

SELF-DIRECTED SUPPORTS FOR OLDER PEOPLE

A review of national and international literature
commissioned by the Home and Community Health Association

August 2017

Abstract

Self-directed support is a service delivery model designed to offer older people choice and control over the care services provided to meet their needs. This document reviews literature that analyses and reports on self-directed support initiatives in New Zealand and abroad. It offers the Home and Community Health Association and its members information about the benefits of self-directed support, the characteristics of successful initiatives and identifies a range of potential pitfalls when designing and implementing self-directed care support initiatives.

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1. Introduction

The Home and Community Health Association (HCHA) has commissioned this literature review as a supporting document and tool to improve members' understanding of self-directed supports. The HCHA is specifically interested in service models of self-directed supports used in health care for older people.

1.1. Objectives

The objectives of this literature review are to:

- Outline how self-directed supports are utilised in New Zealand and international initiatives
- Document the benefits of self-directed supports
- Document the characteristics of successful initiatives
- Identify best practice in regard to obtaining buy-in and measuring success
- Identify areas of concern and areas where extra assistance may be required to successfully implement initiatives
- Highlight information gaps

1.2. Methodology

Literature was sourced from existing HCHA resources, Victoria University, Google's search engine, and the Directory of Open Access Journals. Search terms included key phrases such as:

- “self-directed support health of older people”,
- “health initiatives home supports”,
- “health self-management”
- “self-directed health”.

Abstracts and executive summaries were scanned for relevance. Where these were deemed relevant, full articles were obtained. Material referenced in these articles was also considered for inclusion. Where these additional articles were deemed to add to understanding they were obtained, reviewed and included. Publications were excluded from further review if:

- the full text was not available,
- they were written in a language other than English, or
- once given a thorough reading they were deemed irrelevant for this review.

A total of 32 articles were included in the review.

Diagram 1. 1. Search and review of articles



1.3. What is self-directed support?

The term self-directed support refers to a model of service delivery where the recipient of services has choice and control over their care arrangements, including decisions about what care to purchase and from whom. In essence, self-directed support is designed to increase user's choice and control, enabling them to self-direct care services to meet their changing needs (Geekie and Fraser, 2013).

Self-directed support has its roots in social movements that demand greater self-determination, choice, flexibility and control for people with disabilities¹, consumer rights movements, and an ideological shift towards co-production in service design and delivery (Ottmann, Allen & Feldman, 2009). For example, a recent Australian consumer-directed care initiative was noted to be developed in response to:

“trends towards self-direction in community care and other service settings in Australia and internationally, and anticipates demand for more choice and control by the ‘baby boomer’ generation” (KPMG, 2012, p. 21).

Self-directed support can also be understood as part of a continuum of service models that range from agency-control to consumer-control and options in between. Typically, self-directed support refers to initiatives that enable users to choose and control the

¹ Self-directed support as a model of service provision for older people is in its infancy relative to self-directed support designed for people with disabilities. This review does not include literature about self-directed support for people with disabilities. However, Fernhill Solutions recommends that should HCHA want to develop a deeper understanding of benefits, success factors and limitations of self-directed support, there is likely to be a stronger evidence base to support this amongst literature in the disability sector.

services they utilise and determine where they will purchase these services from. In other words, consumer-control. However, self-directed support is also used to refer to approaches where users are supported to participate in decisions about their care and what services will best meet their needs. This does not necessarily mean they have control over these decisions or the purchase of services to meet their needs.

A range of terms are used to refer to self-directed supports in different countries and health and social service settings (Geekie & Fraser, 2013; Slasberg, Beresford & Schofield, 2012; Scottish Government Social Research, 2011; Ottmann, Allen & Feldman, 2009; KPMG, 2012), including:

- Recipient-directed care
- Personalised care
- Personal or individual budgets
- Consumer-directed care.

In the following section, we outline the way in which healthcare is organised and provided for older people in New Zealand and highlight alignment with the goals of self-directed care. We complete this section by introducing two international initiatives that are drawn on throughout the remainder of the review to support HCHA's understanding of self-directed support initiatives in action.

2. Healthcare for older people in New Zealand

Healthcare for older people in New Zealand is shaped by the legislation and policy agenda set down by the Ministry of Health (MoH) and Accident Compensation Corporation (ACC). The direction taken is in turn influenced by international movements and strategies and the decisions made by governing political parties during each term of Government.

Currently, self-directed care, as a model of service delivery for older people is not **explicitly** part of World Health Organisations strategies that New Zealand is a signatory to, or national health strategies. However, as outlined below self-directed care initiatives - their intentions and benefits - do align with the tenets of international and national strategies. Consequently, self-directed care initiatives could be developed to support the current goals of healthcare for older people in New Zealand.

2.1. The World Health Organisation Strategy includes a focus on alignment with the needs of older people

New Zealand is a signatory to the World Health Organisation (2016) 'Global Strategy and Action Plan on Aging and Health' which is a five-year strategy for action to maximise functional ability for all. The Strategy includes five strategic objectives:

- Commitment to action on healthy ageing in every country
- Developing age-friendly environments
- Aligning health systems to the needs of older populations
- Developing sustainable and equitable systems for providing long-term care
- Improving measurement, monitoring and research on healthy ageing.

The strategy discusses how health systems need to be transformed and designed to "ensure affordable access to integrated services that are centred on the needs and rights of older people" (World Health Organisation, 2016, p.6). The emphasis on the needs and rights of older people in this strategy aligns with the goals of self-directed care service models. These models aim to deliver on older people's rights to care that meets their needs, by enabling choice and control over care selection and how it is purchased.

2.2. Alignment between Ministry of Health Strategy and self-directed support

In New Zealand, the Ministry of Health 'Healthy Ageing Strategy' (2016) sets the benchmark for the next five years for the New Zealand health and social services sector. The strategy supports older people being able to:

- live as independently and actively as possible
- have the information and freedom to make good choices about the care and support they receive
- know that health care workers understand their wishes and support their needs
- are assured that information about their circumstances and needs flows easily between health care workers, in an integrated manner
- are able to access care and support irrespective of their financial position
- experience equitable access to services and equitable outcomes regardless of ethnicity or location
- move easily to and through care settings that best meet their needs
- families, and whānau and carers have the support, information and training they need to help the older people they care for, to provide ongoing rehabilitation in home and community settings.
- District Health Boards bring together data from various sources, know the value and quality of the care they provide for older people in their district and can easily learn from other DHBs.
- Communities are age-friendly, with initiatives to keep people healthy, well-connected, independent, respected and able to participate fully in their communities and with family and whānau (Ministry of Health, 2016, p. 48).

Many of the actions listed in the strategy align with the intentions of self-directed care service models. The strategy discusses the importance of high-quality care delivered closer to home through a well-organised primary health care system. This approach is regarded as "empower[ing] individuals, enabling them to make informed choices and supporting them as they navigate their way through the health system" (Ministry of Health, 2016, p. 22). However, the strategy largely focuses on integration of services, improved communication between care professionals and a desire to provide care for older people in their communities to support independent living. Aside from older people knowing that their care workers understand their wishes and needs there is no direction provided to enable older people to have more choice and control over their care arrangements and no mention of older people's role in procurement decisions. The strategy does not explicitly indicate a shift towards self-directed care.

2.3. ACC Home and Community Support Service offers older people a degree of choice and is oriented towards personal goals

In New Zealand, ACC also contributes to older people's care. When an older person experiences an injury that is approved as 'covered' under the legislation guiding ACC's decision-making, the older person is eligible to receive home and community support services while they rehabilitate from the injury. ACC states that these services are "client-centred and goal oriented, and seek to build on the client's strengths to support their ability to remain living in their home" (Accident Compensation Corporation, 2016, p. 3).

ACC's clients have a choice about whether their support is funded through organisations directly contracted to ACC to provide care, non-contracted organisations or a mix of both. ACC home and community services are understood as people-led in that they provide clients with a degree of choice about the provider of their care, involve clients in setting goals and support clients to stay in their own homes. However, on the spectrum of self-

directed care outlined in Section 1.3 these services align more closely with agency-led care than consumer-directed care because ultimately it is ACC that determines what care will be offered, purchases and manages that care for older people.²

2.4. DHBs use interRAI and Restorative Home Support to develop individualised, goal-based packages of care

In 2011, Parsons, an eminent academic studying healthcare for older people in New Zealand, stated that the current service provision across New Zealand:

“tends to be task based, rigid, non-responsive and un-targeted. ... the current approach to delivery of HCSS has limitations in being able to meet the changing needs of older people who require flexible and responsive service provision to meet increasingly complex needs”
(2011, p. 3).

To address these issues, District Health Boards (DHBs) across New Zealand have started using an International Residential Assessment Instrument (interRai). InterRai provides rules and criteria for assessing whether an older person needs various types of support, including medical care, rehabilitation and support at home (New Zealand Productivity Commission, 2015). DHBs have coupled this with the use of a Restorative Home Support delivery model that aims to improve and restore function through the use of individualised, goal-based packages of care.

The Restorative Home Support delivery model supports improved outcomes for older people, the wider health sector and the home and community support services workforce. According to Parsons (2011), while the model does not focus entirely on improving the independence of clients, it does represent a significant improvement in quality.

A number of DHB's have incorporated this approach into both the short and long-term provision of services (South Canterbury 2004; Nelson Marlborough 2017; Capital Coast 2006; Auckland 2008; Canterbury 2010; Southern 2012) with others planned for 2015 - 2017 (Waikato, Tairāwhiti, Lakes, Taranaki, Waitemata, Hawkes Bay, Hutt Valley).

2.5. The absence of self-directed support initiatives in New Zealand

New Zealand's current approach to healthcare for older people includes emphasis on aligning healthcare services with older people's needs; it is attuned to meeting older people's rights; has set goals to support older people to make choices about their care and to live independently. In many ways, these attributes signal that self-directed care is central to the delivery of care for older people. However, New Zealand has yet to extend older people the degree of choice and control over their care that has been offered in other western nations. This is particularly the case in regard to older people's engagement in procurement of care.

It could be argued that New Zealand shares international views about the importance of older people being supported to exercise choice and control over their care, however, this is being achieved through assessment tools and agency-guided care packages, rather than through a process of enablement that supports older people to fully self-direct their care. In New Zealand, DHBs are exploring different care delivery models that balance their duty of care to older people (including supporting individual rights and choice) while maintaining delivery of quality care to individuals and populations. Brief details of examples where DHBs have explored self-directed care delivery models or developed service models that attempt to deliver on some aspects of self-directed care are presented in the table below.

² ACC also provides a limited self-directed funding service for clients with serious injury, however this is not extended to older people.

Table 2.5.1. Some examples of self-direct support initiatives in New Zealand DHBs

<p>Self-Direct Support Initiative in Waitemata</p> <p>Waitemata DHB proposed an individualised funding programme where following a needs assessment, a client receives money from the MOH and DHB to purchase the services they need themselves (Waitemata District Health Board, 2013).</p> <p>In 2013, Waitemata DHB asked for feedback on the proposal (see New Zealand Productivity Commission, 2015, p.8 for a summary).</p>	<p>Key Characteristics</p> <p>The Waitemata DHB Annual Plan (2016) includes a number of recommendations that have been progressed since the 2013 survey. Including:</p> <ul style="list-style-type: none"> • System integration for older people, where they are reviewing processes between hospital, aged residential care, home and community support service providers, primary care and specialist services, to ensure the right health information is communicated between all providers caring for older people. • The use of <i>interRai</i> assessment tools for older people receiving long-term home and community support service ongoing. The <i>interRai</i> measures will be used to compare and benchmark performance with other DHBs to improve outcomes for older people. <p>N.B. Individualised funding was not advanced. Current efforts appear to focus on integration of services, improved communication between providers and assessment tools that involve older people in the process of planning their care.</p>
<p>Restorative Care in the South Island</p> <p>A Restorative Care approach developed by the South Island Alliance enables the regions five DHBs to work collaboratively to develop more innovative and efficient health services than could be achieved independently (South Island Alliance).</p>	<p>Key Characteristics</p> <p>The Restorative Care approach is defined as: “A flexible approach to health care that respects the individual, and supports them to obtain and maintain their highest level of function, live independently and contribute to their community for longer, and participate actively in decisions about their care” (South Island Alliance, 2016). The approach includes:</p> <ul style="list-style-type: none"> • Assessment using a comprehensive multidimensional assessment (<i>interRai</i>) • Goal-oriented care planning that reflects the individual’s needs and desires • Use of targeted, evidence-based interventions to optimise daily living functions. • Care is provided by a multi-disciplinary team, which meets regularly to review challenging or resource-intensive cases and facilitate the input of other community organisations. • Education for all older people, their carers and professional staff • Encouragement to participate fully in all care decisions, promoting their sense of autonomy and reducing the need for ongoing in-person supervision. • Promotion of active engagement in a range of daily living activities – task analysis, work simplification and assistive technology and telemedicine are used where appropriate. • In time each older person will have a single care plan, which provides a complete view of their care and is shared by all providers.

2.6. Scottish and Australian examples of self-directed support initiatives

In New Zealand, health care for older people currently focuses on supporting independence, integration of services, delivering services in the community (i.e. avoiding hospital admissions) and client participation in care planning. It does not extend to giving older people choice and control over the selection, procurement and management of their care services. In contrast to this, in Scotland and Australia recent initiatives do offer the opportunity for older people to self-direct their care in the fullest sense of the term. In the United States, the focus has largely been on Cash for Care schemes, which in effect provide older people with cash or vouchers to pay for care that would otherwise have been provided in-kind in their home (Ottmann, Allen & Feldman, 2009).

To provide HCHA with an understanding of self-directed support initiatives, the review draws on literature that analyses and reports on self-directed care initiatives in Scotland and Australia (as detailed in the table below). This is supplemented this with information from a robust critical review of initiatives in the United Kingdom and the United States by Ottmann, Allen & Feldman (2009).

Table 2.6.1. Self-direct support initiatives in Scotland and Australia

<p>Self-Direct Support Initiative in Scotland</p> <p>Self-directed care is included in Scotland’s legislation as part of the Social Care (Self-directed Support) (Scotland) Act 2013, which came into force in April 2014.</p> <p>The Scottish Government has invested £58.8M to transition to this new self-directed care approach between 2011 and 2017 (Scottish Government, 2017).</p>	<p>Key Characteristics</p> <p>Local Authority Social Work Departments must offer people who are eligible for social care a range of choices over how they receive their support. This includes:</p> <ul style="list-style-type: none"> • Direct Payments – payment directly to service users to arrange their own support; • Directing the available resource –the user selects the support that they wish and the Local Authority arranges matters on their behalf. • Local Authority ‘arranged’ support where the authority arranges support on the user’s behalf to meet their needs; and • A mix of the above options for distinct aspects of the user’s support. <p>(Scottish Government Social Research, 2012, p. 1)</p>
<p>Self-Direct Support Initiative in Australia</p> <p>Consumer directed care (CDC) and consumer directed respite care (CDRC) was introduced by the Australian Government in July 2010.</p> <p>Consumer Directed Care was introduced to all new Home Care Packages in 2013.</p> <p>Since July 1 2015, both new and existing Home Care Packages are delivered using the CDC model.</p>	<p>Key Characteristics</p> <p>Providers must offer consumers:</p> <ul style="list-style-type: none"> • More choice and flexibility • Support to access relevant information and make informed decisions on the care that is best for them • A partnership approach and better-quality participation • Wellness and reablement, and • Greater transparency <p>Providers are required to:</p> <ul style="list-style-type: none"> • Have conversations about their consumers’ needs and goals • Co-produce care plans • Provide greater transparency to consumers about what

(Aged Care Online, 2016).

funding is available under their package of care and how those funds are spent

- Agree with the consumer the level of involvement they will have in managing their package, and
- Conduct ongoing monitoring and a formal reassessment to ensure that the package continues to be appropriate for them

3. Benefits of self-directed support

Self-directed supports are noted to have benefits for older people, their family, carers and for health and social service organisations. A core goal of self-directed supports is to improve the quality of care for older people by enabling them to exercise choice and control over the care they access. A review of a self-directed support trial in Scotland noted that:

“the most widely mentioned, and for many fundamental benefits for clients and family carers alike concerns the **flexibility and control** that SDS afforded them over their care arrangements. ... [this] enabled [older people] to exercise choice over how their care was delivered. It also enabled them to **make decisions** about what they did or did not do, reflecting in the process their judgement regarding what was desirable, fulfilling and safe.” (Scottish Government Social Research, 2008, p.57)

Additional benefits noted in this Scottish trial included:

- The quality of care provided by Personal Assistant’s was regarded as exceptional. This underpinned the ability of self-directed support to deliver some of the wider benefits commented upon by clients, such as choice and independence.
- Self-directed support enabled clients to continue to live their lives largely as they wished, making decisions about what they did on an hour by hour basis, without having to follow other people’s timetables or fixed routines. Clients retained a sense of their own identify and place in the world that reaffirmed their self-worth.
- Self-directed support enabled families to stay together and family carers to be able to continue in their caring role. Being confident about the quality of delivered care and being able to retain, but share, their caring role left most feeling valued and supported (Scottish Government Social Research, 2008, p.58).

An evaluation of a consumer directed care initiative in Australia highlighted older people’s increased satisfaction with their:

- ability to participate in social and community activities
- quality of home life and close relationships
- ability to visit family and friends
- health and well-being (KPMG, 2012, p. 10)

3.1. Self-directed support can be cost effective and does not cost more than other service models

Literature reviewed for this report yielded limited evidence regarding the return on investment associated with self-directed support initiatives. According to KPMG (2012), European and American studies of consumer directed models of care demonstrate that where the care model is based on a direct payment system, consumer directed care is

more cost effective than agency-directed models. Cost effectiveness occurs as a product of reduced labour costs associated with direct employment of support workers and a reduction in agency case management costs.

The Scottish Government Social Research Unit (2012) reported that there is no evidence to suggest that self-directed support is more costly than other options for delivering social care services.

4. Characteristics of Successful Initiatives

In 2009, Ottmann, Allen & Feldman, published a critical review of a series of cash for care and self-directed support initiatives largely trialed and/or delivered in the United States or United Kingdom to inform the development of an initiative in Australia. In this section, we draw on the recommendations from this review, coupled with characteristics of the Scottish and Australian initiatives introduced in section two, to highlight characteristics deemed necessary for a successful self-directed care initiative. These characteristics can also be considered best practice in regard to the way a programme should be implemented.

Table 4.1. Characteristics of Successful Self-directed Support Initiatives	
Programme Design Features and Process	A system-wide focus that addresses systemic, educational, and cultural concerns as well as community involvement issues.
	Eligibility criteria should include and enable older people to engage in self-directed care. Eligibility should be regarded as a process where older people are aided by social care professionals to construct the necessary safeguards and support structures that enable them to direct their own care arrangements. Age and mental health status should not in themselves be sufficient criteria for inclusion or exclusion from self-direction.
	Choice - Older people should be able to choose from a range of service options including traditional agency-led services and self-directed care options and have the flexibility to alter their choices as their needs change.
	Consultation throughout design and delivery – older people and other stakeholders should be consulted throughout the design and change process and in an on-going manner as part of delivery practices (Scottish Government Social Research, 2008, 2011; Audit Scotland, 2014b). As described by Geekie and Fraser (2013, p. 36) “[E]ngagement with local communities and their ownership of the agenda and experience of the outcomes will be critical in judging success”.
	A programmatic review and continuous improvement process should be in place to improve care outcomes.
Case Management Approach	Organisations need to provide holistic, single-point-of-contact, family-focused case management services.
	Case managers should explore the interests and perspectives of older people, encouraging them to set goals and priorities and translate them, where appropriate, into self-direction.
	Good practice case management is based on:

	<ul style="list-style-type: none"> • An authentically implemented culture of person-centred care and planning; • An ongoing and mutually respectful relationship; • The principle that case managers are facilitators of the control and decision making of care recipients and their families; and • A cooperative approach including the interests of informal carers and families (Ottmann, Allen & Feldman, 2009).
Information and Communication	Older people need to receive simple, clear informational aids to help them understand their programme options and responsibilities and to help them develop and implement their care plan.
	Information needs to widely available and available in multiple formats , with resources available for individuals with differing needs (Scottish Government Social Research, 2011). Examples such as information provided in multiple types of written format (e.g. leaflet, web based) have been used. As have resources aimed at people with impairments such as large font resources or information provided in braille (Getting There, 2017).
	Staff should use applied examples when providing information.
	Case managers should check, not assume , that information has been understood.
	Communication needs to be clear between service providers (be they health professionals or others) and informal carers such as family/whānau members, peers, or others (Audit Scotland, 2014b).
Training	Where older people are to take over care coordination functions, or contractual and financial responsibilities, they must receive full training and support in these activities, with regular monitoring.
Risk Management	Well-designed and clear policies on risk management, duty of care, and client review procedures that balance agency and worker responsibilities with the self- determination aspirations of their program and its participants
	Older people and especially those who are frail, and/or socially isolated should have access to adequate safeguards .
	An enabling risk management process may be necessary to balance client's risk and protective factors and determine appropriate social supports.
	A 'circle of support' programme as well as peer and volunteer support should be considered when care recipients prefer less agency involvement.

5. Obtaining buy-in from decision-makers

The HCHA is interested in understanding best practice in regard to obtaining buy-in for self-directed care initiatives from key decision-makers in the sector and from public sector personnel. This topic was not explicitly covered in the literature reviewed. However, it is notable that in the United States and United Kingdom self-directed care

programmes were initially a product of many years of lobbying by the disability sector with an emphasis on self-determination, human rights and consumer rights arguments. Highlighting the importance of delivering on human rights and self-determination in the care of older people may be a useful approach to garner support from key decision-makers for self-directed care.

In Scotland and Australia trials have shown improved outcomes for older people and their carers, with either no impact on cost or a reduction in cost due to reduced labour and case management costs. These trials have likely contributed to gaining buy-in from decision-makers regarding the benefits of self-directed care for older people.

Further to this, the literature has identified a range of areas of concern in regard to self-directed care and potential pitfalls in the design and delivery of initiatives. It would be important to address these issues carefully with decision-makers to allay their concerns and demonstrate plans to mitigate risks [See section 7 below].

In regard to gaining buy-in from the community more broadly and those with the capability to champion and campaign for change, it is important to focus on the merits of self-directed care to improve the quality and appropriateness of care provided to older people first and foremost. Otherwise self-directed care may be viewed as simply a cost-saving opportunity for governments (Audit Scotland, 2014b).

If a trial or new programme is to be developed, regular and continued consultation throughout the design and change process including clear reasons why the change is being introduced is important to achieve buy-in (Audit Scotland, 2014b). Further to this, when attempting to make cultural and systemic change of the scale like those involved in implementing self-directed support, strong leadership is vital to ensure that the change management process is run effectively (Scottish Government Social Research, 2011; Audit Scotland, 2014b).

6. Measures of success

The literature reviewed did not provide detailed information about the measures used to understand the success of self-directed supports. Publications reporting on the Scottish and Australian trials offer some insights included below (KPMG, 2012) (Audit Scotland, 2014b).

Benefits to older people and carers

- Better quality of life for individuals;
- The extent that CDC enhances community-based care for care recipients and carers
- The extent that CDC is person-centred
- How does CDC increase consumer choice and control?

Take-up of service

- Radical increase in the uptake of Self-directed supports and direct payments;

Equity and Cost

- Is CDC equitable and providing value for money?

Infrastructure

- A sustainable network of advocacy and peer support organisations;
- A sustainable network of independent support organisations for training and supporting personal assistants;
- A proficient body of trained, experienced personal assistant employers;

- An appropriate workforce of trained personal assistants, with regulated employment conditions; and
- Improved partnership working between people receiving support, public bodies and third and private sector providers

7. Potential pitfalls areas of extra support/need

A range of potential pitfalls to plan for and avoid when designing and delivering self-directed care initiative and areas where extra care or attention may be required have been identified.

A lack of partnership between groups working to implement changes in the procurement structure.

This was a particular point of friction in the Scottish initiative, as terms of the new procurement structure were not implemented as designed and the traditional structure of care continued to be offered in preference to new options (ScottishCare, 2015). The priority should be on all parties working together to move towards a new procurement approach and placing the older person at the centre of the process. Further to this, the New Zealand Productivity Commission report (2015) on More Social Services highlighted that new approaches to commissioning and contracting and good performance monitoring would be required for home-based support for older people.

Accuracy of personal budget

Research shows that the process for personal budget allocation needs careful consideration. In some countries where personal budgets are used, an indicative budget is allocated to an individual before a complete assessment of needs has been completed. Following the assessment, a revised budget is confirmed and the difference allocated. In some cases, the difference in pre- and post-assessment funding are large. An underpayment may compromise an individual's ability to provide themselves with adequate care services (Audit Scotland, 2014b), while overpayments pose a financial risk to funders and governing bodies (Slasberg et al, 2012; (Audit Scotland, 2014b).

Elder abuse

As self-directed support programmes typically include direct payments, personal budgets and individual funding models, concerns may be raised about elder abuse. It is important that effective safeguards are put in place that balance client's choice and control with protection and monitoring to ensure elder abuse and misappropriation of funds does not occur (Social Care Institute for Excellence, 2010; New Zealand Productivity Commission, 2015).

Change management to address aged care professionals' concerns

Extensive organisational change management prior to implementation of self-directed care initiatives is needed to identify and address the concerns of aged care professionals. These concerns may include: abuse, neglect, fraud, exploitation, contractual agreements, as well as the capacity of older people; and realistic workload assessments

Access to specialist services and choice for older people in rural communities

When designing and delivering self-directed care programmes, attention must be given to issues facing older people living in rural communities. These older people may have limited access to particular types of services, especially specialist services and carers who can provide culturally and/or linguistically appropriate care. In rural areas, older people may face a lack of choice due to a limited market for providers (University of

Auckland, 2011; Scottish Government Social Research, 2011, Audit Scotland, 2014b; KPMG, 2012; Scottish Government Social Research, 2010).

Lack of trained staff, turnover of staff

Self-directed care initiatives may be hampered by a lack of trained social care staff in the industry, including initial training and ongoing professional development and management support (New Zealand Productivity Commission, 2015). Low wage levels in the care sector is a perennial issue that will require attention (Audit Scotland, 2014b; New Zealand Productivity Commission, 2015; Scottish Government Social Research, 2010).

Administrative burden for older people

Self-directed care programmes need to be designed with the intention of supporting older people's choice and control over their care arrangements. In step with this, it is important that older people are not burdened with unwanted responsibility and administrative tasks around budgeting and procurement of services. The overall programme structure must be simple and comprehensive, requiring a minimum of paper work (Ottmann, Allen & Feldman, 2009).

Self-direction in times of crisis

Self-directed care should not be offered during times of crisis. In recognition of fluctuating health conditions and changing circumstances, older people should be able to move flexibly between self-direction and full case management as needed (Ottmann, Allen & Feldman, 2009).

Findings from Waitemata DHB proposed self-directed care initiative survey

In New Zealand Waitemata DHB proposed an individualised funding programme where following a needs assessment, a client receives money from the MOH and DHB to purchase the services they need themselves (Waitemata District Health Board, 2013). Findings from the feedback on this proposal were summarised as follows by the New Zealand Productivity Commission (2015, p. 8).

Comments in favour of proposal

- An opportunity for clients and their families/guardians to organise and manage their care in a way that most appropriately suits their needs
- Clients enjoy the flexibility and ownership that individualised funding brings
- Individualised funding fits in with clients' lifestyle and makes them feel empowered to make their own choices

Concerns and other comments

- Most likely to work for those who have strong support networks and require flexibility
- Older people with multiple conditions are unlikely to be willing to organise and manage their own care
- Could be easily open to abuse by family, guardians and others involved
- A robust monitoring system needs to be in place
- Needs clear guidelines and access criteria
- Practical issues such as how clients find a replacement when their regular worker is away
- Educating clients on how individualised funding works is critical

8. Research Gaps

In order to understand how self-directed care could operate for older people in the New Zealand context, trials of initiatives with robust evaluations are necessary. These trials need to include models of restorative care where older people are supported to make choices about their care. To understand self-directed care in its fullest sense, it is necessary to undertake research about older people's desire to be involved in managing and purchasing their care, what is required to support older people in this role and what impact this participation in care decision-making has on older people's well-being.

In addition to research with older New Zealanders in general, it is important that we consider the way in which cultural values may shape older people's experience of care and their take up of self-directed care opportunities. Research and trials with robust evaluation that investigate how self-directed supports can be offered within the context of Te Ao Māori to meet the needs of kaumātua and their whānau are necessary. Similarly, there is a need for research around the application of self-directed support for older Pacific people.

Information about international initiatives is also relatively limited, with recent initiatives in Scotland and Australia providing the best examples. These initiatives both began with trials, which were evaluated, albeit with limited reporting of success indicators including return on investment. If trials were undertaken in New Zealand it would be imperative to include clear indicators of success ranging from measures that indicate:

- the effect of self-directed care on older people's access and utilization of care
- the effectiveness of this care
- older people's own experiences of wellbeing (not simply physical health)
- the experience of carers operating within a self-directed support delivery model
- the experience of family members and their perceptions of their older family member's care and wellbeing
- the cost associated with self-directed support and the broader return on investment

To gain a deeper understanding of the benefits of self-directed care, success factors of initiatives and potential pitfalls, it may be prudent to investigate literature from the disability sector where these models of service delivery have been in action for a longer period of time and are more widespread, including in New Zealand.

In sum, New Zealand's healthcare system is currently focused on improving integration, communication between providers and offering care in the community to support older people's independence and meet their health care needs. New Zealand's healthcare strategies and service delivery models do not currently extend to offering older people choice and control in the selection, procurement and management of care services. International examples of self-directed care have demonstrated benefits for older people, their carers and organisations providing services and these benefits have not come at an additional financial cost. Self-directed supports as a service model for healthcare of older people is in its infancy. In New Zealand, more emphasis on older people's right to self-determination as key to their wellbeing and meeting their changing needs is required to pave the way for self-directed support initiatives to emerge.

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