previous choices that led to good or bad outcomes to then help identify goals; and identification of **pathways** towards achieving goals (Barton, 2012). The processes for accessing self-managed funding for several countries described eligible conditions and assessment tools or processes, but did not explicitly refer to capacity to self-manage funds, including:

- **Scotland**: 'Eligible needs' are established through a supported self-assessment tool (Mitchell, 2012b) with input from family or carers to help identify and deliver support that is personalized, preventative, responsive and sustainable (Verhaeghe, 2020)
- **Italy**: People with a range of disabilities or chronic conditions that have both health and social care needs can access a personal health budgets through self-managed funding using vouchers in some regions (Camoni, Picardi, & Venerosi, 2020).
- **Sweden**: Eligibility is based on a physician assessment that outlines the functional disabilities from a long-term impairment resulting in limitations in daily living (Lindqvist & Lamichhane, 2019; Verhaeghe, 2020).

There has been an emphasis on the need to shift from professionally-driven assessments to assessments that are directed by the person themselves (i.e., self-assessment), that may include input from people in their support circle when determining social funding access and support needs (Barnes, 2011; Barton, 2012; Wilkinson-Meyers et al., 2010). There are several reasons for this shift. First, it is recognised that the individual and/or their family or support network are best-placed to judge their wellbeing and their needs (Slasberg & Beresford, 2014). On the contrary, there is evidence of significant gaps between the perceptions of need by health professionals and those of disabled people and their families (Kersten et al., 2000). Moreover, there can be conflicts of interest in professional-led assessments when those professionals also have a duty to not over-commit limited public social care funding (Leece, 2004; Slasberg & Beresford, 2014), and often the assessment is redefined to fit the available resources (Mladenov, 2017) rather than accounting for the person's actual support needs (Slasberg & Beresford, 2016a). For instance, Slasberg and Beresford (2016a) describe an example of a woman who could not go to the toilet at night without assistance, whose needs were met by having a night-time assistant. When budgets were tightened her needs were documented as being met by the use continence pads rather than the more costly personal assistant. This outcome compromised her choice and sense of dignity. Even if self-assessment is allowed, however, a professional review should typically be undertaken to ensure that it has accurately captured the individual's needs (Slasberg & Beresford, 2014).

**Budget allocations**

Once a person meets the eligibility criteria for a personal budget that they can self-manage, it is important that they are given a clear 'ball park' estimate of their funding so that they can plan their supports (Slasberg & Beresford, 2014). Budget size is generally based on the level of support needs, difficulties in daily life and/or previous care packages (e.g., in Sweden, Belgium and England and USA) (Verhaeghe, 2020), rather than the level of impairment per se

(Lindqvist & Lamichhane, 2019; Tarrant, 2020). The funding is then generally calculated based on the cost of care in specific regions given that costs can vary between geographic areas (Verhaeghe, 2020). In England the use of a Resource Allocation System was controversial as the indicative budgets generated were often inaccurate and unhelpful, and were often ignored or manipulated (Slasberg & Beresford, 2016b). Moreover, several studies found that there was little relationship between the upfront funding allocation and what people actually received (Slasberg, Beresford, & Schofield, 2012b), particularly for people with higher value support packages not receiving what the Resource Allocation System provisionally recommends for their indicative budget (Series & Clements, 2013).

### 3.2.2 Self-management for people with limited capability

**Key points from the literature**

i. Younger adults with physical disabilities tend to be the most successful at self-management, whereas most people with intellectual or psychosocial disabilities are often not able to do so without support.

ii. An individual's disability type or severity should not influence access to self-management if they have a delegate or "suitable person" who can help them to manage their funding and supports.

iii. Even if a person has limited capacity, there are ways to enable them to have a say about how their funding is spent (e.g., alternate communication tools, circles of support, peer support and Person-centred Planning).

iv. People who have capacity to self-manage may lack assertiveness or confidence to advocate for themselves and may benefit from an independent representative who can do this on their behalf.

v. Impaired capacity should not be assumed to apply to all decisions about self-managed payments, supports or service use. Capacity may need to be reassessed for different types of tasks or decisions.

vi. Advocacy organisations have an important role to play in supporting self-management across the lifespan for people with impaired capacity

vii. Advanced Directives may help maintain choice and control in self-management for people with fluctuating capacity, such as people with psychosocial disabilities.

One guiding objective of the personalisation movement has been the desire to increase autonomy, independence, choice and control (Benoot et al., 2021). It may be assumed that these are not possible for someone who has limited capability to "*speak, to act and to tell*" another about their needs or wishes (Ricoeur, 2005, as cited in Benoot et al., 2021, p.779). However, even for people who lack the cognitive or communication skills to express their wishes in the expected way, it is nonetheless possible to use alternate communication tools (e.g., signs, symbols, narrative, stories, poetry, discourse) and to involve representatives from the individual's circle of support to enable them to exert choice and control in their self-managed supports and services (Benoot et al., 2021). Moreover, for people living with disabilities "independence" does not necessarily mean that they are able to choose what types of services they prefer without the support of others (Brennan, Traustadóttir, Rice, et al.,

2016). Rather, the qualitative study by Abbott and Marriott (2013) highlighted that everybody, regardless of their level of need or impairment, can be supported in unique, tailored and person-centred ways to maximise their choice and control over day-to-day decisions.

While younger adults with physical disabilities who are keen to "*live full and independent lives, and have the capacity to take control of their lives*" have been found to be better able to manage personal budgets themselves (p.10, House of Commons Committee of Public Accounts, 2016), two broad cohorts of people that typically have limited capacity to self-manage are those with intellectual disability or psychosocial disability. We discuss the key considerations for each of these cohorts further below, however, it should be noted here that the literature supports that self-management is viable for people with complex needs (defined as having needs that are both broad and deep and likely to require multiple services (Gridley, Brooks, & Glendinning, 2014b)). However, it is essential that people with complex needs have assistance from family or independent support organisations (see systematic review of self-directed supports for people with learning disabilities: Harkes, Brown, & Horsburgh, 2014a). In several settings people who have limited capacity to independently choose and control their supports or to self-manage a personal budget must formally appoint a representative to act on their behalf. For instance, in England and Wales a '*suitable person*', based on the statutory framework of the Mental Capacity Act (Department of Health, 2005, as cited in Coles, 2015), must be appointed for people who do not have the capacity to make their own decisions, to give consent, or to manage their personal budget (Coles, 2015). A key guiding principle, however, is that the individual's capacity must be assessed for each decision, and it is not presumed to be impaired for all decisions. For instance, someone may not have capacity for complex financial decisions or processes, but may be able to use small amounts of money or consent to participation in a chosen recreational activity (Abbott & Marriott, 2013). The Mental Capacity Act acknowledges that people have the right to make "*unwise decisions*". While this legal framework serves to protect the rights of vulnerable people, an Adult Safeguarding Coordinator in a qualitative evaluation of safeguarding pilots in the UK highlighted that there can nonetheless be an assumption that people who are receiving direct payments are able to monitor and advocate for their own safety: "*if you are on a Direct Payment or Individual Budget an assumption might be that you are able to protect yourself*" (p.428; Manthorpe et al., 2010). Moreover, although an appointed 'suitable person' may feel that the role acknowledges that they are "*expert care partners*", they often feel that there is no true "*partnership*" with the local authority that exploits their willingness to support the care recipient, and some even feel that they are "*bullied*" into managing unsustainable care packages (p.138-139; Coles, 2015). These types of hostile relationships can have negative impacts on the support person, including feelings of hopelessness and suicidal thoughts, that jeopardises their ongoing capacity to provide support. Therefore, appointed nominees or 'suitable person' should be supported and respected for their expert role in management of the services and supports for budget holder.

Family carers were vital to support people with disability to manage their direct payments (Hamilton, Szymczynska, et al., 2017; Mansell, 2010; Williams, Porter, & Marriott, 2014), sometimes leading to an over-reliance on informal supports, highlighting potential inequity in

self-management if people do not have family support or informal carers (Clark & Spafford, 2002; Ellis, 2007; Glasby, 2014). People who do not have family support tend to drop out of self-management schemes at higher rates (Fleming, McGilloway, & Barry, 2016).

Besides one's capacity to self-manage, a qualitative study in Germany identified that people self-managing their services and supports often lack assertiveness or the readiness to "*go into a conflict*", which can be overcome if "*they have somebody* [a representative] *who does it on their behalf*" (p.641; Junne & Huber, 2014). The systematic review by Lakhani, McDonald, and Zeeman (2018) highlighted, however, that people who do not have the right supports to control their budget and autonomy, and who have limited capacity to self-manage, are more vulnerable and will find it '*almost impossible*' to access and self-manage without support (p.98, Harkes, Brown, & Horsburgh, 2014b).

**Intellectual disability and self-management**

There is broad consensus in the literature that most people with intellectual disability (or learning disabilities) are not able to self-manage their personal budgets without support from someone close to them who has relevant skills and knowledge about self-management (Harkes, Brown, & Horsburgh, 2014b; Turnpenny et al., 2021). In particular, people with intellectual disability may have limited capacity to understand money, plan their spending, act as an employer, or keep and monitor records (Abbott & Marriott, 2013; Hamilton, Mesa, et al., 2017). More than 50% of people with intellectual disabilities are not in control of their own spending money and often rely on another person to decide how much money they can access and spend (Emerson et al. 2005, as cited in Abbott & Marriott, 2013). Abbott and Marriott (2013) interviewed staff supporting people with intellectual disability to explore their perceptions of the abilities of people with learning disability to manage their finances in the context of personalisation. They found that difficulties typically related to:

- Increased risk of financial abuse from staff, support workers, family and friends or in public settings (e.g., when spending money in a store);
- Limited basic financial and numeracy skills and limited "*grasp* [of] *the building blocks and get*[ting] *used to things like budgeting and prioritising spending."* (p.110);
- Limited ability to hold a bank account, or to access money in their accounts, because they do not have appropriate identification, or because of processes related to the role of advocates or appointees in financial institutions; and
- A lack of knowledge and confidence of staff in financial institutions to support financial literacy and money handling behaviour of people with intellectual disability (Abbott & Marriott, 2013).

The systematic review by Harkes, Brown, and Horsburgh (2014a) highlighted that capacity to self-manage can be improved if people with intellectual disability have a circle of support, and if processes such as person-centred planning and peer support groups are used. In a second systematic review, the availability of broader support through advocacy organisations throughout one's life (e.g., Centres for Independent Living in the UK) was considered to be

essential to the success of self-management policies for people with intellectual disability (Harkes, Brown, & Horsburgh, 2014b). For instance, self-management for people with intellectual disability improved if they (and their family) received support from an independent staff member who could help them to organise their plans and express their needs (Lakhani, McDonald, & Zeeman, 2018). Moreover, while people with intellectual disability may have reduced capacity to manage their finances or their social support budget without support, this does not mean that they cannot or should not be involved in choosing what their money is spent on given that "the more choices people have, the more included they are in their local community" (p.29; Hart et al., 2007).

**Psychosocial disability and self-management**

Historically, self-management was either not available for (Carr, 2011b), or would not be offered to (Ridley & Jones, 2002), people with psychosocial disability. Moreover, even when they were eligible for self-managed funding, the rapid review by Laragy, Sanders, and Brophy (2015) highlighted that only 2% and 9% of people with psychosocial disability in Scotland and England, respectively, took up the option. These patterns appear to have been driven, in part, by the assumption that the nature of impairments and fluctuating symptoms and abilities of people with psychosocial disability negatively influence their ability to self-manage their social services or funding (Ridley & Jones, 2002). However, self-directed funding has been recognised as an important means to flexible options to meet fluctuating needs in line with the recovery paradigm (David, Laragy, & Hudson, 2019). To account for fluctuating capacity to self-manage, Spandler and Vick (2006) recommended that people with psychosocial disability have advance directives to ensure that their ongoing needs are safely met during crises.

### 3.2.3   Uptake of self-management

**Key points from the literature**

i.   Self-management uptake has varied from approximately 5% to 42% of eligible social and disability funding recipients in the UK and Norway.

ii.  Self-directed funding accounts for approximately 13-20% of home and community support funding expenditure in the USA.

iii. The majority of people using self-management have a physical disability, and there is lower uptake for people with psychosocial disabilities.

iv.  Knowledge, fear and assumptions about self-management and capacity are significant barriers to self-management uptake.

v.   User-led organisations can facilitate self-management uptake as they allow people to learn about self-management by other experienced budget holders currently using self-management.

When offered a choice between accessing traditional and self-managed service, caregivers and people with disabilities frequently choose self-management (Singer, Biegel, & Ethridge, 2010). However, when faced with a new and unfamiliar system people have been found to be more conservative and predominantly choose to retain existing traditional services (Henwood

& Hudson, 2008), resulting in low and patchy levels of uptake with substantial variations across geography, cohorts and time (Carr, 2011b).

When schemes first implemented self-management, levels of uptake and awareness were low. For instance, a national survey one year after direct payments became mandatory in England found that 58 per cent of service users with physical or sensory disabilities had not been told about direct payments by their social worker (Department of Health, 2004 as cited in Leece & Leece, 2006).

Rates of uptake in specific countries include:

- **England**: from 2000-2003 ≤0.1% of people with long term illness or disability were self-managing their support needs through Direct Payments (Hyslop et al., 2020). More recently, 23% of personal budget self-managed their personal budget in 2016 (Hyslop et al., 2020).
- **Scotland**: from 2000-2003 only <0.05% of people with long-term illness or disability self-managed their support needs through Direct Payments, but 42% of personal budget self-managed their personal budget in 2016 (Hyslop et al., 2020).
- **Wales:** In 2002/2003 <0.03% of people with long-term illness or disability self-managed their support needs through Direct Payments (Hyslop et al., 2020).
- **Northern Ireland:** from 2000-2003 only <0.04% of people with long-term illness or disability self-managed their support needs through Direct Payments (Hyslop et al., 2020).
- **Norway**: the number of people participating in self-management increased nearly four-fold from 2000 to 2010; however, most people have a physical disability (Guldvik, 2003, as cited in Christensen, 2012).
- **USA**: 13% of total expenses in Missouri's Partnership for Hope program for home and community-based services were self-directed (note that this study only reported funding use at the population level, and not by the proportion of budget holders; Barton & Gotto, 2016). In the 2014 fiscal year, about two thirds of waivers (just over half of all personal care expenditure) allowed family caregivers to potentially be paid for provision of personal care services (Friedman & Rizzolo, 2016), but only 21% of the home and community-based services waivers were participant directed in the 2015 fiscal year (Friedman, 2018)**.**

Rates of uptake have varied for different cohorts. In England 79% of people using self-management had physical disabilities in 2001, which reduced to 55% in 2003 as the uptake in other cohorts increased, especially older people (an increase from 10 to 15%) and people with learning disabilities (an increase from 7% to 11%) (Leece & Leece, 2006). People with psychosocial disability have typically had much lower uptake which varies from 15% to 23% of eligible mental health service users, compared with 48-58% of people with a physical disability, and 59-75% of people with a learning disability (Hamilton, Szymczynska, et al., 2017; Webber et al., 2014). Reasons for low uptake by people with mental health conditions include concerns about risks (Carr, 2011a; Ridley & Jones, 2002; Taylor, 2008) and capacity

to consistently manage a budget if they have fluctuating mental health symptoms (Tew, 2011, as cited in Hamilton, Szymczynska, et al., 2017); the level of bureaucracy and paperwork for the budget holder (Laragy, Sanders, & Brophy, 2015); and concerns about the quality of support provided to help them managing their budget (Power, 2014).

While impairment-specific support organisations are considered to be trusted and valued for their expert knowledge, uptake of self-management has been found to be enhanced when people receive assistance from a user led organisation (Strong, 2012), particularly because they provide opportunities to talk with people who are already using self-management (Williams, Porter, & Marriott, 2014). On the contrary, drop out from self-management is heightened for people who do not have family support (Fleming, McGilloway, & Barry, 2016), and for people who experience a personal crisis or health deterioration (Junne & Huber, 2014). Other characteristics that are associated with lower uptake of self-management include:

- Ethnicity, particularly black and minority ethnic communities (Irvine et al., 2017) where access may be partly limited by professionals' misconceptions that people from minority ethnic communities prefer to 'look after their own'; however, staff have recognised that '*It is a myth that we think the big family will look after the learning disabled family membe*r' (p.29; Terashima, 2011).
- Anticipation of discriminatory practice from social and healthcare professionals (Glasby & Littlechild, 2009, as cited in Irvine et al., 2017)
- Inadequate information delivery leading to a limited knowledge about the new system, the influence of peer choices; staff who do not have sufficient training; people fearing increased isolation; frustration about the amount of paperwork involved; and fear of increased risk and losing security associated with traditional services (Bahadshah et al. 2015, as cited in Fleming, McGilloway, & Barry, 2016);
- Level of ability and willingness to self-manage (National Audit Office, 2016)
- Preference to be self-reliant and to use one's own resources to access or pay for social care (Yeung, Partridge, & Irvine, 2016)

## 3.3  Safeguarding, risk assessment and risk management

**Key points from the literature**

i.  The literature highlights that most schemes restrict access to self-directed funding that is managed through direct payments (i.e., self-management) if there is evidence of financial risks (e.g., bankruptcy), if people previously had difficulty with self-managing their funding, or if there are no informal supports to help them manage their funding.

ii.  Safeguarding and risk processes are considered to be 'everyone's business' and should be integrated throughout all aspects of self-management.

iii.  Financial risks are often the focus of safeguarding strategies, but fraudulent funding use is rare. Rather, the most common safeguarding issues are physical abuse or neglect

iv. Conflicts of interest, power imbalances and blurred boundaries with support workers can increase risks for participants.

v. Safeguarding and risk management is not a 'one size fits all' process, and should involve a range of collaborative, person-centred approaches targeted at those at greatest risk of harm, abuse or financial exploitation.

vi. People may need training, support and advice about safeguarding both before commencing to self-manage their supports, and over time.

vii. People with disabilities and their families should be empowered to recognise safeguarding risks, and to mitigate them.

viii. Regular, respectful and supportive reviews of plans and budget spending can improve self-management experiences and appropriate spending.

Safeguarding is defined as the principles and procedures to protect the rights of, and reduce risk of harm for, vulnerable people who are potentially at risk of harm (Aspinal et al., 2019). Risk assessment and safeguarding are crucial for successful implementation of self-management policies and practices (Carr, 2011b), but must acknowledge the importance of "*communication, empowerment and enabling people to take considered risks*" (Department of Health, 2009, as cited in Carr, 2011b, p.16). In one qualitative study a senior manager in safeguarding highlighted that safeguarding and conversations about risk need be woven throughout self-management processes as they are "*everyone's business*" (p. 14; Stevens et al., 2018). However, experts have cautioned that over-emphasising safeguarding runs the risk of "*killing any scope for genuine creativity and gradually allowing the old system to recreate itself under the new language*" (p.5; Glasby, 2011), and that most fears of fraud, misuse of funds or escalation of social care users are not based on the evidence (Fleming et al., 2019). In fact, there is mixed evidence about whether self-management puts people at more or less risk of harm (Aspinal et al., 2019). In this section we summarise the nature of safeguarding issues and risks associated with self-management discussed in the literature, and the approaches to risk assessment and risk management.

### 3.3.1 Self-management and risks

In most settings, self-management of disability funding and services has essentially transferred the risks from the government bodies that had traditionally "block" funded disability services to individuals and their families who are now responsible for choosing their supports and services (Aspinal et al., 2019; Stevens et al., 2018), and adhering to all administrative, financial and legal responsibilities. A social worker employed in a care providing organisation highlighted that self-management moves the service user from a "*protected space… (with a) guarantee of complete care*" to a potentially riskier situation (p.638; Junne & Huber, 2014). This can result in potential harms given that self-management allows people to have greater freedom and control over their purchasing choices, including the right to take risks (Leece, 2004), and to make what could otherwise be considered to be unwise decisions about their supports or purchases. A safeguarding manager in the UK noted in one qualitative study that these types of unwise purchases may be considered acceptable or a learning opportunity as long as people are not "*putting themselves in a position of harm"* (p.12; Stevens et al., 2018).

While overly defensive risk management strategies or risk-aversion may put people at greater risk because they are not adequately supported to make choices and take control (Carr, 2011a), people can and should be empowered to understand risks that may affect them. This includes empowerment to understand how to recognise and identify abuse, neglect or other safeguarding issues (Carr, 2011b); how to take responsibility for their purchasing choices; and how to deal with the consequences of poor purchasing choices (Junne & Huber, 2014). Ultimately, however, risks that arise in self-management should not be the sole responsibility of the budget holder, and risk needs to be shared between the person taking the risk (i.e., the budget holder) and the system that is supporting them. Appropriate safeguarding processes to monitor and plan for risks should ultimately lead to greater safety, as well as enhanced self-determination, self-advocacy, choice and control (Glasby, 2011).

Some research has highlighted that people employing their own supports have reported fewer incidents of abuse and poor quality care; however, it has been raised that this may not be due to lower rates of abuse (Stevens et al., 2018). Rather, the lower reported levels of abuse may be due to poor recognition of risk, danger or abuse (Brennan, Traustadóttir, Rice, et al., 2016), particularly when they otherwise have a positive relationship with their support worker (Small, Mehmet, & Kleinschafer, 2020), and some budget holders only become aware of an issue when others in their social network raise concerns (Aspinal et al., 2019). When abuse has taken place, people may wait until a scheduled review to report it leaving them vulnerable to ongoing harms (Aspinal et al., 2019). Moreover, previous studies have found that people who are self-managing receive less intensive monitoring than people whose funding and services are agency-managed, increasing the possibility that risks and harms will go undetected (Aspinal et al., 2019; Stevens et al., 2018).

While self-management often allows people to employ unregulated care workers or relatives, it is believed that this can increase the risk of poor-quality care, neglect, abuse or exploitation (Aspinal et al., 2019; Leece, 2004; Stevens et al., 2018). These potentially heightened risks have, in part, been linked to the fact that in some settings, such as in the UK, legislation prohibiting "unsuitable workers" from working with people with disabilities does not apply to people who are self-employed, working in unregulated services, or providing support to family members (Manthorpe et al., 2010). On the contrary, however, budget holders have greater choice over who provides support and how that support is provided may actually be safer than those relying on traditional services (Ismail et al., 2017). Either way, some people are reluctant to report potentially abusive or neglectful care, especially when it is from family members (Bowes, Avan, & Macintosh, 2008), so pro-active risk detection strategies are needed. When a safeguarding issue was identified, Aspinal et al. (2019) found that most budget holders were not concerned about the processes through which it was addressed, focusing instead on whether that it had been adequately resolved. In fact, according to those working in safeguarding, most budget holders who had a safeguarding issue were satisfied with quite modest restorative resolutions, such as an apology or reassurance that it would not happen again (Briggs & Cooper, 2018).

**Types of risks**

The main risks that have been identified for people who are self-managing their services include financial exploitation, receiving poor quality services, not receiving the necessary care or support services, or being harmed or neglected (Junne & Huber, 2014; Laragy, Sanders, & Brophy, 2015; Stevens et al., 2018). In the USA, abuse and exploitation were reported to be "*nearly nonexistent*" when people managed their funds (p.99, Brown et al., 2007). While rare, a number of different types of safeguarding issues can arise, predominantly with support workers, including: financial abuse or "irregularities"; poor quality of care (e.g., unreliability and poor timekeeping problems, poor knowledge of the person's health condition, lack of attention to needs and support required, and poor attitudes); concerns about the criminal record of a support worker; deception about levels of need; physical abuse and intimidation; allegations of sexual abuse or rape; and personal assistants ignoring court injunctions preventing specific visitors (Aspinal et al., 2019; Manthorpe et al., 2010). In analysis of a national register of reported abuses in England, physical abuse was the most prevalent (44% of reported abuse), followed by financial (21%), neglect (17%), emotional or psychological (15%) and sexual abuse (3%) (Ismail et al., 2017). Most abuses occurred in the person's own home and were perpetrated by a family member rather than a support worker. Receiving a personal budget through direct payments was not associated with increased incidence of reported physical abuse, highlighting that these risks are present regardless of how the plan is managed. Importantly, however, some people experienced multiple forms of abuse or neglect either concurrently or over time indicating that there needs to be a holistic approach to reviewing safety and wellbeing whenever a single safeguarding issue is reported or suspected (Aspinal et al., 2019).

**Financial exploitation**

Despite a clear priority on supporting the human rights of people with disability, most safeguarding activities in the context of self-management focus on avoiding financial exploitation (Stevens et al., 2018), even though there is no significant increased incidence of alleged financial abuse for people who self-manage their personal budget (Ismail et al., 2017). The literature discusses two key types of financial exploitation: risk of *financial exploitation of people with disability* (e.g., financial liability or risk of being financially exploited by providers or family members), and *financial exploitation by people with disability* (e.g., accidental funding misuse, or fraudulent purchases).

The systematic review by Harkes, Brown, and Horsburgh (2014b) found that in several studies service providers fear that direct employment of personal assistants through a personal budget increases the risk of financial abuse or exploitation of vulnerable people. Moreover, frontline providers have reported that they fear being accused of breaching the law, acting fraudulently, or putting their organisation at risk (Carr, 2011b). Others have reported that they fear that they cannot provide support about service procurement because "*they did not want to risk becoming embroiled in possible questions about financial abuse, irregularities or challenges from families*" (p.110; Abbott & Marriott, 2013). Together these concerns may

negatively influence the degree of choice and control that providers afford to people who are self-managing their services and supports. While some studies have found that social care providers have defrauded service users, such as failing to provide services that have been paid for (Stevens et al., 2018), these misdemeanours are not common.

Historically there has been a high level of mistrust that people who self-manage their funding will misuse public funds or try to "*get as much out of the system as they can*" (p.10; Henwood & Hudson, 2008). Whitaker (2015) described the myth of a "*greedy family fairy-tale*", highlighting the dichotomy that individualised funds are often seen as belonging to the State or the public, but it is the individual with a disability who is responsible for spending it. These types of concerns have led to schemes specifying a range of detailed financial and administrative processes, including proving that budgets are being spent in line with a clear outcomes-focused support plan, and sometimes needing approval for purchases to be completed; however, these processes negatively impact on the flexibility and timeliness of both accessing required services or supports (Mitchell, 2012b).

In some households, self-managed funding may become an integral part of household income with blurred boundaries around appropriate use if family members are being paid to provide support, leading to social care funding being used to cover inappropriate household expenses (Stevens et al., 2018). Such financial abuse is more common in people living in poverty (Stevens et al., 2018). Despite concerns about accidental or fraudulent misuse of funding, it is actually quite rare and has been largely disproven as an issue that is increased when people self-manage their funding compared with those accessing agency-managed funding (Friedman & Rizzolo, 2016). For instance, of 155 potential cases since the beginning of self-management in Germany only five cases required legal action (Junne & Huber, 2014). Rather than purposefully misusing funds, it is more likely that most purchasing errors arise because spending guidelines are not clear and budget holders inadvertently 'overstep' what administrators consider to be reasonable purchases (Laragy, Sanders, & Brophy, 2015). In order to protect service users and schemes from funding misuse, the mixed methods study by Stevens et al. (2018) highlighted the importance of monitoring for financial irregularities as indicators of both financial and other forms of abuse.

Ultimately, people who are self-managing, or their nominees, take on financial responsibility for ensuring they are following appropriate spending and accounting processes. These include management and monitoring of the availability of funds, keeping accurate records of purchases, and having an understanding of the sanctions if there is inappropriate use of their funds (Laragy, Sanders, & Brophy, 2015). Training, guidance and assistance (e.g., through an independent accounting service) is generally needed to support the financial safety and wellbeing of budget holders when they are learning about self-management, and over time.

**Conflicts of interest and professional boundaries**

Professionals working with people who are self-managing their funding may have conflicts of interest, particularly if there are imbalances in power, or if the same people who control resource allocation also have a role in service provision (Stevens et al., 2018; Williams,

Porter, & Marriott, 2014). These conflicts can lead to inadequate funding levels, or negatively impact on whether budget holders can access the best services or supports for their needs.

Once people are receiving support, they often build strong and positive relationships with their support workers. While this leads to improved wellbeing and a sense of safety, a blurring of the line between friend and employee can have negative impacts for both the support worker and the person receiving support. A similar type of blurring of familial and professional boundaries have been reported when people employ friends or family (Stevens et al., 2018). For instance, people may be less likely to report safeguarding issues, or lack confidence to reprimand or dismiss a support worker if they have done the wrong thing when they have formed a friendship (Aspinal et al., 2019). For support workers, those who form closer friendships with the budget holder can feel that they have 'boundless' obligations to provide additional unpaid care, or to do duties that are not defined in their role (e.g., gardening, domestic cleaning, decorating, pet care, healthcare tasks, helping to attend social events, shopping and companionship) (Leece, 2004).

### 3.3.2   Approaches to risk assessment and management

The implementation of self-management options typically placed an emphasis on risk assessment and aversion; however, experts in safeguarding have highlighted that the focus should be on risk enablement, rather than aversion, for people who are self-managing their disability funding. That is, establishing self-management needs to incorporate processes for balance the positive effects of risk taking with the potential harms from avoiding risk altogether (Manthorpe & Moriarty, 2010, as cited in Carr, 2011a). Managing risk is largely about the individual's context. Therefore a clear understanding of the risks for each person is required, which is optimised when efforts are made to get to know people well, including learning about their interests and what matters most to them (Glasby, 2011) rather than using rule-based processes or checklists (Carr, 2011a). When potential or actual injury or harm does arise, however, it is important that employers ensure the safety of both staff and the budget holder (Methven, 2009), and that a positive risk taking ethos is embodied (Carr, 2011a).

To improve the efficiency and accuracy of safeguarding initiatives, a risk-stratified approach has been recommended where there is greater focus on safeguards for people who really need them (Glasby, 2011). Regular reviews can help monitor appropriate spending in line, which may also be triggered through financial monitoring or alerts when budgets appear to be spent on something that is inappropriate (Stevens et al., 2018). Safety may also be enhanced if people receive advice on how to recruit and check the work or criminal history of their support workers (Stevens et al., 2018).

In the UK, the 'Making Safeguarding Personal' approach included the development of a toolkit that provides guidance on

> "*achieving best evidence skills, signs of safety, attachment-based approaches, peer support, forums and circles of support, family and networks including group conferences, mediation and conflict resolution,*

*and restorative justice as potential mechanisms to improve person-centred working in safeguarding.*" (p. 209; Mitchell & White, 2015).

An evaluation of Making Safeguarding Personal found that processes involving safeguarding practices took no more time than traditional approaches, but led to better outcomes while saving time and resources over time as people were empowered to better manage their own safety (Cooper et al., 2016, as cited in Briggs & Cooper, 2018). Successful and timely implementation of safeguarding practices was facilitated when people valued transparency and collaboration, had a single point of access for reporting or discussing concerns, and used asset-based approaches to draw on individuals' strengths to manage or mitigate risks (Briggs & Cooper, 2018). Moreover, using a person-centred approach to risk management actually avoided unnecessary meetings, and led to quicker resolution of safety issues (Mitchell & White, 2015). Successful protection of safety and wellbeing were hampered, however, when there were too few resources (e.g., staff, money, time.) to manage the volume of referrals and alerts (Briggs & Cooper, 2018).

### 3.3.3  Strategies to reduce risks associated with self-management

A range of strategies can be used to reduce or manage risks in addition to embodying safeguarding principles in all aspects of social care funding and practice. To support financial safety and independence for people with intellectual or cognitive disabilities, Abbott and Marriott (2013) identified the need to develop further information and resources that include detailed 'good practice' examples and vignettes on how to deal with financial issues, including success stories of working with people with intellectual disability across the life course and level of need. They also recommended a dedicated telephone line that people with disability, staff, advocates and family members can use to get advice on money and benefits. 'Champions' in financial services could also be identified or trained to provide guidance and support to people needing help to access, manage or account for finances in their self-managed personal budget (Abbott & Marriott, 2013). Other key recommended strategies to reduce risks in self-management include:

- Choosing *not to offer* self-management, to *withdraw* self-management as an option, or to only allow *partial* self-management (Stevens et al., 2018).
- Providing *information or training* to budget holders and providers from *safeguarding experts* (Manthorpe et al., 2010) on how to identify, manage and respond to abuse or low quality care over time and multiple formats (Aspinal et al., 2019; Laragy, Sanders, & Brophy, 2015). Just providing information is not likely to bring about positive outcomes if there is insufficient advice on how to recognise poor quality care, abuse and/or neglect, especially for people with impaired capacity or who are new to social care or self-management (Aspinal et al., 2019).
- Establishing a 24/7 *legal telephone advice line* to manage self-management risks (Laragy, Sanders, & Brophy, 2015).
- Building risk assessment and capacity building *into the support plan* (Carr, 2011a).
- *Empowering people* to define their own risks and to recognise, identify and report abuse, neglect and safeguarding issues (Carr, 2011a), and use *asset-based*

*approaches* to identify strengths and networks to help the budget holder and their family to manage risks (Mitchell & White, 2015).

- Appointing a *delegate, nominee* or '**suitable person**' to support the individual to make good decisions about their funding (Stevens et al., 2018).
- Enhancing *community participation and integration*, which can help improve safety by making the budget holder visible and present in the community, and connecting them with a range of people who can detect and react when their safety has been compromised (Glasby, 2011).
- Ensuring people have access to *practical support* to manage their supports and risks through peers or user-led organisations (Glasby, 2011).
- *Monitoring spending against support plans* and having *regular reviews* to ensure that self-management is working well for the individual (Carr, 2011a; Harkes, Brown, & Horsburgh, 2014a, 2014b). This may include *increasing monitoring* through the involvement of other agencies or parties (e.g., relatives, companies or user-led organisations) if there are serious safety concerns (Stevens et al., 2018).
- Offering regular and respectful contact with *safeguarding experts* who can provide advice on how to manage risks or risk assessments (Manthorpe et al., 2010).
- Using a *Risk Enablement Panel* or *Best Interest meeting* to assess risks for people self-directing their care if there are doubts about their safety (Manthorpe et al., 2010).
- Helping people to *check references* of potential support workers to minimise the risk of abuse or exploitation (Manthorpe et al., 2011, as cited in Harkes, Brown, & Horsburgh, 2014b; Manthorpe & Lipman, 2015)
- Supporting *training* and *culture change* for providers in order to build a risk enablement culture across the sector (Carr, 2011a).
- Establishing *contingency plans* to outline the budget holder's choices and preferences if they are in a crisis (Glasby, 2011; Henwood & Hudson, 2008).
- *Reviewing wellbeing* when funding is reduced or eligibility is tightened to ensure that people do not lose access to supports that are needed (Power, 2014).

## 3.4 Social, environmental and political context of self-management

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**Key points from the literature**

i. Self-management is most strongly linked to both the human rights movement to enable greater choice and control for people living with disability, as well as the neoliberal political philosophy that reduces government power and control over services and increases consumer choice and control to stimulate the development and competitiveness of the social services market.

ii. The implementation of self-management schemes led to radical changes to access to existing services. The proportion of support workers with low skills who may be required to perform roles outside the agreed role description has been reported to have increased.

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iii. Self-management has increased the 'precariousness' of working conditions for support workers, which should be addressed through requirements for appropriate contracts, and conditions that protect the workers' rights.

iv. To best meet the needs of people with disability, a policy evaluation highlighted that the social and disability services market should focus on supporting the capacity of smaller 'human scale' services to meet the needs of service users while ensuring that they align with policy and practice requirements.

v. User-led organisations and peer networks can provide important and trusted information and advice on how to self-manage, such as information about self-management; how to choose or plan services and recruit support workers; and how to manage the administrative requirements of accounting, payroll and employment law.

vi. People with access to advocacy are more successful at negotiating and coordinating their self-managed supports.

vii. In some countries there are organisations that allow people to pool their funding with other budget holders in order to participate in shared activities, and to manage the recruitment and payment of support workers.

viii. Family members are often critical to the success of self-management; however, training in person-centred planning and self-management may be beneficial to ensure that family understand how to best advocate on behalf of the budget holder and their needs and wishes.

In this section of the review, we discuss the important foundation of political philosophies and policies in the establishment and operation of self-management schemes, as well as the support service environment, and the availability and involvement of advocates and user led organisations. Moreover, fundamental to the successful implementation, use and outcomes of self-management is whether budget holders have family or other people from their circle of support who can assist them in the self-management of their budget.

### 3.4.1 Government, politics and community

Personalisation and individualised funding have predominantly been implemented in countries that endorse social democracy, neoliberalism, and human rights philosophies. In the context of *social democracy* 'normalisation' policies have supported the provision of financial resources and supports to enable people with disabilities to live in the community and to participate in society, including with the use of self-managed disability supports (Laragy, 2010). *Neoliberalism* represents the philosophy of removing power from government through marketization of services, stimulating the private sector to develop and provide care services that are traditionally government-funded (Pike, O'Nolan, & Farragher, 2016) in order to increase consumer self-determination, choice and control over services that meet a person's needs (Dickinson, 2017; Power, 2014; Stevens et al., 2018). Moreover, marketization through the *New Public Management* paradigm (Dursin, 2021) focuses on providing more efficient delivery and cost-effectiveness of public services by reducing welfare provision and allowing competitive markets to form (Simpson & Price, 2010).

The neoliberal approach, assumes that people who are afforded the responsibility of identifying or procuring their own supports and services have the capacity to be self-directing, autonomous, and rational, and that they are able to choose or create services that meet their needs (Leece, 2004; Stevens et al., 2018). Moreover, according to policy makers tensions remain in such markets between the need for unregulated support markets and those who value unionisation, professionalization and regulation of the workforce (Power, 2014). In light of the *human rights* approach, the United Nations Convention on the Rights of Persons with Disabilities is internationally recognised as an important foundation for recognising and upholding the rights of people with disability, particularly within schemes that allow self-management (Power, 2014).

In many countries self-managed funding is decentralised and regulated at a State or local authority level (e.g., Canada and the UK), which allows citizens to receive funding and supports that is appropriate for someone in their geographic area (Nally, Moore, & Gowran, 2021). Local factors play an important role in the success of self-management, particularly taking into account existing places or relationships (Mitchell, 2012a), and the cost of services in their neighbourhood (Nally, Moore, & Gowran, 2021). Moreover, a policy maker in England highlighted in one qualitative study that grassroots movements have played an integral role in driving change '*on the ground*' to meet the needs of people with disability (p.840; Power, 2014). Localised approaches can also include the use of community capacity building strategies to influence community attitudes towards people with disabilities while also increasing access, inclusion, choice and confidence of people with disability (David, Laragy, & Hudson, 2019). However, localised regulation of self-management can lead to inconsistent approaches and processes across regions (Harkes, Brown, & Horsburgh, 2014a) resulting in what has been referred to as a '*postcode lottery*' that can entrench existing inequities, and limit the freedom of people with disability to choose where and how they live (Shrubb, 2011). Moreover, a policy maker from the USA who participated a qualitative study highlighted that those working in local government often lack knowledge and skills needed to implement self-managed funding in a way that yields positive outcomes for their citizens (Power, 2014). Rather, cultural change and consistency in '*quality, equity, and equality of opportunity*' (p.13; Carr, 2011b) in self-managed social care ultimately needs to come from a national government strategy (Power, 2014) that is ideally aligned across multiple systems (e.g., disability, health and justice).

### 3.4.2   The support service environment

Self-management of individualised funding has transformed the ways that services can be accessed, and the types of services that are available. When budget holders directly employ their own supports they often favour support workers with few qualifications who are cheaper, which may lead to a workforce with fewer skills (Junne & Huber, 2014) and higher turn-over or stability (Ismail et al., 2017). Moreover, self-management can increase the "*precariousness*" of support work (e.g., due to casual and irregular hours), place greater pressure on providers (e.g., to work outside the agree scope of practice), and increase the risk that the budget holder's needs will be poorly met if they cannot access appropriate skilled workers (Camoni,

Picardi, & Venerosi, 2020). Other impacts for both support workers and budget holders are discussed further below in relation to employing support workers (Section 3.7).

Choice and control over self-directed support requires the availability of a 'thick', diverse and mature market that can provide services for people with a range of needs (David, Laragy, & Hudson, 2019). Moreover, access to skilled support advice or coordination is considered to be fundamental for people who have reduced capacity to identify or purchase appropriate supports (Williams, Porter, & Marriott, 2014). However, the anticipated marketization impacts of citizens purchasing their own supports has not always been is unlikely to occur in many settings without a concerted effort on enhancing the market, and providing access to service brokerage, support planning and finance advice to enable people to access services and build those market forces (Abbott & Marriott, 2013; Dickinson, 2017). The increased use of self-management in the disability sector coincided with reduced funding of traditional services, which led to fears that traditional services that were still needed would be lost (Harkes, Brown, & Horsburgh, 2014b; Leece & Leece, 2006). Moreover, reduced demand for traditional services in preference for unregulated support providers was feared to paradoxically lead to reduced choice by reducing the scale of traditional services (Sims & Cabrita Gulyurtlu, 2014). In some setting these outcomes have occurred with the closure of many day centres (Malli et al., 2018) and the exit of "*some major providers* [of disability support services who] *have collapsed or withdrawn from the market*" (p. 414; Hudson, 2018). Another potential downside of self-managed funding relative to traditional services is reduced collective service provision in preference of individual support (Arksey & Baxter, 2012); however, we discuss the potential for innovation in the procurement of supports through user-led collectives and pooled budgets below (Section 3.4.3).

In a review of existing policy and strategies for bolstering adult social care commissioning in the UK, Hudson (2018) recommended implementing a policy shift towards local and small providers that operate at a 'human scale', particularly those that are co-designed and run by front-line workers and people with disabilities. There is evidence that small scale services can more effectively meet the needs of service users than large-scale services (Care Quality Commission, 2017a; Hall et al., 2014, both cited in Hudson, 2018) as they typically hold more expertise about issues, needs and preferences for support in local communities. Larger *Community Catalyst* organisations can also support small organisations to build their capacity to support people with self-managed budgets, as well as to negotiate policy or regulatory matters (Hudson, 2018). Finally, to support a service environment that meets the needs of people with disability, Hudson (2018) also recommended that social and disability support policies take a holistic view to the funding of individual needs (e.g., social care, transport, housing, health, and education). The importance of holistic "whole life" plans was also emphasised in another narrative review (Mitchell, 2012a). Finally, to support the implementation and success of self-management, Hudson (2018) recommends that providers should prioritise asset-based approaches, and build the resilience, wellbeing and participation of people with disability, while also endorsing the purchase of supports from employers or providers that are recognised as ethical, transparent, tax-compliant and not-for profit.

### 3.4.3 Other stakeholders that support self-management: Advocacy, peer support and user-led or disability organisations

In addition to the political climate, funding regulators and support service environment several other types of individuals and organisations play an important role in the success of self-management. In particular, the availability of services or individuals who provide advocacy, advice or support, including disability representative organisations, user-led organisations, peer support networks, and cooperatives as well as the person's circle of support are essential in self-management.

There are four main types of advocacy that can support people who are self-managing their budget, including the use of supported decision making when choosing supports, or simply to ensure that the budget holders wishes are realised (Newbigging, Ridley, & Sadd, 2021). In *statutory advocacy* the advocate is a paid professional whose role as defined in law is to protect the person's procedural rights, and to support them to assert those rights (Flynn, 2013). A statutory advocate is needed for people who have substantial difficulty with decision-making, and no appropriate person is available to support them from their social circle (Newbigging, Ridley, & Sadd, 2021). In the context of health and social care, the advocate should be independent from the health or social care service provider and the funders (Newbigging, Ridley, & Sadd, 2021). Any other person may provide *citizen advocacy* to support a person, or speak on their behalf, whereas in *peer advocacy* the advocate has a similar experience of living with disability, and *self-advocates* are able to speak for themselves. There is a large body of evidence across several countries highlighting that access to advocacy is important in the context of self-management (Carr, 2011b). People who are better able to self-advocate, or who have someone to advocate for them, are more successful at negotiating and coordinating their self-managed supports (David, Laragy, & Hudson, 2019). Moreover, funding of advocacy for families with children who have intellectual disabilities and safeguarding risks leads to improved outcomes and significant cost-savings (Bauer et al., 2015). A mixed methods study of statutory advocacy in England concluded, however, that access to advocacy was generally poor or not working, particularly if 'law-based' principles of advocacy were used rather than 'value-based' concepts focused on the importance of supporting the participant's voice in decision-making (Newbigging, Ridley, & Sadd, 2021).

While access to statutory advocacy appears to be limited, peer support and peer advocacy have been instrumental throughout the independent living and personalisation movements (Hyslop et al., 2020), playing an important role in empowering people with disability to self-advocate (Power, Bartlett, & Hall, 2016). For instance, peer advocacy can help people to build knowledge and skills needed to maintain access to services or to participate in the community (Power, Bartlett, & Hall, 2016), as well as to self-assess their needs and to develop their support plan and then purchase appropriate supports (Williams, Porter, & Marriott, 2014). Peer support has traditionally been accessed via Disability Representative Organisations and User-Led Organisations (ULOs); however, informal support is also available through online networks (e.g., see Pearson & Trevisan, 2015), informal family networks (McNeill & Wilson, 2017) and '*word of mouth*' (social worker, p.12; Stevens et al., 2018). As the processes and

responsibilities involved in self-management are complex, several studies have recommended that schemes employ "*expert direct payments (self-management) recipients*" who can provide advice on self-management to budget holders (p. 162; Arksey & Baxter, 2012; Katzman, 2018).

Historically, ULOs have played a key role in providing advice and information about social care and service access through a peer support model (Manji, 2018). In some countries, particularly across the UK, people who chose to self-manage their personal budget could access planning support through ULOs, as well as advocacy, peer support, information and advice (Strong, 2012). In many schemes, ULOs and small organisations were given additional funding to build their capacity to support people who were self-managing (Hyslop et al., 2020). National surveys in the UK showed that the majority of self-management schemes provided access to peer support through ULOs, which increased from 64% of schemes in 2003-04 to 75% in 2004-06 (Hyslop et al., 2020). In particular, ULOs provide advice to people with disability about various aspects of self-management including: information about self-management; how to choose or plan services and recruit support workers; and how to manage the administrative requirements of accounting, payroll and employment law (Pearson, 2012, as cited in Barnes, 2011; Manji, 2018; Williams, Porter, & Marriott, 2014). Representatives from ULOs have also historically provided training and advice based on their lived experience to staff working within the disability sector to improve attitudes or awareness about supporting self-management (Carr, 2011b). Moreover, some ULOs facilitate a "cooperative" approach where budget holders can pool their funding, which we discuss further below.

Two studies in England evaluated the impact of transferring resources from traditional authorities to ULOs for support planning in 2009-10 (Strong, 2012; Williams, Porter, & Marriott, 2014). A review also explored the activities performed by peer networks in the context of personal budgets (Hyslop et al., 2020). Altogether, these authors concluded that people typically need intensive help when they begin to manage their personal budget, and that peer networks and ULOs are ideally positioned to provide that support through a flexible approach that helps people to '*move towards independent planning at their own pace*' (p.1197; Williams, Porter, & Marriott, 2014). Altogether, the key findings on the roles and benefits of involving peer networks and ULOs in self-management, plan management and accessing services included:

- **Peers and ULOs are respected as independent experts:** Peer networks are often viewed as trustworthy because they are independent of the statutory sector, and they hold a rich body of knowledge on living with disability. However, ULOs may also deliver services and support, which can raise conflicts of interest when they also act as a voice of disabled people, and an agent of the self-management scheme.
- **Empathic listening and person centred**: People appreciate it when peers from the ULO use an empathic, person-centred and "human" approach to explore goals and longer-term aspirations. The ULO planner helps budget holders to think about possibilities they never previously considered, and people with newly acquired

disabilities appreciated the planner's sensitivity to the adjustment to their new identity. The collaborative approach used by peers helps the person to self-assess their needs and plan their budget through the use of accessible methods (e.g., pictorial plans or documents) and person-centred language that acknowledges their lived experiences. Flexibility for people with different needs and experiences was recognised as important.

- **Sharing information about self-management**: Peer networks often provide training for potential users of self-management. Budget holders appreciate that peers in ULOs have good knowledge about self-management (e.g., as a "route map" of the whole process), want to know their indicative budget, and what they could or could not purchase. People also report that they needed information on what to expect from the process, and how to manage their budget or any other issues once supports were in place. People who received advice and education about self-management from ULOs were more likely to decide to self-manage their personal budget.

- **Support to purchase services**: ULO planners often gave advice on whether and how they should become an employer or procure supports from a traditional service and helped them to find opportunities in the community through 'brokerage', particularly if services were not available in thin markets where there is limited capacity to purchase supports. Ongoing support over time was vital to ensure that support planning accounted for changes in preferences, needs or goals over time. Some peer networks can also provide support for payroll and accounting responsibilities.

- **Accessibility, reach and continuity of support**: Peer networks have created information or training in various formats (e.g., DVDs, videos, computer-based information, and pictorial and written information), and people liked it when they received information in accessible formats (e.g., easy read, large font). ULOs can be more effective than traditional local government departments at accessing hard to reach people, and typically remain engaged more regularly and for a longer period than those working directly within a social or disability government agency.

- **Efficient support**: Family members appreciate it when support planners were efficient and respectful of the limited time that they may have to attend planning meetings.

- **Family and budget holder involvement**: Involvement of family was integral in many cases, but participants needed 'the right balance' in the contributions from family members and the budget holder when identifying the individual's aspirations and needs.

- **Structures and resources.** To allow them to continue to support people in self-management the ULOs needed ongoing strategic funding, and consistency in leadership.

Based on these findings, Williams, Porter, and Marriott (2014) recommended three broad levels of support planning from a ULO or peer, depending on the capacity and needs of the budget holder:

1. A "**hands off**" approach is appropriate for people who have capacity to make their own plan (with or without informal supports) and may only need information about their rights, or their indicative budget.

2. A "**hand over**" approach is typically needed for people who need support from the ULO planner to write their plan (with or without input from an informal support person). People with this level of support may need assistance to explore their goals and aspirations, or to understand what supports are appropriate or available. In the hand over approach people may need ongoing contact to review and maintain their plan.
3. The "**hand in hand**" approach is recommended for people with more complex needs, including needing support to explore goals and aspirations. People in this group will need more support to generate and write their plan through person-centred planning processes in which the planner takes the time to get to know the person and find out what they really like. People in the 'hand in hand' approach likely need assistance to find out what supports are available, or to broker opportunities if they don't currently exist. Similar to the hand over approach, people being supported hand in hand will need structures in place to provide ongoing support and to review their needs and supports over time.

While self-management directly led to personalisation of services and supports used by individuals, in some settings budget holders have organised their care through cooperatives or by pooling their funding with other budget holders to improve the cost-efficiency of their budget or to reduce their overall spending. For instance, people can share the cost of supports with other budget holders to attend social activities that thereby enhance their social participation (Reindl, Waltz, & Schippers, 2016). Pooling funds can allow people to develop their interests, social networks and participation in the community when they participate in social activities with other budget holders (Sass & Beresford, 2012, as cited in Roulstone & Hwang, 2015). Roulstone and Hwang (2015) explored collective approaches used in Sweden, England and Wales and highlighted that the success of cooperatives was dependent on "*good commissioning, accessible information and responsiveness to impairment diversity*" (p.854). Cooperatives are common in Scandinavia, and in Sweden they are used across multiple sectors, not just for social and disability services. However, in the context of disability supports, the Stockholm Cooperative for Independent Living is ULO cooperative that was created and managed by disabled people. The Director of that cooperative explained members "*pool their state insurance funds for PA* [personal assistants] *services in the form of direct payments… (which) enhance the quality of support disabled people received as we had greater control over our personal assistants*" (p. 850) while showing "*that the financial side would not be abused*" (p. 856). People can join the cooperative if they require >20 hours assistance per week, and they pay a portion of their self-managed funds into an account within the cooperative which is then used to pay their support workers wage, as well as employment, insurance and administrative overheads. Existing peer members of the cooperative train new members in how to manage their supports. In England, people can transfer their direct payments into pooled funding together with other budget holders in the RUILS organisation. The service director explained that through RUILS "*you can not only enjoy spending time with others who enjoy similar activities to you, but can make better use of your money. For example, paying one personal assistant to support and organise a group activity can be more cost effective.*" (p. 857). In another region in England "cluster" cooperatives bring together up to 15 services users in a geographic region where they can

pool their budgets and share the responsibility and expense of employing support workers and managing the administrative requirements. While benefits have been reported from pooling funding, for some people these strategies can lead to unmet needs when sharing a support worker with another person who has higher support needs (Manji, 2018).

Sometimes rather than advocacy, people may simply need advice about self-management and related financial matters. In the UK, a *Money Advice Service* was established to provide free and unbiased advice to any citizen about money matters, and in 2008-2009 accessible materials were developed specifically for people with learning disabilities, which included information on independent living and the associated financial implications (Abbott & Marriott, 2013). Several studies have recommended increased access to local organisations that can provide essential advice or training on how to access and self-manage a personal budget, including the volume and complexity of paperwork and the recruitment, training and management of support workers (Harkes, Brown, & Horsburgh, 2014b), discussed further below in Sections 3.5 and 3.7.

### 3.4.4  Family, carers and circles of support

As noted earlier, if the budget holder has limited capacity to self-manage without support it is necessary to appoint a suitable family member or independent person who is responsible for ensuring that they are appropriately using their funding and fulfilling the administrative requirements (Brennan, Traustadóttir, Rice, et al., 2016; Carr, 2011b). There is often an assumption that family carers will provide care and accommodation for the whole life of a family member with a disability (Laragy, Sanders, & Brophy, 2015). Family members usually have vital experience and skills in the budget holder's needs and preferences, as well as the use of person-centred approaches, managing and training staff, and appropriate strategies to manage challenging behaviours (Coles, 2015). Moreover, people from some communities have a stronger beliefs about the role of family in caring roles (Yeung, Partridge, & Irvine, 2016). However, family members may also use a paternalistic approach and interfere or override the needs and preferences of the budget holder (Fleming, McGilloway, & Barry, 2016), and also require training in how to manage the funding on behalf of the budget holder (Fleming, McGilloway, & Barry, 2016). Moreover, it is now being increasingly recognised that carers should be asked how much help they are willing and able to give, and whether they have independent support needs (Mitchell, Brooks, & Glendinning, 2015). An assumption that the service user will have access to informal care can undermine the carer's right to choose whether and how they will support their family member (Clements et al., 2009, as cited in Hamilton, Szymczynska, et al., 2017); however, in one study carers reported that they did not feel pressured to provide care (Moran et al., 2012).

## 3.5  Facilitators of self-management

**Key points from the literature**

The *social, political and scheme design enablers* of self-management are:

i.  When legislation, policy and guidance is codesigned with people with disability and user-led organisations
ii.  Quality assurance mechanisms are incorporated from the outset
iii.  Finance and regulatory departments are able and willing to support self-management
iv.  Appropriate methods are used to establish adequate need and goal focused budgets that can be used flexibly
v.  There are clear purchasing guidelines, including what can and cannot be purchased, allowing for maximum flexibility and creativity
vi.  Evaluation to assess the effectiveness of the scheme is incorporated into the scheme

The *workforce-focused supports and enablers* of self-management are:
vii.  An open and supportive culture change is encouraged to ensure self-management is appropriately delivered and supported in the sector
viii.  Timely and comprehensive workforce training, particularly for disability support planners, managers and those involved in safeguarding and risk management
ix.  Protection of workplace conditions and support worker rights to a safe workplace
x.  There is a developed market from which appropriate services can be accessed

Processes and resources *needed by budget holders and their support networks* to access and use self-management:
xi.  Culturally appropriate, accessible, clear and timely access to information and supports so that they can make an informed choice about whether and how they want to self-manage their budget and supports
xii.  There are person-centred processes to plan, and purchase supports of services with input from circles of support and family
xiii.  Processes accommodate existing social capital and cognitive, physical and cultural needs so that budget holders can be actively involved in planning and choosing their supports
xiv.  User-led organisations, peer support and "champion" self-managers are available to provide advice and practical support across all stages
xv.  Budget holders and their support networks can access training to understand and effectively use self-management
xvi.  Tools and support services are available to help budget holders manage the administrative requirements of self-management
xvii.  There is ongoing access to support, regular reviews, monitoring and planning meetings to ensure that budgets and purchased supports are appropriate and adequate, including mechanisms to accommodate changes in capacity and needs over time, and to manage risks

Many facilitators of the implementation and use of self-management and individualised budgets have been identified. In particular, successful implementation and use of self-management relies on appropriate and adequate infrastructure, workforce training and supports, as well as processes and tools to support budget holders and their networks to meet

the administrative requirements (Dickinson, 2017; Fleming et al., 2019; Laragy & Ottmann, 2011; The Health Foundation, 2010).. Moreover, Fleming et al. (2019) highlighted in their systematic review that the most successful schemes enable creativity and flexibility, support positive risk taking and help budget holders to set achievable short term goals in the context of a longer-term vision.

In line with the social model of disability, this section of the review first focuses on the mechanisms needed in scheme design, the disability sector and workforce to enable people with disability to successfully access and use their self-managed budget. We then summarise the processes and supports needed by people with disability to make an informed decision about whether they want to self-manage, and to enable them to successfully self-manage their supports.

### 3.5.1 Social, political and scheme design enablers

The social, political and scheme design enablers of self-management implementation and uptake focus on the importance of co-design of policies or guidance; simplification of processes and administrative requirements; conducting regular reviews and having quality assurance processes; ensuring that finance and regulatory departments can support self-management; and having appropriate mechanisms to establish and use adequate and flexible budgets, including clear purchasing guidelines and evaluation of effectiveness. Key facilitators in scheme design, implementation and policy are further summarised below:

- Legislation, policy and guidance should be *codesigned* between governments and people with disability, their families and user-led organisations to ensure that the resulting documentation protects the rights of people with disability and ensures that the wording cannot be miss- or re-interpreted during decision making or appeals (e.g., appeals; Laragy, Sanders, & Brophy, 2015; Nally, Moore, & Gowran, 2021).
- *Simplifying paperwork* and administrative requirements, while ensuring that adherence and accountability are still monitored through *regular reviews* (Harkes, Brown, & Horsburgh, 2014a) and *quality assurance mechanisms* (The Health Foundation, 2010).
- As self-management changes the way that people access and purchase supports, success requires changes across multiple systems and markets (Verhaeghe, 2020). It is important that *finance and regulatory departments* are "*on board*" (p.7) and able to support self-management with clear processes to support payments and monitoring (The Health Foundation, 2010). The organisation responsible for supporting plan management must have sufficient allocation of frontline staff and managers with expertise in self-management (Henwood & Hudson, 2008). In settings where multiple funding streams are available (e.g., in the UK where people can pool funds from multiple systems, including social, health, education and justice) these should be smoothly integrated with clear guidance on the system responsible for monitoring and oversight (Harkes, Brown, & Horsburgh, 2014a).
- Appropriate methods should be used to establish budgets that align to the individual's *needs and goals* (McNeill & Wilson, 2017). This requires the use of appropriate methods to assess needs, including self-assessment, that are outcome focused. Schemes should

also consider the support needs of family carers (Laragy, Sanders, & Brophy, 2015), and their willingness to continue providing care (p.28; Glendinning, Mitchell, & Brooks, 2015).

- Even though some studies have found that most people continue to choose traditional or 'regulated' services (Slasberg & Beresford, 2015), there should be permission to use budgets *flexibly* and *creatively* (Dickinson, 2017). People should also have the flexibility to move between self-managed and plan or agency-managed budgets as their capacity or needs change over time (Arksey & Baxter, 2012; Aspinal et al., 2019).
- People need and want clear *purchasing guidelines*, including what can and cannot be purchased, that also allows for maximum flexibility and creativity (Dickinson, 2017).
- Mechanisms should be included to enable the *evaluation* of changes in the costs and effectiveness of self-management to enable improvements in policy, guidance or supports to budget holders (The Health Foundation, 2010).

### 3.5.2  Workforce capabilities to facilitate self-management

While self-management places responsibility on budget holders to source and choose their supports, many will have difficulty making informed decisions about self-management unless they can access knowledgeable and supportive staff (Gridley, Brooks, & Glendinning, 2014a). Workforce-focused enablers of self-management therefore typically focus on the need to support positive culture change about self-management; provide training to the workforce; protect the rights and safety of workers; and foster the development of a mature service market. Key facilitators for the workforce and market are further summarised below:

- Encouragement of *culture change* to endorse informed and positive attitudes about self-management (Carr, 2011b; The Health Foundation, 2010). A collaborative approach is needed that encourages shared understanding and expertise between staff, people with disability and their networks (Fleming et al., 2019). Culture change should be facilitated through leadership from senior managers (Mitchell, 2012a) to ensure that self-management is appropriately delivered and supported in the sector. Moreover, a key focus of culture change should be on empowering people with disability and to discourage patronising or disabling practices (Lakhani, McDonald, & Zeeman, 2018; Laragy, Sanders, & Brophy, 2015).
- Provide *workforce training* to staff involved in assessment, decision-making and service provision (Carr, 2011b), such as disability support planners, managers, frontline staff, support brokers and those involved in safeguarding and risk management (Fleming et al., 2019; The Health Foundation, 2010). Training should seek to ensure that the rules and legislation for self-management are not misinterpreted (Nally, Moore, & Gowran, 2021). The literature highlights that workforce training should focus on:
  - o Improving knowledge, skills and positive attitudes about self-management practices to foster culture change (Carr, 2011b; Mitchell, 2012a), raise awareness about who is eligible and capable of self-management (Harkes, Brown, & Horsburgh, 2014b);
  - o Preparing staff for changes in funding, roles and responsibilities (The Health Foundation, 2010);

- o Promoting equality and diversity awareness, and challenging misunderstandings and myths about risk and capacity for certain groups, especially people with psychosocial or intellectual disabilities (Carr, 2011b);
  - o Teaching methods and practices for conducting assessments and obtaining information from budget holders and their family about the individual's needs, goals and goals, including person-centred practices to support self-direction (Lakhani, McDonald, & Zeeman, 2018); and
  - o Enhancing capacity and knowledge of recovery principles to support self-management in the context of psychosocial disability (David, Laragy, & Hudson, 2019).
- Appointing *key workers or case managers* who can provide consistent planning support and advice to people who are self-managing (Mitchell, 2012a).
- Protecting *workplace conditions* and the rights of support workers to a safe workplace (Dickinson, 2017).
- Enabling a *developed and mature market* from which appropriate services can be accessed (Dickinson, 2017); however, where services are not available people may need to create bespoke opportunities through brokerage (Richardson et al., 2020; Williams, Porter, & Marriott, 2014).

### 3.5.3  Enablers for budget holders

Several processes and resources are needed by people with disability so that they can make an informed decision about whether to self-manage, and so that they can then successfully self-manage if they choose to do so. These facilitators broadly refer to the need to have access to information about self-management; empowerment to self-manage and self-direct through person-centred processes; access to user-led organisations, peer support or self-management "champions" for advice and support; training in how to successfully self-manage; tools and supports to manage the administrative requirements of self-management; and ongoing planning support and budget reviews. Given the range of support and advice needs to help budget holders to successfully employ support workers, these points are summarised separately in Section 3.7. Key facilitators for budget holders are further summarised below:

- Budget holders need culturally appropriate, accessible, accurate, clear and timely *access to information* so that they can make an *informed choice* about whether they want to self-manage their budget and supports, and so that they can then successfully self-manage (Harkes, Brown, & Horsburgh, 2014b; Terashima, 2011). Once people choose to self-manage, they often need ongoing access to information about program policies, how much funding they have been allocated, what types of services or supports they can purchase, and the accounting and reporting requirements (Laragy, Sanders, & Brophy, 2015; Verhaeghe, 2020). They also need information about the responsibilities of being an employer (e.g., recruitment, payroll, tax, insurance, payslips; McNeill & Wilson, 2017). No single mechanism was identified that provided the necessary information and support needed by people who are self-managing in the rapid review by Laragy, Sanders, and

Brophy (2015). Instead, a range of sources and providers of information have been identified, and information may be accessed through:

- o Written materials or websites (McNeill & Wilson, 2017);
- o Information sessions (Small, Mehmet, & Kleinschafer, 2020);
- o A helpline that both budget holders and staff can call for advice (Harkes, Brown, & Horsburgh, 2014b);
- o Advice through 'counselling visits' to provide advice and ensure that needs are being met (The Health Foundation, 2010);
- o Resources developed by user-led organisations and peer networks (e.g., DVDs, videos, computer-based information, and pictorial or written information; Hyslop et al., 2020); and
- o Disability, peer and carer groups or events (Laragy, Sanders, & Brophy, 2015), which are often trusted more than government sources and events which some people considered to be "*propaganda*" (p. 496; Small, Mehmet, & Kleinschafer, 2020).

- *Person-centred processes* to successfully shift power from agencies to budget holders (Fleming et al., 2019; Topping, Douglas, & Winkler, 2020) and to ensure that self-management is focused on the budget holder rather than being a "*professionally led concept*" (p. 52; Mitchell, 2012a) focused on process, auditing or administration (Carr, 2011b). Budget holders may need to be empowered in the assessment processes to explore their needs and goals, and to choose their supports (Lakhani, McDonald, & Zeeman, 2018), in a way that safeguards the budget holder's rights (Slasberg & Beresford, 2015). These processes should, however, involve input from circles of support (Fleming et al., 2019; Gridley, Brooks, & Glendinning, 2014a) and family members (David, Laragy, & Hudson, 2019; Lakhani, McDonald, & Zeeman, 2018; The Health Foundation, 2010).

- It is necessary to accommodate *individual differences* (e.g., socio-demographic, cultural, cognitive, and physical needs; Dickinson, 2017; Fleming et al., 2019), as well as *social capital* available through existing social networks or whether the budget holder has advocacy needs (Carey, Crammond, & Malbon, 2019; Dursin, 2021).

- A strong and collaborative *support network* or *circle of support* should be defined, including both paid and unpaid individuals who can facilitate sourcing information, recruiting staff, building networks and accessing support for administrative and management tasks (Fleming et al., 2019). Levels of support that the budget holder needs for decisions will likely vary with the complexity of each decision (Lakhani, McDonald, & Zeeman, 2018).

- *Training for budget holders* and their support networks to understand and use self-management, to understand processes for staff recruitment and management, and to learn administrative and accounting skills (Fleming et al., 2019). Moreover, training can help budget holders and their support networks to manage and detect potential abuse or other risks (Carr, 2011b).

- *User-led organisations, peer support networks, advisory boards, 'navigators', support brokers,* and *'champion'* self-management budget holders are valuable as they can provide: advice and practical support to people new to self-management on how to

manage their budget, purchase supports, recruit staff, and complete administrative requirements (Arksey & Baxter, 2012; Fleming et al., 2019; Harkes, Brown, & Horsburgh, 2014a; Lakhani, McDonald, & Zeeman, 2018; The Health Foundation, 2010). These sources of assistance are especially likely to be beneficial for people with more complex health and social care needs (Gridley, Brooks, & Glendinning, 2014a), and for people who are employing their own support workers (Fleming et al., 2019).

- Access to tools and support services that help budget holders to *manage the administrative requirements* of self-management. While people with previous business or work experience can often manage the administrative requirements of self-management, others may prefer to outsource those tasks to a bookkeeper or payroll service (Laragy, Sanders, & Brophy, 2015).

- Access to *ongoing support*, and providing opportunities for *regular reviews* can help people to manage the requirements of self-management and ensure that it working well for them (Harkes, Brown, & Horsburgh, 2014a). In the past, planners or social care agencies have often left people with minimal access to support, financial monitoring and advice soon after they opt in to self-managing their budget (Arksey & Baxter, 2012); however, there is growing recognition that people need consistent levels of support for periods "*measured in years, rather than months*" (p. 185; Simpson & Price, 2010). Monitoring should include mechanisms to review changes in capacity and needs over time, to determine whether the budget holder is not benefiting from self-managing their supports (Harkes, Brown, & Horsburgh, 2014a), and to manage risks (Carr, 2011a; Harkes, Brown, & Horsburgh, 2014a, 2014b). However, reviews should be conducted in a supportive manner otherwise budget holders report that it '*feels like the social worker is scrutinising in a very judgemental manner, rather than supporting me*' (p. 1915; McNeill & Wilson, 2017).

- Budget holders want regular *planning meetings* in which they can explore and express their preferences, needs and goals (Lakhani, McDonald, & Zeeman, 2018), especially as their situation, needs or capability changes or to know what they should do when they have unspent funds that have accumulated (Arksey & Baxter, 2012). Ongoing professional support is especially important for co-ordination of diverse services for people with severe and complex needs (Gridley, Brooks, & Glendinning, 2014b).

## 3.6 Barriers to successful self-management

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**Key points from the literature**

*Social, political or scheme design* barriers:

i.  The literature focuses on challenges in administering funding, particularly across multiple systems, consistencies in processes, and implementing safeguarding.

ii. Most scheme-specific barriers are discussed in relation to how they affect the workforce or budget holders and their families.


Barriers and challenges for the *disability sector workforce:*

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iii. Staff who *lack awareness or knowledge* about it, or have insufficient experience with self-management

iv. Staff often act as *gatekeepers* because they worry that the system will be overwhelmed, people will not be able to cope with the demands of self-management, or budget holders might be abused or exploited.

v. *Power or culture conflicts* between different types of providers that impedes a collaborative approach to service delivery

vi. *Conflicts of interest* from dual roles (e.g., planning support and service delivery)

vii. Restrictive and *patronizing, paternalistic, and authoritarian attitudes about potential users' capabilities* that negatively impacts on genuine choice and control for budget holders

viii. Staff can be *reluctant to transfer power* to service users who then take on the responsibility of what types of services or supports they access, and from where.

ix. Concern for the *sustainability of self-management*, including longer-term impacts on the privatisation of social services and the *closure of existing collective services* like day centres.


Barriers and challenges for *budget holders and their support networks*:

x. Insufficient *access to information and training*;

xi. Limited ability to make the most of self-management options due to low *social capital and networks*;

xii. Difficulties managing complex *bureaucratic processes and requirements*;

xiii. Limited true choice and control for people who *difficulty articulating their needs or goals*;

xiv. Limitations on what can be done through self-management if there is *insufficient funding or flexibility* in how funds can be used;

xv. *Poor availability of skilled service providers and support workers* impedes how easy it is to successfully self-manage; and

xvi. The stressful aspects of self-management can lead to *negative emotions*.

Most of the barriers to self-management include the absence, poor delivery, or fragmentation of the features identified to be integral to facilitating successful implementation and use of self-management schemes. There were only a small number of issues in the literature that were specific to the barriers for the scheme or agencies supporting self-management delivery, several barriers have been reported for the workforce and for budget holders and their support networks.

### 3.6.1 Social, political and scheme design barriers

The main barriers from the perspective of the scheme relate to:

- challenges with administering or integrating funding across different funding streams (e.g., in the UK)

- inconsistencies in eligibility, processes and funding availability across geographic areas (Harkes, Brown, & Horsburgh, 2014a) and between related systems (Davey, Fernandez, et al., 2007; Riddell et al., 2006), normative policy frameworks (Barnes, 2011)
- fragmentation of their administration across the market and regulators (Dursin, 2021).

These issues are thought to arise primarily through poor accountability, particularly when policies are implemented too quickly, and when there has been insufficient consideration of potential effects on the lives or actions of key stakeholders (Hudson, 2018). This highlights the importance of using *human-centred design, consultation* and/or *co-design* when implementing policies that will have a significant effect on the way that people access support.

### 3.6.2  Barriers and challenges for the disability sector workforce

People with disability have faced many barriers to accessing self-management due to workforce-related factors, including staff attitudes and beliefs about self-management and about people with different types of disability (Leece & Leece, 2006). The key barriers to implementation and uptake of self-management linked to the workforce and providers include:

- Staff who *lack awareness or knowledge about it*, or have insufficient *experience with* self-management (Harkes, Brown, & Horsburgh, 2014a; Commission for Social Care Inspection, 2004, as cited in Leece & Leece, 2006), particularly when they are not aware of what types of supports can be self-managed and how (Mitchell, 2012b). Some studies have found that staff are resistant to the implementation of self-managed budgets regardless of who or how it is implemented, or for some types of supports or services, or people with some types of disability (The Health Foundation, 2010).
- Often people working within agencies administering self-management are consciously or unconsciously being *gatekeepers who control access* to self-management for people who may be eligible and able to self-manage. For instance, staff have been reported to limit access because they:
    - fear that people with disability will 'flood the system' (p. 85; Fleming et al., 2019);
    - assume that some people would not be able to cope with self-management, or that they did not "*deserve*" self-managed funding (p. 93; Harkes, Brown, & Horsburgh, 2014a); or
    - worry that vulnerable people will be abused or exploited (Fleming et al., 2019).
- *Conflicts in power and culture* between different types of providers that impedes their willingness or ability to work collaboratively when supporting people who are self-managing (Mitchell, 2012a).
- *Conflicts of interests* can arise between service providers and users, or when staff have multiple roles (e.g., planning support and service provision; Lakhani, McDonald, & Zeeman, 2018), and negatively impact on the success of self-management.
- Restrictive and *patronizing, paternalistic, and authoritarian attitudes about potential user's capabilities* negatively impacts on the individual's involvement in the assessment of their needs or choice and control when selecting their supports

(Fleming et al., 2019; Leece & Leece, 2006). Moreover, staff may overpower the budget holders if they are uncomfortable with acknowledging the individual's preferences (Verhaeghe, 2020).

- *Reluctance to transfer power to service users* (Leece & Leece, 2006). This appears to relate partly to a perceived threat to the traditional role and autonomy of service providers (Sims & Cabrita Gulyurtlu, 2014), particularly for social workers who have a "*giving and doing*" tradition (p. 10; Henwood & Hudson, 2008). Other staff report that they fear transferring purchasing power and responsibility to budget holders who may accidentally or fraudulently misuse public funds (Mitchell, 2012b), even though there is little evidence of funding misuse (Fleming et al., 2019).
- Staff have expressed concerns that self-management is *not sustainable* and that it focuses too much on individual rather than collective needs and objectives (Henwood & Hudson, 2008). Staff have reported fears that self-management will lead to *privatisation* of services (Leece & Leece, 2006) and *closure of existing services* such as day centres (Harkes, Brown, & Horsburgh, 2014a) resulting in job losses as well as a decline in the quality and choice in available supports for service users (Fleming et al., 2019). People from existing organisations also fear that people with self-managed budgets would 'poach' staff from agencies (Fleming et al., 2019).

### 3.6.3  Barriers and challenges for budget holders and their support networks

The majority of the evaluations of self-management schemes have focused on identifying barriers to their success for people with disability and their support networks. Key barriers that have been identified, and that are discussed below, include:

- issues relating to access to information and training;
- the impact of poor social capital and networks;
- difficulties managing complex bureaucratic processes and requirements;
- difficulties with articulating needs or goals;
- having problems with planning, funding and budget levels;
- poor availability of skilled service providers and support workers; and
- experiencing negative emotions from challenges with overseeing self-management processes.

One of the most significant challenging components of self-management relate to the directly employment of support workers; however, the barriers specifically linked to these issues are summarised in Section 3.7. Moreover, further discussion of potential negative outcomes and unmet needs are discussed below in Section 3.8.

**Unmet information, advice and training needs**

A lack of accurate information and advice in accessible formats is one of the most commonly cited issues with self-management that is reported by people with disability and their support networks (Lakhani, McDonald, & Zeeman, 2018; Leece & Leece, 2006; Simpson & Douglas,

2016). Moreover, sometimes information that is no easy to access or understand because it uses confusing terminology or is presented in inaccessible formats (e.g., small fonts; Harkes, Brown, & Horsburgh, 2014a). People have reported issues with understanding the eligibility criteria for self-management, the advantages and disadvantages of taking up a personal budget, and what the funding can be used to purchase (Fleming et al., 2019; Hutton & King, 2018). Related to the issues around lack of guidance on appropriate use of funding is the fact that some families and households also have difficulty isolating a child or family-member's disability-related needs from broader parts of family life (e.g., employing support workers to attend family celebrations; Whitaker, 2015). A lack of information impedes the capacity and readiness to make informed decisions about whether to self-manage, planning and budgeting to purchase appropriate supports, and correctly following the required administrative processes (Harkes, Brown, & Horsburgh, 2014b; Lakhani, McDonald, & Zeeman, 2018; Verhaeghe, 2020). The systematic review by Fleming et al. (2019) highlighted insufficient information access and training in self-management resulted in budget-holders having insufficient skills and knowledge to manage key processes, particularly how to employ support workers and how to establish respectful working relationships.

**Poor capital, support networks and individual differences**

The systematic review by Carey, Crammond, and Malbon (2019) highlighted that the success of self-management is ultimately impacted by an individuals' level of social capital (i.e., resources available through social connections), economic capital (i.e., access to existing financial resources), cultural capital (i.e., skills, networks and participation typically built through formal education), and symbolic capital (i.e., social class, social networks and social position). Moreover, there is evidence that self-management is disproportionately taken up by people who have higher levels of education and those with more financial, social and cultural resources who are better able to understand and take advantage of the processes involved in self-management (Hamilton, Mesa, et al., 2017; Hamilton, Szymczynska, et al., 2017). For instance, Mavromaras, Moskos, and Mahuteau (2016) noted that "*participants and families who were confident, educated and able to articulate support needs had better outcomes than those with less capacity to understand the Scheme, including participants with intellectual disability*" (p. 37). For instance, a person will be better able to access and use self-management if their formal education and previous work experience enable them to find and understand information and navigate bureaucratic systems, or if they are able access advocacy and support through their existing informal networks. Indeed, people who tend to have the most comprehensive packages are those who are most articulate and vocal (Manji, 2018).. However, many people with disability do not have access to support networks or social capital that can help them to self-manage (Brooks, Mitchell, & Glendinning, 2017; Small, Mehmet, & Kleinschafer, 2020). For instance, people from a working class or low income backgrounds usually have less experience in employing and managing people or budgets (Fleming et al., 2019; Leece & Leece, 2006), or may not have access to or experience with the right type of bank account (Leece, 2004). Moreover, there may be conflicts within family and support networks (Lakhani, McDonald, & Zeeman, 2018), particularly if the budget holder's

support networks are potentially "*serving their own interests*" (p. 75) rather than those of the budget holder (Fleming et al., 2019). In addition to the role of social capital, individual differences in health, including potential self-neglect, and fluctuating psychiatric symptoms or social isolation can lead to increased difficulties in meeting one's disability support needs through self-management (David, Laragy, & Hudson, 2019; Fleming et al., 2019).

**Challenging bureaucratic and administrative processes**

Complex and cumbersome bureaucratic processes as well as requirements to complete detailed and sometimes what appears to be unnecessary paperwork are major barriers that increase the workload for people with disability or their family when they are self-managing their budget (Fleming et al., 2019; Harkes, Brown, & Horsburgh, 2014a; Simpson & Douglas, 2016) These issues have been reported to be worse for people with high support needs who are managing larger budgets and more complex support arrangements (Coles, 2015), or for people with psychosocial disability who have been found to find these types of tasks to be particularly onerous and complex (Laragy, Sanders, & Brophy, 2015). Moreover, people with psychosocial disability have been reported to have greater difficulty with navigating and using disability systems and websites (Mavromaras, Moskos, & Mahuteau, 2016). To address those barriers, the acceptability of tools for budget management needs to be considered in their design, with testing by people with diverse needs and abilities. In some settings people need to keep their personal budget funds separate from their other household finances, such as through a dedicated bank account (Fleming et al., 2019). In one study, it was clear that a separate account was needed for each family member with a budget, which further increased the complexity of financial monitoring (Whitaker, 2015). Importantly, the time required to oversee compliance takes up time that could otherwise be used to recruit and work with competent support staff or to provide care (Hutton & King, 2018). The bureaucratic processes can also create a sense of risk aversion and distrust that budget holders will not appropriately use their funding (Fleming et al., 2019).

**Inability to articulate support needs and to purchase appropriate supports**

The study by Strong (2012) highlighted that people who have been receiving traditional services do not become "*well-informed, confident, micro-commissioners overnight*" (p. 84) once they begin to self-manage their own budget. Rather, many people have difficulties with recognising their support needs, or knowing where and how to purchase appropriate supports to meet those needs. If people are not given appropriate advocacy or support to self-direct they may be denied the opportunity to make informed choices (Barton, 2012) or be left vulnerable due to unmet needs (Sims & Cabrita Gulyurtlu, 2014). Alternatively, some people may identify goals that are not feasible or too expensive to be realistically achieved (Barton, 2012), highlighting the importance of focusing on what is appropriate to "*live an ordinary life*" rather than aiming for a luxurious standard of living (The Health Foundation, 2010; Wilkinson-Meyers et al., 2010).

## Availability, preferences and costs of services

Several systematic reviews have highlighted that the lack of existing services or high costs, particularly in rural and remote areas, leads to unmet needs (Lakhani, McDonald, & Zeeman, 2018; Simpson & Douglas, 2016). Moreover, predefined budgets may not adequately reflect the actual cost of services or supports that are needed, again resulting in unmet needs (Hutton & King, 2018). Parents have reported that their child can fall through the gaps when they are transitioning from youth to adult services, and that the onus falls on the parent "*cold-calling businesses, trying to find a small job or volunteer position, as well as advertising for, interviewing, and training people to take a YA* [young adult] *out in the community. This left little time for a parent's own pursuits, including paid work*." (p. S303; Anderson, Lupfer, & Shattuck, 2018). A scoping review by Topping, Douglas, and Winkler (2020) has highlighted that the majority of disability support workers have low skills and limited qualifications, are on low wages and working casually, which can result in high turnover thereby negatively impacting on the stability and quality of support that can be accessed (Mitchell, 2012b; Moriarty, Manthorpe, & Harris, 2019). In particular, it can be difficult for people to find support workers with the necessary skills to meet their needs, particularly mental health expertise for people with psychosocial disability (David, Laragy, & Hudson, 2019). Finally, some people are hesitant to take on a self-managed budget because they are already satisfied with the coordinated care that they receive through traditional services and worry that they may lose that access with a personalised self-managed budget (Hutton & King, 2018).

## Inadequate or inflexible budgets

People with disability have reported that needs assessment processes are not sufficiently tailored to their own needs, and do not capture the potential for a transition in impairment level, which can result in under or over-estimation of funding to meet needs (Fleming et al., 2019). Some schemes are described as being "*too rigid or inflexible*" (p. 73), which negatively impacts on whether and how budget holders can meet their needs (Fleming et al., 2019). Moreover, many studies have reported that people often receive insufficient levels of funding to meet their needs, or that reductions in their funding over time leads to unmet needs. Several systematic and scoping reviews have highlighted that budgets often do not accommodate all of the resources that are needed (Fleming et al., 2019; Lakhani, McDonald, & Zeeman, 2018; The Health Foundation, 2010) and may only be sufficient to partially cover personal care needs (Nally, Moore, & Gowran, 2021). Insufficient funding levels then result in family members needing to "*fill in the gaps*" (p. 5) and "*pick up the tab*" (p. 27; Laragy, Sanders, & Brophy, 2015) for hidden costs, administrative charges and unmet needs (Fleming et al., 2019). Moreover, delays in accessing or receiving funding due to administrative processes (e.g., governance, sign-off and agreements on funding use) can lead to additional stress, financial pressure and unmet needs for people with disability and their families while they first start to self-manage their supports, or when they have to meet ongoing payroll and service use costs (Fleming et al., 2019). The provision of inadequate budgets was particularly pronounced when the available social and disability funding was reduced during the global financial crisis in 2008 (Malli et al., 2018). Policy makers have acknowledged that reductions

to social and disability funding is "*inescapable*" (p.843; Power, 2014). However, policies and schemes need to account for strategies to reduce potential harms from changes in funding for people with disability given that fear of losing access to services due to funding leads to heightened stress for budget holders (Fleming et al., 2019). Finally, when budget holders are expected to use their funding within a set time-period they sometimes make inappropriate or ineffective purchases to use up the funding (Lakhani, McDonald, & Zeeman, 2018), partly because they fear that funders will "*claw it back*" (p. 281; Whitaker, 2015) if there are unspent funds (Arksey & Baxter, 2012; Fleming et al., 2019).

**Negative emotions of budget holders**

Systematic reviews have highlighted that people who have difficulties with the bureaucratic processes and level of responsibility of self-management experience increased confusion, stressed and feel "*daunted*" (p. 82; Fleming et al., 2019; Simpson & Douglas, 2016). People have also reported feeling guilty that they are "*asking for too much*" (p. 82; Fleming et al., 2019), and that they are not sure how they would cope if they lost their support network (e.g., if their parents died; Fleming et al., 2019). Finally, the review by Fleming et al. (2019) found that some people are suspicious of the system because they have experienced restrictive or disabling process, and that agencies did not fully embrace the concept of individualised funding undermining their potential for success.

## 3.7   Recruitment and retention of staff

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**Key points from the literature**

i.    It can be difficult to understanding how and where to recruit suitable support workers, including how to find out about a potential worker's relevant work or criminal history, particularly in countries where support work is not regulated.

ii.   People do not usually have *prior experience in employment-related processes* including recruitment, supervision, training, timetabling, and payroll.

iii.  The *availability and retention of support workers,* especially in rural areas, limits choice and stability of care. Retention is negatively impacted by the fact that many support workers are paid *at or near minimum wage*, overhead expenses (e.g., travel time and expenses) are not usually paid, and they often work a small number of irregular hours.

iv.   Budget holders become an employer and must act in accordance with *employment law.*

v.    Independent *companies or cooperatives* can provide advice and support for recruitment and brokerage, writing contracts, training support workers, and setting up or overseeing payroll, insurance and tax-related processes.

vi.   Many people rely heavily on *personal contacts, social networks* and *"word of mouth"* to recruit support workers. Others may 'poach' agency staff or employ family and friends if it is permitted.

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vii. Budget holders can often *set their own wages* that may be lower or higher than recommended in order to get value for money or improve retention of workers, respectively.

viii. Having the *dual role* of both employer and support recipient can create challenges for budget holders, particularly if the support worker is not performing well.

ix. Budget holders may find it *difficult to discipline or dismiss* a support worker if they have formed a close relationship with them, or if they have employed family or friends.

Self-management schemes typically allow budget holders to directly employ their own support workers. To do so, the budget holder has responsibility to recruit, hire, train and manage their own staff (Katzman, 2018). In the UK when self-managed funding was first introduced only five percent of people employed their own staff, but this later increased to thirty percent when councils were urged to make self-management the default budget management option (Skills for Care, 2018, as cited in Slasberg & Beresford, 2020), and a growing number of workers continue to be employed directly (Woolham et al., 2019). The scoping review by (Manthorpe et al., 2011) has highlighted that when budget holders are able to choose their own support workers they can recruit people with whom they have good 'personal chemistry' and shared interests. However, taking on employment responsibilities increases the complexity of self-management for the service user and/or their family. In particular the benefits and challenges in directly employing support workers include:

- In countries where support work is *not regulated* budget holders can experience difficulty understanding how and where to recruit suitable support workers (Harkes, Brown, & Horsburgh, 2014a, 2014b; Lakhani, McDonald, & Zeeman, 2018).

- Few people have *prior experience in employment-related processes* including recruitment, supervision, training, timetabling, and payroll matters (Fleming et al., 2019; Manji, 2018; Manthorpe et al., 2011).

- There can be difficulties with the *availability and retention of support workers* (The Health Foundation, 2010), especially in rural areas (McNeill & Wilson, 2017). For instance the systematic review by Fleming et al. (2019) included a quote from one qualitative study participant that '*my carers seem to come and go all the time; I only receive direct payments to pay for a few hours a week, so it is not enough for someone to leave an [other] employment for and a few hours don't always appeal.*' (p.79).

- Becoming an employer requires that people act in accordance with *employment law* (Sims & Cabrita Gulyurtlu, 2014).

- Often the staff recruitment and employment responsibilities are *managed by a carer or family member* (Manthorpe et al., 2011).

- In some countries employment-related processes are supported by linking budget holders with *private companies or cooperatives* that can provide advice on:
  - recruitment processes and brokerage (Abbott & Marriott, 2013);
  - how to write a contract and establish fair and safe working conditions, and define the scope of practice in line with the individual's plan (Manthorpe et al., 2011; Moriarty, Manthorpe, & Harris, 2019);

- training support workers (Harkes, Brown, & Horsburgh, 2014a); and
- setting up or overseeing payroll, insurance and tax-related processes (Harkes, Brown, & Horsburgh, 2014a; Nally, Moore, & Gowran, 2021).

- Budget holders may need assistance to obtain *work history and references* and criminal history checks for potential workers in order to protect them from harm (Harkes, Brown, & Horsburgh, 2014a; Manthorpe et al., 2010).

- Many people rely heavily on *personal contacts, social networks* and *"word of mouth"* to recruit support workers (Manthorpe et al., 2011; McNeill & Wilson, 2017). Others choose to 'poach' agency staff, or employ family and friends if it is permitted (Arksey & Baxter, 2012). However, employing family members can increase risks to the budget holder, particularly if "*carers risk becoming dependent on the care recipient for their earnings/income*" (p.655; Arksey & Morée, 2008).

- Budget holders can often *set their own wages* that are either lower or higher than recommended in order to get value for money or improve retention of workers, respectively (Lakhani, McDonald, & Zeeman, 2018). Moreover, austerity measures generally led to a reduction in recommended wages for support workers (Moriarty, Manthorpe, & Harris, 2019). Many support workers are, however, paid *at or near minimum wage* and overheads (e.g., travel time and expenses) are not usually paid. Moreover, support workers may be given irregular and minimal work hours (Moriarty, Manthorpe, & Harris, 2019), further contributing to the high turnover of support workers (especially those who are not family members) and the risk of receiving low quality support (Lakhani, McDonald, & Zeeman, 2018).

- Having the *dual role* of both employer and support recipient can create challenges for budget holders, particularly if the support worker is not performing well (Lakhani, McDonald, & Zeeman, 2018). For instance, budget holders may find it *difficult to discipline or dismiss* a support worker if they have formed a close relationship with them, or if they have employed family or friends (Arksey & Baxter, 2012; Manthorpe et al., 2011)

## 3.8 Outcomes for people with disability and their support networks

**Key points from the literature**

**Outcomes for people with disability:**

i. Higher levels of satisfaction;
ii. Improved or sustained levels of quality of life, general health and mental health, as well as reduced hospitalisations;
iii. Increased social and community participation;
iv. Increased choice, control, autonomy, empowerment, independence, and freedom as well as creativity and flexibility to use funding to access needs-led supports; and
v. Increased work outcomes, and reduced interactions with the justice system.

vi. Overall, there appear to be *fewer adverse effects for people who are self-managing* their funding compared with people receiving a managed budget as long as they are given appropriate support.

vii. Minimal impact on *housing* arrangements or independent living;

viii. Potential for *reduced safety and unmet needs*, but these are not increased relative to having other forms of a budget or support.

ix. The level of responsibility associated with self-management, including anxiety related to maintaining records and reporting on funding use, in addition to making choices, can increase *stress and burnout* for budget holders.

Outcomes for **family and informal support** networks:

i. *Better quality of life and reduced guilt* when spending time to maintain their own wellbeing because the budget holder is receiving support.

ii. *Improved relationships* in the family, reduced pressures and capacity to participation in paid work, either as the budget holders support worker or in outside paid roles;

iii. The burden of overseeing administrative and financial tasks, and the recruitment and training of support workers, leads to *increased stress for family members*.

**What influences outcomes**?

i. People with *lower social capital* or living in remote areas influence how well people can engage with and benefit from self-management schemes.

ii. *Disability type* influences outcomes, such that people with neurological impairments, psychosocial disabilities and complex needs have greater difficulties with accessing adequate funding and supports through self-management, and therefore require additional assistance from the scheme or their circle of support.

iii. People who had *access to information and purchasing guidance*, as well as *administrative supports*, have better outcomes.

iv. Better outcomes and experiences are reported when people are *included in assessment and planning processes* and receive ongoing support.

v. The *availability of appropriate services* influences on whether self-management can positively influence choice, control and self-direction.

vi. While not pertinent to the issue about whether or how someone can self-manage their disability budget, several studies report that people who self-manage often have larger budgets and it may be the increased *level of funding* that leads to better outcomes.

vii. When self-managed budgets are reduced people experience negative impacts on family relationships, employment opportunities, social participation, and the level of unmet needs.

viii. *Accessing support from user led organisations* has been found to play a key role in improving the successful implementation of self-management schemes, which help people to manage the planning and implementation of their budget.

ix. Having a *circle of support*, including support or input from family members is integral to achieving positive outcomes; however, it is important that the willingness and capacity of informal supports to assist the budget holder is assessed.

The marker of success for self-management is ultimately whether people's lives have improved since they have taken greater control over their services and supports (Carr, 2011b), and that they are more satisfied with their social care (Yeung, Partridge, & Irvine, 2016) and achievement of life goals (Teague & Boaz, 2003, as cited in Webber et al., 2014). Most evaluations of self-management programs have focused on the effects of self-management on a range of life domains for people with disability and their family and support networks as well as the factors that appear to impact on those outcomes. It should be noted, however, that in much of the literature the budget holder's own perspective is often not addressed (Junne & Huber, 2014), and outcomes are often examined from or through the perspectives of staff, providers or family. Moreover, it is not always clear if respondents in studies are comparing the effects of self-management with other ways of receiving supports, or to life without any social and disability funding (Slasberg & Beresford, 2016b). Moreover, with the exception of some randomised controlled trials in the USA that show a range of positive outcomes from the cash and counselling self-directed support program for people with psychosocial disability (Barczyk & Lincove, 2010; Shen et al., 2008), there are few high quality evaluations of self-management (Dickinson, 2017; Verhaeghe, 2020). As a result many schemes have continued to effectively be "*flying blind*" (p.24; Dursin, 2021) on the assumption that this is the right approach to enhance quality of life, choice and control (Harkes, Brown, & Horsburgh, 2014b). Below we summarise the main outcomes of self-management for people with disability, and their social and support networks.

### 3.8.1 Outcomes and experiences for people with disability

Overall, self-managed funding and supports, and not just having a personal budget per se, have been linked to better outcomes compared with people receiving traditional 'block funded' services or services available directly through the local council (Glendinning et al., 2008; Hatton & Waters, 2011). People who are self-managing their funding have both positive and negative views about the value and effectiveness of the scheme in meeting their needs (Arksey & Baxter, 2012; Netten et al., 2012). However, benefits are diminished if there is insufficient funding or people are unable to manage responsibilities associated with self-management (Laragy, Sanders, & Brophy, 2015). The key outcomes that have been reported for the budget holder in relation to self-management are summarised in this section of the review, and include higher satisfaction, quality of life, general health and mental health; increased social and community participation; increased choice, control, autonomy, empowerment, independence, and freedom as well as creativity and flexibility to use funding to access needs-led supports; and better social, economic and justice outcomes. Minimal effects on housing outcomes have been reported. Adverse outcomes (e.g., potential for reduced safety or unmet needs) are typically not higher than other budget management options but are reported in some studies.

**Satisfaction**

Overall self-management schemes in Australia, England and the USA have been found to improve satisfaction (Verhaeghe, 2020). Nearly all studies included in three systematic reviews reported positive effects of self-management or individualised budgets on client satisfaction (Dickinson, 2017; Fleming et al., 2019), including people with psychosocial disability (Webber et al., 2014). People in the UK have been reported to be "*overwhelmingly positive*" (p.162) about direct payments compared with previous receipt of traditional services (Stainton, Boyce, & Phillips, 2009). In the USA, people self-directing their care were up to 90% more likely to be very satisfied with how they led their lives than the control group (Robert Johnson Wood Foundation, 2007, as cited in Carr, 2011b), including people with psychosocial disability who reported higher satisfaction with service delivery, reliability and 3.3-fold higher odds of being satisfied with their caregiving schedule, and 4.1-fold higher odds of being satisfied with the overall care arrangement than people receiving agency based supports (Shen et al., 2008). Similar findings have been reported for people with learning disabilities with personalised budgets (Woolham and Benton, 2009, as cited in Manthorpe et al., 2011; Poll et al., 2006, as cited in Sims & Cabrita Gulyurtlu, 2014). However, in another study in the UK Hatton et al. (2008, as cited in Hamilton, Mesa, et al., 2017) found that only 29% of people were satisfied with their safety and security, 36% were satisfied with their economic wellbeing and 47% were satisfied with their health and wellbeing.

**Quality of life, general wellbeing and health outcomes**

In the UK, more than seventy five percent of people with personal budgets, most of whom used self-managed direct payments, reported that their funding had significantly improved their quality of life (Hatton & Waters, 2007, as cited in Harkes, Brown, & Horsburgh, 2014a; UK Parliament Public Accounts Committee, 2016, as cited in Slasberg & Beresford, 2016b; Waters & Hatton, 2014). From the broader literature, however, inconsistent effects on quality of life have been reported. Some studies report positive effects on satisfaction with how one is spending their life (for adults aged 18-64 years, Mean Difference (MD) =20.5, p<0.001 in Arkansas; MD=13.3, p=.001 in Florida; and MD=16.5, p<.001 in New Jersey; Brown et al., 2007). However, other studies have only shown significant improvements only for some service users including people with mental health problems, learning disability and older people (Netten et al., 2012) or no significant differences when compared with people who were not self-managing their budget (Conroy et al., 2002; Glendinning et al., 2008). For specific cohorts, improvement in quality of life has been reported for people with intellectual disability (Harkes, Brown, & Horsburgh, 2014b; The Health Foundation, 2010), psychosocial disability (Glendinning et al., 2008; Shen et al., 2008; Vick & Spandler), and children with disabilities (Simpson & Douglas, 2016).

Studies have also found improvements in physical health and use of health services for people given the opportunity to self-direct their care (Alakeson, 2008; Glendinning et al., 2008). A review of outcomes of personal health budgets in 11 OECD countries found better health outcomes, but the evidence was weak and not universal for all budget holder cohorts

(Gadsby, 2013). Other studies have found improved care arrangements, continuity of care and relationships with health professionals (Davidson et al., 2013), but no differences in activities of daily living (Woolham & Benton, 2013), self-perceived health (Glendinning et al., 2008), or mortality in the first 12-months (Forder et al., 2012; Jones et al., 2013). For people with psychosocial disabilities self-management was associated with improved physical health outcomes for 59% of survey respondents (Hatton & Waters, 2011) and spending less time in psychiatric hospital (Laragy, Sanders, & Brophy, 2015). A qualitative study evaluating experiences of using personal budgets found that participants reported using their funding to support their health by participating in sport, going to the gym or purchasing equipment to exercise at home (Larsen et al., 2015), highlighting potential ways that flexible personalised funding might support health outcomes.

Positive psychological outcomes have been reported in several studies (Haslam, 2017, as cited in Sanderson & Hawdon, 2019; Stainton, Boyce, & Phillips, 2009; Waters & Hatton, 2014). Systematic and narrative reviews have highlighted positive effects of personal budgets on mental health and psychiatric symptoms (Dickinson, 2017), psychological wellbeing (Carr, 2011b), self-image, self-belief (Fleming et al., 2019) and self-esteem (Verhaeghe, 2020). In particular, the systematic review by Webber et al. (2014) found that in most studies people with psychosocial disability reported improved hope and recovery and overall mental health. Moreover, the most common outcomes from self-management for people with psychosocial disability is an improvement in mental and emotional wellbeing, including feeling more relaxed, less stressed, more positive, and less depressed (Larsen et al., 2015). The meta-synthesis in the review by Fleming et al. (2019) found that people reported feeling more confident, safe and 'cared for', and that they had more hope and a positive outlook on life, which altogether led to increased resilience, self-worth and lower stress and anxiety. It is thought that these psychological benefits arise in part because self-management provides people with more opportunities for self-determination than traditional service access (Eriksson, 2014), and because people can access supports that enhance their recovery and daily living as well as their social and community participation (Larsen et al., 2015).

**Social and community participation**

Several systematic and scoping reviews have highlighted that self-management facilitates social participation and community integration, use of community facilities, and social relationships (Dickinson, 2017; Fleming et al., 2019; Harkes, Brown, & Horsburgh, 2014a; Laragy, Sanders, & Brophy, 2015; Manthorpe et al., 2011; The Health Foundation, 2010; Webber et al., 2014). However, some studies have reported no differences in community participation (Caldwell & Heller, 2007). The effects on social participation are particularly prominent when budget holders use their funding to allow them to participate in activities in their communities (Carr, 2011b; Katzman, 2018)**,** as well as education and training, employment or job seeking, or shopping (Laragy, 2010). Participants in qualitative studies have reported that their self-directed budget led them to develop deeper and longer lasting relationships (Stainton & Boyce, 2004, as cited in Stainton, Boyce, & Phillips, 2009), and allowed them to meet new people with common interests when they took up a new hobby or

participated in sport (Fleming, McGilloway, & Barry, 2016; Larsen et al., 2015). Moreover, safeguarding experts have highlighted that when "*people feel more in control of their lives they are more likely to be able to keep themselves safe*" (p.10; Stevens et al., 2018). Finally, benefits also include improved relationships within families (Simpson & Douglas, 2016), particularly reducing the sense of guilt some people may have by reducing the informal care demands on family members (Arksey & Baxter, 2012; Larsen et al., 2015). The positive changes to relationships can also foster improved attitudes from family members with increased focus on the abilities, passions and interests of the budget holder (Fleming, McGilloway, & Barry, 2016).

**Choice, control, flexibility, independence, and freedom**

Enhanced choice, control, independence, autonomy and empowerment are identified as some of the main benefits of self-management in several systematic reviews (Dickinson, 2017; Harkes, Brown, & Horsburgh, 2014a; Simpson & Douglas, 2016; The Health Foundation, 2010; Webber et al., 2014), and narrative reviews (Hande & Kelly, 2015; Slasberg, Beresford, & Schofield, 2012a; Verhaeghe, 2020). Four out of five studies examining choice and control in one review reported improvements for people with psychosocial disability (Webber et al., 2014). An early evaluation of self-management found that 72% of people felt that they had more choice and control over their lives (Hatton & Waters, 2007, as cited in Harkes, Brown, & Horsburgh, 2014a), which was not associated with the level of funding they had been allocated (Netten et al., 2012).

Key aspects of choice and control identified in the systematic review by Fleming et al. (2019) related to how, when, where and by whom support is provided. Executing greater choice and control then leads to improvements in confidence, autonomy, self-determination, self-direction, self-reliance, empowerment and the growth that comes when you have freedom to make mistakes (Lakhani, McDonald, & Zeeman, 2018; Larsen et al., 2015; Verhaeghe, 2020; Webber et al., 2014). Moreover, the increase in choice and control relate to feeling that the budget holder has more involvement in decisions about the activities that they participate in and who supports them (Aspinal et al., 2019), effectively transferring power to the budget holder (Christensen, 2012). For families, choosing supports for their child allowed them to secure improved "*continuity of care*" (p.1,913) that was often lacking in agency-based services (McNeill & Wilson, 2017), especially when they were transitioning from child to adult services (Mitchell, 2012b). The benefits linked to choice and control are particularly apparent when people are permitted to spend their funding flexibly in ways that meet their needs (Porter & Shakespeare, 2016; Simpson & Douglas, 2016).

One scoping review has critiqued whether self-management truly enhances choice and control for the budget holder (Sims & Cabrita Gulyurtlu, 2014) given that their families and staff often influence, direct or curate the options from which they can choose (Brennan, Traustadóttir, Rice, et al., 2016; Richardson et al., 2020). In particular, despite having self-managed funding some people felt that decisions are still made about them rather than with them (e.g., selecting their support workers; Aspinal et al., 2019), and a mother from Sweden highlighted that

decisions can even be made in the best interests of staff "*if the assistants group together and become too powerful*" (p.613, Brennan, Traustadóttir, Rice, et al., 2016). These issues are especially pronounced for people with intellectual disabilities, but have also been reported by people who do not have well established peer support networks who can be overwhelmed by the additional work involved in self-management (Manji, 2018).

Diminished choice can be heightened when people experience discrimination or prejudice from the broader community that leads them to limit how they access community settings (Small, Mehmet, & Kleinschafer, 2020). Some people have also reported having less control over their care and support than other social care groups (Cheshire West & Chester Council, 2010 as cited in Verhaeghe, 2020) or since they became NDIS participants (e.g., people with psychosocial disability; Mavromaras, Moskos, & Mahuteau, 2016). Others reported increased choice and control when they switched from self-managing their direct payments to having a managed personal budget (Aspinal et al., 2019). Finally, choice and control has been reported to be contingent on having access to clear information (Strong, 2012). In summary, therefore, it appears that people only experience greater choice and control if they receive sufficient information and support to understand how to manage their funding, and if they are sufficiently involved in self-directing and selecting how their funding is used.

**Creativity, flexibility, value for money, and needs-led support**

Flexibility in how time and funding can be used has frequently been identified as a benefit of self-management in systematic reviews (Fleming et al., 2019; Laragy, Sanders, & Brophy, 2015; Webber et al., 2014). Flexibility involves being able to use funding in innovative or creative ways (Laragy, Sanders, & Brophy, 2015), and to secure services that are more reliable (McNeill & Wilson, 2017). Moreover, it involves using funding in ways that are tailored to individual needs (Dickinson, 2017; Fleming, McGilloway, & Thomas, 2021; Topping, Douglas, & Winkler, 2020), especially for people with more complex needs (Harkes, Brown, & Horsburgh, 2014a) or for people with a preference for culturally appropriate supports (e.g., employing a Chinese speaking personal assistant; Irvine et al., 2017). The systematic review by Lakhani, McDonald, and Zeeman (2018) highlighted that self-directed funding can help people step away from the "*dull and unvaried*" services available through traditional mainstream services (p. 308). In some settings people may even be able to purchase items that were not eligible under traditional funding (e.g., a cheap mobility scooter rather than an expensive electric wheelchair; Fleming, McGilloway, & Barry, 2016). Alternatively, flexibility means that people can continue to purchase traditional services or supports if they prefer (Benoot et al., 2021; Carr, 2011b). Either way, self-management allows people to maximise value for money by shopping around and saving some costs by "*removing the middle man*" (p. 66; Fleming et al., 2019); however, see discussion of the challenges in handling hidden costs above (Section 3.6.3).

**Housing and independent living**

Few studies have focused on housing outcomes related to self-management. The systematic review by Simpson and Douglas (2016) identified that families were less likely to put their child in institutional care if they accessed self-directed funding. In the Netherlands, parent-initiated supported living settings have successfully allowed people with disability to live alongside peers, to exercise choice and control, increased social participation, and saving living expenses through communal activities (Reindl, Waltz, & Schippers, 2016). However, in some settings people with self-managed funding have reported that they have limited "*genuine choice*" (p.37) about where they live and with whom (Dursin, 2021). Moreover, Slasberg and Beresford (2020) have highlighted that the number of people accessing self-managed funding in the UK has not had an impact on the number of people with disability living independently.

**Social, economic and justice outcomes**

Self-management has improved access to education and training (Carr, 2011b; Laragy, Sanders, & Brophy, 2015), and participation in work or volunteering roles (Larsen et al., 2015), although one systematic review found inconsistent effects on work participation for people with psychosocial disability (Webber et al., 2014). People who self-manage their budget and employ their own staff have reported that they learned important transferrable skills that may improve longer term work outcomes, such as understanding how to collect timesheets, and complete tax returns; development of interpersonal skills and skills in recruitment, supervision and setting up a care team and rosters (Arksey & Baxter, 2012). Other systematic reviews have found that people developed better financial stability (The Health Foundation, 2010), and spent less time in criminal justice settings (Laragy, Sanders, & Brophy, 2015) when they used self-managed funding.

### 3.8.2 Adverse outcomes, safety or unmet needs for people with disability

Recent systematic reviews have concluded that, overall, there appear to be fewer adverse effects for people who are self-managing their funding (Fleming et al., 2019; Webber et al., 2014) when people are given appropriate support (Laragy, Sanders, & Brophy, 2015). For instance, there are no differences in the incidence of: challenging behaviours (Conroy et al., 2002), psychological 'ill-health' on the General Health Questionnaire (Glendinning et al., 2008), hospitalisations, but there was a decrease in mental health service use (as reported in five studies included in the systematic review by Webber et al., 2014). In qualitative studies, few people reported that there has been no benefit or negative outcomes (Larsen et al., 2015). Other studies have examined the incidence of risks for people who are self-managing, levels of unmet needs, stress and anxiety related to self-management, which we summarise below.

**Safety, risks and unmet needs and reduced service access**

There is evidence that self-management is safe (Benjamin, Matthias, & Franke, 2000), and people have reported that they experience no change in financial, physical or sexual abuse (Ismail et al., 2017), or less abuse and exploitation when they employ their own support

workers than they did with traditional services (IFF Research, 2008, as cited in Glasby, 2011). However, Ismail et al. (2017) found a small increase in the allegation of emotional abuse in people who were self-managing their budgets (18 per cent) compared with people holding an agency managed personal budget (10 per cent) or who did not have a personal budget (15 per cent). The majority of allegations for emotional abuse were from informal carers (e.g., family or friends) rather than a support worker.

Most studies have reported no increase in unmet needs for daily living (Caldwell & Heller, 2007), or lower odds of reporting unmet needs (Brown et al., 2007). However, some studies have reported that there is a discrepancy between the level of individual needs and the services available to meet them (Breda et al., 2004 as cited in Verhaeghe, 2020). Moreover, people report fearing that they will lose access to existing traditional services (Fleming, McGilloway, & Barry, 2016) which leads to increased fragmentation of social networks and isolation if those services do close (e.g., day services; Hamilton, Mesa, et al., 2017). Some people with psychosocial disability reported that they received fewer supports once they became NDIS participants (Mavromaras, Moskos, & Mahuteau, 2016), although it is not clear if those participants were self-managing. Finally, one study found fewer unmet needs for activities of daily living in the control group compared with those with individualised funding on one measure but there were no differences on a second measure of instrumental ADL-related unmet needs (Benjamin, Matthias, & Franke, 2000).

**Stress and anxiety**

Taking on the responsibility of managing a personal budget has been reported to increase stress particularly the unsettling effect of change, and the burden of administrative tasks (Larsen et al., 2015), which puts budget holders and their families at risk of "*burn-out or disengagement*" (p. 1377; Fleming, McGilloway, & Barry, 2016). Moreover, while increased choice and control are considered hallmarks of self-management, several studies have highlighted that some people feel uncomfortable making choices about their care and wanted more professional support (Davidson et al., 2013). For some people, having too many choices can feel like a burden and could increase feelings of stress, anxiety and uncertainty (Schwartz, 2004, as cited in Simpson & Douglas, 2016; Vick & Spandler, 2004), especially for people who find it difficult to articulate their needs (Verhaeghe, 2020). However, the level of anxiety depends on the type of choice as noted by one Norwegian mother: "*with clothes it's easy. If she's between two sweaters she just chooses what she wants. Choosing is difficult*" (p.614; Brennan, Traustadóttir, Rice, et al., 2016). Finally, financial matters can cause a range of concerns for budget holders, including:

- fear of losing funding in future plans elicits a persistent sense of anxiety (Manji, 2018);
- delays in receiving payments puts the budget holders personal finances at risk and increases feelings of insecurity and stress (Junne & Huber, 2014); and

### 3.8.3  What impacts on the effectiveness of self-management?

While there are clearly many potential benefits from self-management several commentators have highlighted that this "*may not be unanimously positive*" (p.634; Junne & Huber, 2014; Manji, 2018) and many criteria have been found to influence whether and how self-management can improve the lives of people with disability. Dickinson (2017) highlighted that "*how you implement is as important as what you implement*" (p.8). There are better results when there is more flexibility in how budgets can be used (Sanderson & Hawdon, 2019) and people are supported to overcome the administrative challenges of self-management (Laragy, Sanders, & Brophy, 2015). The broader literature also highlights differences in outcomes related to several individual, scheme and social factors, which we summarise below, including:

- The budget holder's socioeconomic characteristics
- The type of disability
- The nature of administrative supports available and access to information
- How needs have been assessed and the planning support processes
- The level of funding available
- Risk management processes
- The availability of supports
- The types of supports and services that are purchased
- The quality and nature of relationships with support workers
- Access to peer support networks or advocacy
- Having a circle of support, including support or input from family members.

**Socioeconomic characteristics**

The success of self-management has been found to depend on contextual variables (David, Laragy, & Hudson, 2019; Laragy, Sanders, & Brophy, 2015; Simpson & Douglas, 2016) including the budget holder's personal circumstances (e.g., socioeconomic status, minority group status, geographic location), resources (e.g., circle of support, income), and the capacity to self-advocate. The systematic review by Carey, Crammond, and Malbon (2019) found that a range of socioeconomic characteristics were associated with improved outcomes in personalisation schemes, including "*education, being employed, having capable networks and support, knowledge and skills in navigating complex systems, household income, knowledge of where to access information and the capacity to self-manage individual budgets*" (p. 4). Self-management requires administrative, financial and interpersonal skills that essentially benefit people who already have higher levels of social capital (Carey, Crammond, & Malbon, 2019), and these schemes have the potential to exacerbate existing social and health inequities if appropriate assistance is not available (Topping, Douglas, & Winkler, 2020). People from ethnic minorities have also reported poor knowledge of supports available to them (Irvine et al., 2017), and have had lower levels of engagement with self-management schemes (The Health Foundation, 2010). Age differences are also apparent with increased problems for young people transitioning between child and adult services, particularly due to changes in the young person's social and legal status (Mitchell, 2012a). However, receiving transition support allows young people to understand self-management and learn how to

negotiate their funding and service use. At the other end of the spectrum fewer beneficial outcomes and greater dissatisfaction has been found for older people (The Health Foundation, 2010), who have reported greater difficulty with managing the administrative and legal responsibilities associate d with self-management (Roulstone & Hwang, 2015). As a result older people often prefer to receive traditional services (Leece & Leece, 2006).

### Disability type

In addition to the differences in the levels of uptake of self-management across cohorts with different types of disabilities (Section 3.2.3), outcomes also appear to vary across disability types. For instance, the rapid review by The Health Foundation (2010) found that people with psychosocial disabilities were most satisfied with their budgets but other scoping reviews highlighted that people with neurological impairments, psychosocial disabilities and complex needs have greater difficulties with accessing adequate funding and supports when they are self-managing (Sims & Cabrita Gulyurtlu, 2014; Topping, Douglas, & Winkler, 2020). On the contrary, people who are better able to identify their needs, choose their supports and manage the financial and human resources elements of self-management (Stevens et al., 2018).

### Administrative support, assessment and planning, and risk management

It has been recognised that self-management is not likely to improve outcomes unless there is a "*supportive framework of integrated resources, interventions and knowledge bases*" (p.56) (Mitchell, 2012a) to help the schemes, providers and people with disability to get the most out of the system. Indeed, several factors related to access to information, administration, assessment and planning have been found to impact on outcomes. Satisfaction and positive outcomes are highest for people who received sufficient information early about self-management so that they could make an informed decision (Williams, Porter, & Marriott, 2014). Moreover, outcomes are improved for people who report that they receive spending guidance, and ongoing assistance to manage administrative tasks (Arksey & Baxter, 2012; Laragy, Sanders, & Brophy, 2015) such as accounting support or information management systems (Dickinson, 2017). Independent planning support or brokerage (Roeher Institute, 2000, as cited in The Health Foundation, 2010), a clear strategy to support budget holders through local user led organisations like the *In Control* organisation (Duffy, 2005), and receiving assistance to self-direct their funding are also associated with increased practical and psychological benefits for budget holders (Peterson, Buchanan, & Falkmer, 2014). Further, the rapid review by the The Health Foundation (2010) highlighted that success appeared to be linked to supportive signposting and assistance to navigate and access the scheme, as well as receiving training on how to manage money, budgeting and accounting requirements, how to access required services, and how to employ and manage staff.

The success of self-management is influenced by whether plans are based on an accurate assessment of needs, and people have received sufficient resources that can be used flexibly (Slasberg & Beresford, 2015). Indeed, studies and reviews have found that people are more satisfied and have better participation outcomes if the local authority made "*the process easy,*

*and they feel fully included in budget setting and support planning*" (p.5, Waters & Hatton, 2014), and they could flexibly use their funding (Sanderson & Hawdon, 2019). Several studies and reviews have identified that better outcomes are reported when staff use person-centred and respectful practices when assessing needs and helping people to plan their self-managed supports and budget use (David, Laragy, & Hudson, 2019; Lakhani, McDonald, & Zeeman, 2018; Laragy, Sanders, & Brophy, 2015; Manthorpe et al., 2011; Williams, Porter, & Marriott, 2014). For instance:

- respectful communication and listening skills;
- involvement of the person with disability in their own assessment;
- provision of support to help people to identify their own needs and aspirations;
- acknowledgement of the lived experience and expertise of people with disability and their family or other connections;
- enabling shared decision making; and
- assessors and planners have relevant expertise.

Ultimately, however, it is not always clear whether it is self-management per se that leads to better outcomes, or if improved outcomes are due to better planning and case management (David, Laragy, & Hudson, 2019; Dickinson, 2017). Finally, while some people report that they led to reduced choice and control after safeguarding concerns are investigated (Aspinal et al., 2019), implementation of the safeguarding approach in England changed the work culture to focus more on outcomes designed with people, rather than process measures (Briggs & Cooper, 2018), which naturally influences the success in achieving better outcomes.

**Availability and purchase of services or supports**

Further to the impact of access to information, noted above, rapid and systematic reviews have emphasised that uptake of self-management and outcomes are influenced by knowledge and availability of appropriate services and activities to purchase (David, Laragy, & Hudson, 2019; Harkes, Brown, & Horsburgh, 2014b; Laragy, Sanders, & Brophy, 2015). Thin markets and geographic remoteness (Dickinson, 2017) or a lack of appropriate services (David, Laragy, & Hudson, 2019), however, limit choice, control and self-direction. Improved outcomes have been linked with the shift in focus from daily living to person-centred goals and outcomes in self-management schemes (Manji, 2018). Moreover, the use of funding to purchase community or leisure activities in mainstream settings (Fleming, McGilloway, & Thomas, 2021), and to employ support workers rather than purchasing traditional services has been found to be associated with better outcomes (Slasberg & Beresford, 2020; Waters & Hatton, 2014). In part, these impacts on outcomes are probably partly driven by the fact that when people are able to employ their own support workers they can develop better and more satisfying relationships with them (Camoni, Picardi, & Venerosi, 2020; Nally, Moore, & Gowran, 2021). Moreover, when people have better continuity of care, such as through employing a family member, there are better health outcomes (e.g., fewer respiratory infections, bed sores or pressure sores) (Laragy, Sanders, & Brophy, 2015).

**Funding levels**

Self-management is reported to lead to improved outcomes only when there is the right level of funding in the budget to purchase necessary supports (Laragy, Sanders, & Brophy, 2015; Nally, Moore, & Gowran, 2021). In Northern Ireland, one study found that the majority of participants felt that their self-managed direct payments allowed them to access services that could not be matched by local agency-managed funding options (McNeill & Wilson, 2017). Likewise, in England it is thought that outcomes are better for people who are self-managing because they receive about 44-80% more funding than other service users (Slasberg, Beresford, & Schofield, 2012a; Woolham & Benton, 2013). Slasberg, Beresford, and Schofield (2012a) showed that larger weekly budgets were associated with 11 out of 14 outcomes for people in a previous study by Hatton and Waters (2011). It therefore appears that having a larger budget if you are self-managing allows people to not only access enough support to meet their daily living and self-care needs, but also to participate in leisure and social activities (Slasberg & Beresford, 2016b). Moreover, some people may not receive increased funding until they reach a crisis point (Beresford and Andrews 2012; Parish 2011, both cited in Hamilton, Mesa, et al., 2017), highlighting the need for early intervention and contingency plans, especially for people with fluctuating needs.

**Accessing peer support networks and advocacy**

The involvement of user led organisations that provide peer support and advice has been reported to play a key role in improving the successful implementation of self-management schemes (Carr, 2011b). For example, people who had multiple contacts with peer networks before taking on a personal budget were better able to manage the planning and implementation of their budget (Williams, Porter, & Marriott, 2014). This is believed to be because peer networks:

- have lived experience with disability and self-management
- skills for identifying and procuring or brokering service,
  provide ongoing support
- are able to build the confidence of people with disability to understand, access and manage self-management (Hyslop et al., 2020) while enabling the budget holder to still feel that they are in control (Campbell et al., 2011, as cited in Hyslop et al., 2020).

Moreover, involvement of ULOs is associated with improved outcomes because budget holders perceive that they are independent from the statutory authorities, have a positive approach to risk, don't push people into accepting self-management, and don't focus on containing expenses (Hyslop et al., 2020). Rather, ULOs and peer networks focus on helping people to use their budgets to live independently (Davey, Snell, et al., 2007), which may be a key reason why receiving support from a peer network leads to improved outcomes.

**Family and support networks**

The presence of a 'circle of support' including both informal (e.g., family, friends) and paid (e.g., broker, support workers) networks is integral to successful implementation of self-management (Brennan, Traustadóttir, Rice, et al., 2016; Fleming, McGilloway, & Barry, 2016; Harkes, Brown, & Horsburgh, 2014b). However, Brooks, Mitchell, and Glendinning (2017) suggest that the benefits of self-management with the support of family may be jeopardised if there has been no assessment of the actual willingness and ability of the family member to provide support. Living in individualised housing with the support of a parent has been reported to increase participation in hobbies and sports compared with when the budget holder attended day centres or lived in traditional institutions (Reindl, Waltz, & Schippers, 2016). People from middle class backgrounds who have a supportive family tend to be able to better navigate the complexities of self-management schemes leading to better outcomes (Lakhani, McDonald, & Zeeman, 2018). However, having another family member or person assisting the budget holder to manage their funding and supports can lead to limited choice and control unless they use person-centred methods to aid self-direction (Sims & Cabrita Gulyurtlu, 2014). Moreover, social participation outcomes are negatively impacted when the support worker's availability and preferences are prioritised over the budget holders' own choice and agency (Hamilton, Mesa, et al., 2017).Finally, people who do not have a strong network of support have been found to have limited success in self-management (Fleming, McGilloway, & Thomas, 2021).

### 3.8.4  Outcomes and experiences for family and carers in the support network

Self-management not only has the potential to improve the lives of people with disability, but also those of their families and support networks (Hamilton, Szymczynska, et al., 2017; Mitchell, Brooks, & Glendinning, 2015). In particular, family and informal carers report increased satisfaction, general wellbeing and quality of life, improved relationships and social participation of family members, and increased participation in paid work, as well as secondary benefits when the budget holder's life is improved. However, the increased administrative burden can also lead to increased stress and financial burden for family members.

**Improved satisfaction, wellbeing and quality of life**

Family carers supporting a budget holder who is self-managing their disability supports and services are heavily involved in organising and coordinating their supports, and overseeing the administrative requirements (Glendinning et al., 2008). However, despite increased administrative demands several systematic, rapid and narrative reviews have highlighted that family members and informal supports have better quality of life and worry less about the budget holder when they are self-managing their services compared with when they received traditional services (Laragy, Sanders, & Brophy, 2015; Simpson & Douglas, 2016; Singer, Biegel, & Ethridge, 2010). In one study wellbeing of carers was similar to that of adults in the general population, and was significantly higher than the wellbeing of carers who were not accessing self-managed funding (Robinson et al., 2012, as cited in Simpson & Douglas,

2016). Predictors of improved quality of life and psychological wellbeing for family carers include: being satisfied with support planning processes (endorsed by 88% of carers), having a positive relationship with the service user, being able to take a break from caring, spending fewer hours in the caring role, not living in rental accommodation or experiencing financial difficulties, and receiving a larger budget (Jones et al., 2014). Moreover, the systematic review by Laragy, Sanders, and Brophy (2015) emphasised that even when carers do not receive direct funding to support their wellbeing, they experience direct or indirect benefits when their family member's quality of life is improved. For instance, reduced admissions to hospital and criminal justice contacts, improved work participation and confidence for the budget holder, and the knowledge that they are receiving high quality supports, leads to lower stress and increased wellbeing for their family members (Hatton & Waters, 2013; Laragy, Sanders, & Brophy, 2015). However, some studies have found that self-management leads to increased anxiety about the future (Turnpenny et al., 2021), and negative impacts on wellbeing for a small proportion of family carers (Hatton & Waters, 2011)

**Improved relationships, reduced pressures and work participation of family**

Family and carers have reported that their family member's access to self-managed funding allows them to spend more quality time with them, leading to reduced strain or pressure (Arksey & Baxter, 2012; Turnpenny et al., 2021) and improved relationship quality (Larkin, 2015; Moran et al., 2012). Moreover, when budget holders are able to pay a family member as a support worker that they traditionally provided for free meant that the family member, most often a woman (Brennan, Traustadóttir, Rice, et al., 2016), did not have to choose between paid work and caring (Laragy, Sanders, & Brophy, 2015). While many carers report that receiving a wage for providing support to the budget holder recognises the value of their care for them, others report that it can lead to negative outcomes including a sense of obligation or that their caring was not appreciated as much as it was when it was previously done for no pay (Grootegoed, Knijn, & Da Roit, 2010). When austerity measures were implemented and funding levels reduced for the majority of budget holders there was a widespread assumption that unmet needs would be met by family members who were "*expected by governments to altruistically undertake this customary role*" often at the expense of other employment opportunities (p. 1,429; Malli et al., 2018). In the UK, carers who were supporting a family member with a self-managed budget spent more time caring for them than people receiving conventional services (81 hrs versus 72 hrs per week; Jones et al., 2014), posing potential opportunity costs associated with self-management. However, some carers have reported that their family member's access to self-managed funding increased their own opportunities for employment or gave them choice about whether to be renumerated for their caring work (Larkin, 2015; Moran et al., 2012; Woolham et al., 2016).

**Choice, control, involvement, and access to breaks**

Improved outcomes for carers include the benefits from being involved in activities that support the wellbeing of their family member (Carr, 2011b), and improved health and

wellbeing because they are able to take more breaks from the caring role. Jones et al. (2014) found that a larger proportion of carers who have a family member with self-managed funding plan their supports directly with the budget holder compared with people accessing traditional services (38% vs 12%). Both family members and budget holders like being able to choose who provides their support, such as support workers who are already well known to them (Whitaker, 2015). Moreover, self-managed budgets can give greater flexibility and control over what the budget holder does with their time, including when and how services are accessed, leading to positive impacts for carers (Moran et al., 2012; Turnpenny et al., 2021). However, Hamilton, Szymczynska, et al. (2017) found that some parents reported being actively excluded by mental health staff during planning meetings, which increases the risk that support arrangements will break down: "*it's a real glaring error that there is no [space] in that support plan that actually lets you put in carers' needs*" (social worker, p. 1,442; Mitchell, Brooks, & Glendinning, 2015).

Self-managed funding may allow family and carers to take more breaks because they have flexibility to employ support workers thereby reducing the pressure on family to provide care (Manthorpe et al., 2011), or when accessing respite care (Hatton & Waters, 2013; McNeill & Wilson, 2017). This can allow family members to have more free time to participate in exercise or to resume other interests (Laragy, Sanders, & Brophy, 2015; Larkin, 2015; Turnpenny et al., 2021). For instance, families and carers hare reported that they have been able to '*have a social life outside of caring*' (p. 56; Simpson & Douglas, 2016), including visiting relatives and friends, going shopping, attending doctors' appointments, or just doing nothing without feeling guilty that they are doing something for themselves (Moran et al., 2012).

**Adverse outcomes for family or informal carers**

The most commonly cited disadvantages of self-management for family and carers is the level of burden on them to oversee the administrative and record keeping responsibilities of a self-managed budget, particularly when the budget holder has limited capacity to do this themselves (Hamilton, Szymczynska, et al., 2017; Mitchell, Brooks, & Glendinning, 2015). Family carers who take responsibility for a self-managed budget are essentially expected to "*become managers, accountants, auditors and commissioners*" (p. 281; Whitaker, 2015). They have to coordinate services and supports, manage tax and insurance requirements, monitor financial accounts and keep receipts and invoices on behalf of the budget holder (Laragy, Sanders, & Brophy, 2015; Mitchell, Brooks, & Glendinning, 2015; Whitaker, 2015). The administrative burdens are even higher when budget holders directly employ their support workers (Moran et al., 2012). Altogether these responsibilities can lead to increased stress and anxiety for family members, and cause tension in family relationships (Laragy, Sanders, & Brophy, 2015; Turnpenny et al., 2021).

Families that are able to better manage the administrative requirements of self-management typically have previous experience in managing budgets, professional training or work experience that helps them to know how to explore their options, understand legislative requirements, and negotiate with stakeholders (Moran et al., 2012; Turnpenny et al., 2021).

For other family carers it is more appealing to use a support service to help them with the administrative and legal aspects of budget management (e.g., tax and national insurance matters or payroll companies) as they worry about the responsibility tied to managing a large sum of money, and potentially making mistakes (Moran et al., 2012; Turnpenny et al., 2021). However, ultimately many family members recognise that the administrative responsibilities are the "*pay off*" to enable them to "*live as you want to*" (p. 281; Whitaker, 2015).

## 3.9   Costs and cost-effectiveness of budget self-management

**Key points from the literature**

i.   Most studies have found that self-management *costs less and is more cost-effective* than agency-managed funding; however, existing evaluations are limited, and the evidence is considered to be weak.

ii.  Self-management is *more costly when people start to self-manage* compared with people accessing supports funded directly by an agency or local authority (e.g., block funded services), but costs taper over time as budget holders become more competent.

iii. Operating *costs are reduced* in self-management when funds are paid less frequently, and once budget holders are confident and competent to manage independently.

iv.  Funding *financial services* to support payroll or accounting to people self-directing and self-managing their funding can reduce the time and cost for the scheme to conduct audits and monitoring.

Internationally, goals of personalisation and self-managed social care budgets has been to improve the lives of people with disability, stimulate the capacity of the private sector to provide services, and improve access to more effective and individualised services. However, a major goal of self-managed funding has ultimately been to reduce costs and welfare liability (Carr, 2011b; Dickinson, 2017; Laragy, 2010; Verhaeghe, 2020). Moreover, in countries like Belgium there was a focus on reducing the use and cost of residential care (Verhaeghe, 2020), whereas in England self-managed budgets were intended to be "*at least as cost effective*" (Department of Health, as cited in Glasby & Littlechild, 2002) or "*better value for money*" (p.8, National Audit Office, 2016) compared with traditional services. For instance, self-managed funding should lead to more economical and efficient procurement of services that meet the needs of the budget holder (Terashima, 2011). Moreover, as highlighted earlier, people accessing self-managed supports (Section 3.7.1), and their families (Section 3.7.4), have increased opportunities for participating in paid work. Self-management therefore increases the potential for broader economic benefits through increased tax contributions (Katzman, 2018).

Before summarising the findings on the cost impacts of self-management, it is important to define the differences between costs, cost-efficiency and cost-effectiveness:

- *Cost* analyses simply examine crude differences in the allocation or use of funding between different programs;

- *Cost-efficiency* analyses examine whether outcomes can be maintained or improved at a lower cost; and
- *Cost-effectiveness* analyses examine whether the cost of a new way of working leads to better or maintained outcomes relative to the costs.

With these analyses defined, the vast majority of self-management evaluations have only examined differences in costs (or funding levels) and have rarely examined the direct relationship between costs and outcomes. Moreover, several other important limitations of cost-related analyses should be considered:

- It is often difficult for researchers to identify appropriate comparison groups both over time and between different plan management conditions. For instance, several of the same characteristics that impact on whether someone can and will self-manage may also impact on their level of support needs or odds of having a good outcome (Gadsby, 2013, as cited in Dickinson, 2017)
- The "*woodwork effect*" (p. 839; Power, 2014) has influenced the number and type of people accessing disability supports through self-management due to changes in eligibility criteria, often opening up funding to people who did not previously use residential services or who relied on informal sources of support (Nally, Moore, & Gowran, 2021). For instance, these effects might lead to increased total costs of a scheme (e.g., in Sweden; Brennan, Traustadóttir, Anderberg, et al., 2016), but lower average budget size (e.g., in New Zealand) if there is an increase in the proportion of budget holders who have low support needs (Dickinson, 2017).
- It can be difficult to identify the effective component of self-management when multiple funding streams are consolidated, such as the personal health budgets in the UK (Harkes, Brown, & Horsburgh, 2014a), or multiple processes are changed concurrently (e.g., safeguarding, case management, funding access).
- Most studies do not account for the economic and social impacts of self-management on the potential work participation of informal supports (Katzman, 2018).
- There is poor capture of the relative costs of implementation, disability budgets, and the costs of informal care, uncompensated out of pocket expenses, unmet needs and undelivered care (Carr, 2011b; Mitchell, 2012a; The Health Foundation, 2010), with hidden costs being noted as one of the most 'unsustainable' aspects of self-management schemes (Fleming et al., 2019).
- Budgets are often not based on true needs or costs, and are often redefined to correspond with the level of resources available (Mladenov, 2017; Slasberg & Beresford, 2016a), particularly in the context of austerity (Laragy, Sanders, & Brophy, 2015).

With these limitations in mind, we now summarise insights on the cost savings, cost-effectiveness and value for money from self-management schemes.

**Cost savings**

Several studies have shown that personal budget schemes appear to cost less when compared with traditional packages (Carr, 2011b), including for people with complex needs (Dickinson, 2017). Cost savings are thought to reflect reduced administrative and organisational costs, as well as lower costs for employing support workers (Carr, 2011b). More recently, however, the validity of claims that self-management is more cost-efficient have been challenged (Pearson & Ridley, 2017), and some have argued that when it is properly implemented self-management may be more expensive than conventional models of disability support (Mladenov, Owens, & Cribb, 2015; Slasberg & Beresford, 2015; Slasberg, Beresford, & Schofield, 2012a).

In *Europe*, Glendinning (2009) found no evidence that increased competition between providers had reduced costs (cited in Carr, 2011b); however, other studies found that people were spending 30-50% less with personal budgets than with traditional services in Germany and the Netherlands, respectively (The Health Foundation, 2010). In The USA, the Californian In-Home Supportive Services Program model was initially more expensive than traditional services, although the programs became cost-neutral after the first few years (Feinberg, Wolkwitz, & Goldstein, 2006, as cited in Singer, Biegel, & Ethridge, 2010). Finally, some studies reporting health service and nursing home cost savings (Robert Johnson Wood Foundation, 2007, cited in Carr, 2011b).

The largest number of evaluations of differences in costs of self-managed budgets have been undertaken in the UK. Between 1999-2015 most studies found that there was either no difference in costs, or that self-managed budgets were cheaper, and that people could purchase supports at a lower rate without agency overheads; however, there was some evidence of higher budget values and an increase in the time and funding needed to help set people up when the first begin to self-manage. Key findings over time in the UK include:

- **1999-2000:** An early pilot evaluation found that direct payments were cheaper (£735,867) than traditional services (£764,560) when providing the same level of support (Dawson, 2000, as cited in Stainton, Boyce, & Phillips, 2009).
- **1999-2001:** For people accessing personal assistance through self-managed direct payments, costs were substantially lower than the cost of "in-house services" (p. 168), omitting agency overheads, particularly when paying family or friends allows greater flexibility in care that is needed at short notice (Stainton, Boyce, & Phillips, 2009). Other studies have found that self-managed funding represents value for money but does not save costs (Glasby & Littlechild, 2002 as cited in Fleming et al., 2019).
- **~2006**: The Audit Commission (2006) found that "*councils did not fully understand how to set prices at a level that achieved cost savings while ensuring sustainability and growth in the supply of provision*" (cited in Carr, 2011bp.17)
- **~2007**: An evaluation by Davey, Fernandez, et al. (2007) found that direct payments were cheaper for people with a learning disability, and slightly more expensive for people with physical and sensory disability; however, these estimates did not account for levels of support needs (Stainton, Boyce, & Phillips, 2009).

- **2007-08**: Support costs did not differ between people accessing individualised budgets (mean=£280, median=£170 per/week, range: £2 to £950) and comparable service users without an individualised budget (mean=£390, median=£350 per/week, range: £3 to £1190) (Jones et al., 2014).
- **2006-07**: There were no differences in average weekly costs for people receiving personal budgets than a comparison group (£279 versus £296, respectively Glendinning et al., 2008); however, there were higher assessment (Jacobs et al., 2013) and management-related costs (Glendinning et al., 2008; Jones et al., 2012) including the cost of a care coordinator to support people to self-manage and plan their funding use (Carr, 2011b).
- **~2007-09**: Direct payments cost less than traditional care packages (Stainton, Boyce, & Phillips, 2009), but there are high start-up and delivery costs for direct payment and personal budgets (Jones & Netten, 2010) and some support needs may be "absorbed" by the individual's informal support network (Carr, 2011b)
- **2008-09**: weekly costs of people accessing self-managed funding were £355 compared with £268 for the comparator group (Woolham & Benton, 2013).
- **~2012:** spending on direct payment recipients who are employing their own staff was about 80% higher the value of supports to all others (Slasberg, Beresford, & Schofield, 2012a), and care managers spend longer assessing needs for people receiving self-managed budgets compared with authority managed budgets (Jones et al., 2012): "*matching people to resources is time-consuming, difficult and dependent on so many conditions... It may be inefficient*" (p.1259; Spicker, 2013).
- **2010-2015:** Spending on adult social care reduced by 7%, partly due to the fact that local governments set lower pay rates (Dickinson, 2017).

Stainton, Boyce, and Phillips (2009) found that there were financial savings linked to self-managed budgets when:

- Funds were paid less frequently (e.g., monthly versus weekly) due to less duplication of administrative processes related to billing, fund collection and accounting;
- Once people were competently self-managing their supports care managers spent less time supporting them compared with other service users as long as systems of accountability were in place; and
- People who were self-managing took advantage of the payroll support services, which simplified and reduced the time required for staff to audit budget holders.

**Cost-effectiveness and value for money**

The systematic review by Fleming et al. (2019) found that several studies showed that individualised funding was more cost-effective. For instance, in the USA the levels of cost-effectiveness ranged between 7-16% (Fleming et al., 2019). Brown et al. (2007) found that higher costs in people self-managing their services in Arkansas and New Jersey appeared to be attributable to relative differences with people accessing agency-based care who received less care than expected based on their care plans, whereas lower costs for those with self-

managed budgets in another state (Florida) appeared to be driven by the fact that most people had developmental disabilities and accessed services through waivers thereby reducing the budget accessed through Cash and Counselling. The earliest cost-effectiveness evaluation in the UK was conducted by Zarb, Nadash, and Publication (1994) who found that direct payments gave budget holders a higher degree of choice, control, reliability and user satisfaction at 30-40% lower costs per hour than service-based supports. However, in that study direct payment recipients typically used 45-80% more services than those accessing traditional agency-based supports, so the overall costs were actually higher (Manji, 2018; Slasberg & Beresford, 2015). The narrative review by Carr (2011b) highlighted that self-management led to better outcomes that were considered to be beneficial relative to the costs incurred. Other evaluations in the UK have found that self-managed personal budgets generated substantial improvements in outcomes and satisfaction (Alakeson, 2010, as cited in The Health Foundation, 2010) with about 10% lower costs compared with traditional service users (Leadbeater, Bartlett & Gallagher, 2008, as cited in Carr, 2011b). Similarly, while Forder et al. (2012) found no difference in the total costs for people with psychosocial disability accessing personal budgets compared with a control group, there were significantly better outcomes for those receiving a person budget indicating that they were cost-effective.

While self-managed funding may not always result in cost savings (Stainton, Boyce, & Phillips, 2009), systematic reviews have highlighted that individualised funding offers better value for money and potential for cost-saving when funds can be used creatively and flexibly (Fleming et al., 2019; Lakhani, McDonald, & Zeeman, 2018; Webber et al., 2014). Moreover, paying family members to provide support can be more cost-effective as they are typically more willing to receive lower wages as that is preferable to unpaid labour and there is no need to cover overheads charged by agencies (Friedman & Rizzolo, 2016; Stainton, Boyce, & Phillips, 2009). Finally, personalised funding could lead to short-term cost savings for budget holders who previously had to pay for items or supports "*out of pocket*" (p.275, Verhaeghe, 2020).

**Factors that impact on costs or cost-effectiveness**

When people are given the opportunity to self-assess and participate in shared decision making about their supports (Lakhani, McDonald, & Zeeman, 2018) there can be cost-savings, and "*most people do not make frivolous or excessive demands, and often seek only minor adjustments and flexibilities to their support*" (p.11; Henwood & Hudson, 2008). While reducing the complexity of accounting and auditing may reduce some of the barriers to self-management, this can have undue impacts on costs. For instance, when accounting requirements were relaxed in the early 2000s in the Netherlands there was a substantial growth in costs for self-managed disability supports, which were later brought back in line by applying financial limits and new eligibility rules (Verhaeghe, 2020).

# 4. Concluding remarks

In summary, this review has highlighted that self-direction of disability funding, predominantly through self-management of a personal budget, has been implemented widely around the world. Overall, there are many benefits associated with self-management for people with disability, their family and support networks, as well as for governments or funding agencies. These benefits have been reported for all forms of self-direction and appear to be enhanced when people self-manage their budget. However, it is important that facilitators are optimised, particularly providing people with accurate and timely information, support, training, and tools so that they can manage the operational, administrative, reporting, and legal requirements. As the plan management option that suits a budget holder may change throughout their lives, it is important that there is flexibility for budget holders to vary their plan management methods over time. While safety and risks have not generally been found to be increased for people who are self-managing their funding, this is likely because most schemes have taken a cautious and proactive approach to risk containment.

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