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Perspectives of Self-Direction: A systematic review of key areas contributing to service users' engagement and choice-making in self-directed disability services and supports

Abstract

Self-directed disability support policies aim to encourage greater choice and control for service users in terms of the health and social care they receive. The proliferation of self-directed disability support policies throughout the developed world has resulted in a growing amount of research exploring the outcomes for service users, and their families and carers. Our understanding of the issues faced by people with disabilities, particularly how they make health and social care decisions and the key areas that determine their engagement with service providers within a self-directed environment is limited. A synthesis of research is timely and can provide knowledge for service-users and health and social care support providers to ensure their successful participation. A systematic review guided by the PRISMA approach explored (1) the key areas determining service users' engagement with self-directed disability services and supports, and (2) how service users' make informed decisions about providers. In October, 2014, and April 2016 three databases —MEDLINE, CINAHL and Web of Science — were searched for research and review articles. Eighteen sources met the search criteria. Findings were mapped into either: key areas determining service user engagement, or service users' informed decision making. Findings concerning key areas determining engagement fell into three themes—personal responsibility for budgeting, personalised approaches, and a cultural shift in practice and delivery amongst service providers. Findings about decision-making yielded two themes— supporting informed decision making and inhibiting informed decision making. Literature suggests that self-directed models of care may provide service users with increased control over the services that they receive. Increased control for some service users and their families requires independent external decision making support, particularly around the domains of budgeting, planning and hiring. Future research must continue to investigate the

perspectives of service users pertaining to their engagement, as their participation is central to the effectiveness of the approach.

Keywords: self-directed policy, disability, health and social care, informed decision making

What is known about this topic

Self-directed disability support policies are more frequently being enacted to encourage a greater level of choice and control for service users.

Ensuring successful service user and health and social care provider participation within self-directed environments is a complex process that requires adjustments to the ways disability health and social support is offered.

What this paper adds

Service users' make service provider decisions based on familiarity with the provider, flexibility in the provider approach and service users experiential knowledge.

Dedicated independent advisory boards and support officers that provide budgeting, planning and hiring support will benefit some service users throughout their engagement with self-directed policies.

Introduction

The belief that people with disability are capable of determining their own life choices—including where and with whom they live, how they support themselves and what they aspire to achieve—is relatively recent. The rise of the disability rights movement in the United Kingdom and the United States during the 1960s, and later in other countries such as Australia and New Zealand during the 1970s, prompted a wave of new thinking about services for people with disability (Berger 2013, Oliver & Barnes 2012).

Historically, services for people with disability had largely been premised on the belief that they needed to be sequestered in institutions, away from mainstream community life. Their social exclusion meant they had limited education and even more limited employment prospects, which in turn resulted in their economic exclusion (Borsay 2005).

However, the shift to community based living options following the closure of large scale, segregated institutions in most western societies during the 1980s and 1990s did little to ensure the full social and economic participation of people with disability in their mainstream communities (Carling-Jenkins 2014). The rhetoric of inclusion was not always matched by the real-world results. Instead of liberating people with disabilities into their broader society, economy and culture, many community based services continued to congregate, segregate and isolate people with disability. Too many people with disabilities were still not given real choice, or voice, in where they lived or with whom they lived.

Self-direction aims to enable people with disability to control and manage the resources for their support, and make their own choices about the services they engage with (Espiner & Hartnett 2012, Gross *et al.* 2013, Eriksson 2014). The origins of self-direction models can be traced to the rise of the ‘independent living movement’ in the United States during the 1970s (Gross *et al.* 2013, Sims & Cabrita Gulyurtlu 2014). The most rapid developments in personalised approaches to health, disability and social care services—providing more flexibility and greater choice and control for service users—have occurred in the last decade (Sims & Cabrita Gulyurtlu 2014). This is evidenced by recent legislation across a variety

of developed countries including the National Disability Insurance Scheme Act (2013) in Australia, the Social Care (Self-directed Support) (Scotland) Act 2013, and the National Health Service (Direct Payments) Regulations 2013 in the United Kingdom.

Several recent literature reviews have canvassed the outcomes of self-directed, personalised approaches to service delivery for people with learning disabilities (Harkes *et al.* 2014b, Sims & Cabrita Gulyurtlu 2014) and people with other disabilities, who have significant support needs (Crozier *et al.* 2013). One study has suggested that shared decision-making about personal support, care and treatment—including personal management of their health budget— can result in improved care-related quality of life and psychological wellbeing, together with some cost-savings to the government (Jones *et al.* 2013). While the potential for positive outcomes for people with disabilities within a self-direction framework is increasingly recognised within public policy and research, these studies also note the risk of an increased vulnerability of people with disability, specifically if they do not have the right supports to control their budget and autonomy (Jones *et al.* 2013, Sims & Cabrita Gulyurtlu 2014).

Despite widespread support for the concept of self-directed models, the variability in research findings raises important questions about the implementation of self-directed approaches, and there remains some level of ambiguity about important self-direction concepts such as choice and control. Specifically, reviews synthesising research exploring the implementation and outcomes of self-directed approaches for people with disabilities up until 2011 (Harkes *et al.* 2014b, Sims & Cabrita Gulyurtlu 2014), and 2012 (Crozier *et al.* 2013) have emphasised that limited research in the area exists, and as a result it is difficult to ascertain the perspectives of service users and professionals about self-directed approaches to service provision, and how self-directed approaches impact the health and social care of service users. For example, Crozier *et al.* (2013) reviewed the impact of self-directed care systems and models for people with disability over a 12 year period, 2000-2012. The authors found that the implementation of self-directed approaches was variable, but more importantly, that the unique views of service users were not well understood. Similarly, outcomes of reviews into personalisation and self-directed support for people

with intellectual disabilities (Harkes *et al.* 2014b, Sims & Cabrita Gulyurtlu 2014) have found minimal empirical research relating to the impact of self-directed support programs for such groups.

Consequently, our understanding of the issues faced by people with disabilities, particularly how they make health and social care decisions (Mitchell 2012b, Harkes *et al.* 2014a, Mitchell 2014a) and the key areas that determine their engagement with service providers within a self-directed environment (Harkes *et al.* 2014b) remains limited.

There has been greater uptake of self-directed models for disability health and social care service and publication of research studies since earlier reviews, and since the roll-out of the National Disability Insurance Scheme in Australia and the Social Care (Self-directed support) Act in Scotland. An up-to-date review of self-direction research may provide more detailed evidence and insight into service user and professional perspectives of self-directed programs beyond findings reported by earlier studies. Findings from this review will potentially facilitate a deeper understanding of engagement with self-direction from the perspective of user groups and provide further insights into how service users come to make informed decisions about choice and control of their support services.

Review Aims

This review aims to synthesise findings from to most recent self-direction literature to answer the following questions:

- 1.) What key areas determine service users' engagement with self-directed models of health and social support?
- 2.) How do self-directed service users make informed-decisions and choose their service providers?

Methodology

Given rapid advances in self-direction policy and practices for people with a disability, this systematic review summarises original peer-reviewed research articles and reviews in self-direction published over a four year period between 2012 and April 2016. It employs the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) approach (Moher et al., 2009). This review builds on the three earlier systematic and scoping reviews of research in self-direction conducted between 1996-2012, which were published throughout 2012-2014 (see Harkes, Brown, and Horsburgh, 2012; Crozier, Muenchberger, Colley and Ehrlich, 2014; and Sims and Cabrita Gulyurtlu, 2014).

Two systematic searches for literature were conducted. The first search was conducted on 29th October 2014 to identify literature published between 2012 and 2014. The second search was conducted on 14th April 2016 to identify literature published between 2014 and 2016. For both searches, three databases, MEDLINE, CINAHL, and WebOfScience were searched using the string, 'disab*' and ('self-deter*' OR 'self-direc*' OR 'client-cent*' OR 'consumer-direc*'). (No definitions or limitations were provided for the term 'disability'). Database results were downloaded into Endnote and duplicates removed by matching title and author. After removing duplicates, a single researcher read the titles and abstracts of each article in consecutive rounds. Articles were included for a full review if they explored the perspectives of service users, their family and/or their carers in (a) evaluating or (b) providing their opinions about self-directed support programs or aspects of self-directed support, for example, choosing health providers. Articles were also included for review if they synthesised research focusing on the perspectives of carers, service users and families arising from their experiences of, and engagement with, a particular self-directed support program. The review excluded articles if they were (a) not peer-reviewed, (b) unavailable in the English language, or (c) a commentary or description of a self-directed system or model without user, carer or family member perspectives.

Results

A flow chart detailing the number of articles retrieved and reviewed at each stage is shown as Figure 1. A search of the literature within the study timeframe initially provided 1222 articles; after removing duplicates, 927 articles remained. This selection was reduced to 131 articles after reviewing the titles and omitting articles that did not meet inclusion criteria. A review of the abstracts based on the same search criteria resulted in 24 articles for full review. No articles were removed after a full text review of the articles identified during the October 2014 search, leaving 12 for inclusion in the review. Eight articles were removed after a full text review of the articles identified during the April 2016 search, leaving 4 for inclusion. Forwards and backwards searches were conducted on 9th December 2014, for the articles identified during the October 2014 search. After forwards and backwards searches, two articles were considered relevant for inclusion. Consequently, a total of 18 sources met the review criteria.

Characteristics of Studies

The key information from each of the 18 articles in this review has been included in Table 1. Eleven research papers included studies from Australia (Dew *et al.* 2013), Finland (Eriksson 2014), New Zealand (Espiner & Hartnett 2012), Germany (Junne & Huber, 2014) the United Kingdom (Mitchell 2012a, Mitchell 2012b, Mitchell 2012c, Kendall and Cameron 2014, Mitchell 2014b) and the United States (Heller *et al.* 2012, Gross *et al.* 2013, Timberlake *et al.* 2014, Lombe *et al.* 2016, Swaine *et al.* 2016). Six of the research papers included the perspectives of carers or stakeholders involved with supporting care services, family members, and/or service users (Espiner & Hartnett 2012, Mitchell 2012a, Gross *et al.* 2013, Eriksson 2014, Junne & Huber, 2014, Kendall and Cameron, 2014, Mitchell 2014b, Mitchell 2014a, Swaine *et al.* 2016). Three of the research papers included perspectives of family members or caregivers (Heller *et al.* 2012, Mitchell 2012b, Timberlake *et al.* 2014); one included the perspectives of a combination of family members or caregivers and service providers (Dew *et al.* 2013); and two articles

explored the perspectives of service users who had support from parents or guardians when necessary (Mitchell 2012c, Lombe *et al.* 2016). Six of the eleven research articles (Mitchell 2012a, Mitchell 2012b, Mitchell 2012c, Mitchell 2014b, Mitchell 2014a, Timberlake *et al.* 2014) focused specifically on self-directed policy for young people with disability. The three review articles aimed to synthesise research from the perspectives of program administrators and service users, and placed findings within the context of government and service delivery policy in the United Kingdom (Harkes *et al.* 2014b, Sims & Cabrita Gulyurtlu 2014), and Australia (Crozier *et al.* 2013, Harkes *et al.* 2014b). Finally, four sources focused on self-directed policy for people with developmental or intellectual disabilities (Heller *et al.* 2012, Espiner and Hartnett 2012, Gross *et al.*, 2013, Eriksson 2014), three for people with learning disabilities (Mitchell, W. 2012b, Harkes *et al.* 2014, Sims & Gulyurtlu, 2014), three for people with disabilities with degenerative conditions (Mitchell, W., 2012c, Mitchell, F., 2014a, 2014b), four for groups with a variety of disabilities (Mitchell, F., 2012a, Dew *et al.* 2013, Crozier *et al.* 2013, Junne & Huber, 2014, Kendall and Cameron 2014, Lombe *et al.* 2016, Swaine *et al.* 2016), and one for people with autism (Timberlake *et al.*, 2014).

Data Analysis

This review aimed to synthesise findings from recent research about user perspectives of self-directed services and support; in particular, (1) what key areas facilitate service users engagement with self-direction, and (2) how service users and their carers make informed decisions and select service providers. The data analysis software NVivo was used and all full text manuscripts included in this systematic review were treated as sources for coding. Data analysis involved two phases. Initially findings were broadly categorised into two categories aligning to each research question: first, key areas impacting engagement, and second, service users informed decision making and selecting of service providers. Following, findings relating to each research question were reviewed in depth and findings grouped into common themes using an inductive approach (Elo & Kyngäs 2008, Hsieh & Shannon 2005).

In response to the first research question about service users' engagement with self-directed systems of service delivery, analysis of the reviewed literature found three key areas, namely personal responsibility for budgeting, personalised services, and a cultural shift in practice and delivery. Underpinning each key area were potential issues for service users and distinct aspects that may have an impact on their engagement. In response to the second research question about how service users and their families select health and social care providers, analysis of the literature revealed attributes which support informed-decision making, and attributes which inhibit informed-decision making. Underpinning each of the themes were distinct aspects, which were demonstrated as positively contributing or negatively contributing to making choice. Figure 2 provides an overview of the themes and subthemes identified through the data analysis process. The themes and subthemes identified are discussed in detail in the following section.

Finally, the methodological quality of studies included in this review were appraised using the Mixed Methods Appraisal Tool (MMAT) (Pluye *et al.* 2011). The MMAT supports the appraisal of quantitative, qualitative and mixed-methods studies for systematic reviews. Studies are scored against a set of criteria using dichotomous responses: 1 for 'yes' or 0 for 'no'. The grading criteria is specific to study design, for example, descriptive quantitative studies and interpretive qualitative studies each have their own distinct grading criteria. The methodological quality of studies in this review were appraised using the MMAT by both AL and DM and an interrater reliability score was obtained through the percentage method (McHugh 2011). The percentage method provides a percentage value representative of the number of uniform response across researchers, and is appropriate when aiming to obtain interrater reliability of two researchers that utilise a grading scale employing dichotomous responses options. Within this study the percentage of uniform responses across researchers was 85%.

Personal Responsibility for Budgeting

Self-directed services aim to involve people with disabilities and/or their families or carers in planning, managing and organizing their budgets and supports (Espiner & Hartnett 2012, Gross *et al.* 2013, Eriksson 2014). Service users and carers may become involved in the hiring, training, and firing of support staff, organizing resources and developing the budget (Gross *et al.* 2013). The direct assignment of an agreed amount of funding to people based on their personalised plans (rather than as block program funding grants to non-government service provider-organisations) arguably promotes that person's control and agency in decisions affecting their life (Eriksson 2014), and can result in favourable health and wellbeing outcomes. Studies within this review support this perspective (see Gross *et al.* 2013, Lombe *et al.* 2016, and Swaine *et al.* 2016). For example, Gross *et al.* (2013) explored the experiences of adults with significant intellectual and developmental disabilities and their carers who were supported to set their own budgets and manage their supports and services. Their study found that service users and their carers used their flexibility to make more cost-effective decisions in their choices about the design and delivery of their services—for example, they might opt to employ family and friends. For service users with an intellectual and/or physical disability interviewed by Swaine *et al.* (2016), the consumer directed program provided them with 'greater flexibility with their schedule and more control of their services, such as hours of support and whom they could hire' (p.4). Additionally, fifty percent of service user participants indicated that their participation resulted in higher levels of independence, and freedom, and almost half of the participants indicated that their participation impacted their health favourably. Similarly, Lombe *et al.* (2016) explored the perspectives of service users engaging in a consumer-directed support program where budgeting was central. While the program did not cover all of the resources identified as important by participants, over ninety percent of respondents indicated that the resources purchased through the self-directed support program favourably impacted their quality of life.

On the other hand, carers have also identified planning and budgeting within the self-directed model as a challenging process (Crozier *et al.* 2013, Dew *et al.* 2013, Junne & Huber 2014, Kendall and Cameron 2014, Timberlake *et al.* 2014) where participants might be exposed to risks (Junné & Huber

2014). Budgeting in self-directed environments has been characterised as pressure-filled due to the intensive, time-consuming work required. Additionally, it has been described as stressful for decision makers as they have a personal awareness of the impact their decisions have on the lives of service users (Gross *et al.* 2013). Some service users and carers report that they have been making decisions and navigating the service system on their own without training or support (Dew *et al.* 2013, Gross *et al.* 2013, Junne & Huber 2014, Sims & Gulyurtlu 2014). On occasion, the recommended time periods by which budgets were meant to be exhausted has been minimal and as a result, money may have been used ineffectively (Dew *et al.* 2013). Some participants within self-directed programs carry a risk of liability as they are being held financially accountable for money, which was spent in a way that was not approved by the agencies distributing payments (Junne & Huber 2014). While planning and organisation processes might ease over time (Dew *et al.* 2013, Junne & Huber 2014), Harkes *et al.* (2014b) caution that such complexity may 'place vulnerable people at risk of abuse or exploitation' (p. 97). For example, some participants have indicated that the budgeting supported by care organisations may be a mechanism to ensure cost-cutting and potentially limit service users' choice and control (Kendall and Cameron 2014). In contrast, self-directed approaches have been identified as advantageous to service users who have the support of family or carers, are from middle-class backgrounds, and who have education which supports their ability to navigate such complex funding environments (Dew *et al.* 2013).

The ability to self-budget may also affect the quality of service being offered, for better or for worse (Crozier *et al.* 2013). Personalised budgeting allows service users or their carer or parents to negotiate the level of wages for support. This may allow service users to pass on a greater amount of payment to those who are providing services, compared to the agency-delivered approach (Crozier *et al.* 2013). For some service users this flexibility has resulted in a higher quality of service with less staff turnover (Crozier *et al.* 2013). For example, the re-identification of service users as consumers, may result in providers of health and social care providing support of a higher standard (Kendall and Cameron 2014). While this is encouraging, other literature shows that the personal budgeting approach may have adverse impacts such as lower service quality (Junne & Huber, 2014, Sims &

Cabrita Gulyurtlu 2014, Swaine *et al.* 2016) as a result of employing un-credentialed or unqualified carers working within unregulated environments (Mitchell 2012a). For example, some participants have indicated that it is difficult to undertake a supervisory role while also being the recipient of services, and that some hired persons did not perform their job in a reliable manner (Swaine *et al.* 2016). This is especially so when participants feel as though they have been under budgeted for their support needs and so, due to financial constraints, they are forced to employ ‘unqualified staff as care assistants’ (Junne & Huber, 2014, p.639).

Personalised Services

Recent literature characterises the self-directed approach as supporting personalised service delivery. This is in contrast to the traditional approach where organisations provided a limited range of services and activities scheduled in a fixed, non-negotiable timetable to a group of people. This in turn serves to institutionalise service users and sustain dependency (Oliver & Barnes 2012). Service users have suggested that the self-directed approach must ensure the development of extra-curricular activities that align with their interests and aspirations, and a greater choice in these activities (Espiner & Hartnett 2012, Gross *et al.* 2013, Eriksson 2014). Traditional extracurricular activities offered to service users with significant support needs have been characterised as dull and unvaried (Espiner & Hartnett 2012, Gross *et al.* 2013) and a self-directed approach has been identified as a means to positively address this issue. For example, Espiner and Hartnett (2012) explored the perspectives of service users—adults with an intellectual disability—and families about a soon-to-be implemented self-directed program in New Zealand. Their research results emphasized the importance of effectively facilitated meetings (including the use of assisted communication strategies) for the service users to express their aspirations, including employment related goals. Planning meetings enabled service users to discuss the activities and goals they would like to take part in and achieve, and how their specific plan could encourage such possibilities. Similarly, Eriksson (2014) explored the perspectives that service users (people with intellectual and developmental disabilities and physical disabilities), their families and support staff had about a pilot program that focused on self-direction. Service users expected that such an approach would directly contribute towards their ability

to receive extra-curricular activities that are of interest to them. Families also expected that they would have direct input into the development of such activities (Eriksson 2014). Clearly, from the service users' perspective, their direct involvement in the development of activities and programs is both central to the self-directed approach and a key benefit.

Findings on the ability for self-directed programs to enable participants to engage with services of their choice are mixed. There are positive examples of self-directed funding models where funding was delegated directly to service users who reported that their participation enabled access to services, supports and activities that they may not have otherwise experienced (Dew *et al.* 2013). In contrast, other participants have found that the health and social care programs approved by funding agencies are limited (Junne & Huber 2014). Nevertheless, the tailoring of activities and schedules to match the unique needs of service users, such as adults with intellectual and developmental disabilities, has the potential to provide them with new and diverse life experiences. This in turn opens up new opportunities for them and their families in ways that they may not have previously been aware of or considered, including the option to live away from their parents with support; choose alternative forms of work suited to their skills and interests; and, participate in extracurricular community and volunteer related activities (Gross *et al.* 2013).

A Cultural Shift in Organisation Practice and Service Delivery

Cultural shifts need to take place across organisations, service providers and, indeed, possibly the community in general to ensure a planning culture in where service users with disabilities are at the centre (Eriksson 2014, Kendall and Cameron 2014). Mitchell (2012b) characterises an organisational cultural shift as involving a change in the way that service users are addressed and engaged throughout the self-direction process. This can only be accomplished when organisations shift their culture from institutionalised rigidity to one which allows flexible, diverse, and responsive service delivery approaches (Mitchell 2012a, Eriksson 2014, Kendall and Cameron 2014). At the same time, service provider personnel need to move away from a belief that people with disabilities are unable to

arrange their own services to an empowering belief in people with disabilities (Mitchell 2012a, Eriksson 2014, Kendall and Cameron 2014).

Mitchell (2012b) suggests that service providers and practitioners need to develop an understanding of the distinct family and support structures available for each service user and be clear about the roles and obligations of each person involved in the self-direction process. The literature provides examples of ways to encourage cultural shifts in organisations and among providers' practices. Some participants suggest that a higher level of service user involvement with the entire process could contribute towards a cultural shift amongst service providers (Kendall and Cameron 2014).

Additionally, professional development and training are identified as avenues to support the cultural shift amongst service providers, and furthermore encourage an environment where service users can engage with self-directed support systems (Espiner & Hartnett 2012, Mitchell 2012a). To support service user engagement, practitioners need to be trained on how to gather service user and family perspectives about goals and outcomes, and place their perspectives throughout program delivery (Espiner & Hartnett 2012, Mitchell 2012a). Training should also emphasise the centrality of supporting individual evaluation (Mitchell 2012a), and consider including service users and their carers throughout the facilitator training process as it further aligns with the personalised approach (Espiner & Hartnett 2012). Some carers have indicated that they would benefit from training to better support their clients (see Swaine *et al.* 2016). This is particularly so for participants who have not worked in the area previously, and who were not caring for a family member of whom they had personal knowledge (Swaine *et al.* 2016).

Espiner & Hartnett (2012) found that adults with an intellectual disability benefitted from meeting with an independent staff member, who worked with service users and their families in organizing their plans. Service users reported that these planning meetings provided a space where they were comfortable to express their needs (Espiner & Hartnett 2012). The staff member's role was to facilitate and communicate information in accessible ways, and this included the use of a scrapbook with pictures to help the service users communicate their preferences. The completed plan was also produced pictorially, which supported the service users' ability to refer to their plan and make

appropriate adjustments (Espiner & Hartnett 2012). Similarly, the development of assessment and evaluation tools tailored to service users' unique needs and preferences may ensure that their evaluations are also accounted for (Mitchell 2012a).

In response to the second research question relating to how service users and their families select their service providers, analysis of the literature resulted in several factors that were either (a) supporting informed decision making or (b) inhibiting informed decision making.

Supporting informed-decision making

Parents and guardians who assumed the responsibility of the decision maker for an adult with significant intellectual and developmental disabilities reported that self-directed approaches provided them with greater control, access and choice over their support services (Gross *et al.* 2013). They also reported that while having choice is important, they regarded it as a means to an end; that is, to make sure that service users achieved the outcomes they wanted, including increased levels of independence, improved health and wellbeing, and more inclusive participation in their community (Gross *et al.* 2013).

Diverse factors were found to facilitate choice and decision making among parents, carers and service users. Studies included in this review identified comfortability and competence as both important determinants of how service providers were chosen. Families and service users tended to choose staff based on the service user's level of comfortability and familiarity with the person being hired (Gross *et al.* 2013, Timberlake *et al.* 2014). For example, Timberlake, Leutz, Warfield and Chiri (2014) explored the perspectives of the families of adults with intellectual and developmental disabilities participating in a home-based support services program. Service users engaging with the program were able to hire and provide funding to personal support workers of their choice. Most service users engaging with the self-directed program chose to hire family members as their personal support workers. Their choice was based on having a longstanding relationship with the family member, and being comfortable with that person. The importance of being comfortable with those providing support was also identified by Heller *et al.* (2012). Heller *et al.* (2012) found that caregivers had the

highest satisfaction when their support staff comprised siblings, or friends of the service user—in other words, people with a strong relationship to the service user. Additionally, parents and guardians identified that it was important to find people who had the competence to support their adult son or daughter with a disability (Gross *et al.* 2013). This competence requires that providers administer their work in a way which is personable and flexible, and are able to respond to the dynamic and demanding requirements of their work (Timberlake *et al.* 2014). Consequentially, parents have also reported that they choose practitioners who view their role as more than a job (Gross *et al.* 2013). Developing a relationship with the service user was identified as paramount, and practitioners were hired based on their dedication and ability to develop a relationship with the service user.

Choices made by young people with disabilities and their parents were described as ‘sitting on a continuum where individuals may have zero knowledge and input’ compared to extensive knowledge and input into how decisions are made (Mitchell 2012b, Mitchell 2012c). Some young people with disabilities who make their own health-related decisions report that they prefer to have their parents’ involvement and parental involvement throughout such decisions is a standard practice (Mitchell 2012c). The ability for young people with disabilities, in particular, to make informed choices about their care, support and services is affected by their age and cognitive capacity (Mitchell 2014b).

People who are older and/or have a higher cognitive ability are more likely to take on a greater role in making decisions about their support services. The significance of the decisions made also has an impact on the level of service user control, where big decisions such as medical surgery have required greater parental involvement, while smaller decisions lesser parental involvement (Mitchell 2012c).

Findings from Mitchell (2014b) indicate that a service user’s agency or power to make decisions, together with their social capital, for example family and professional relationships and resources, affect the their ability to make informed choices. The use of professional entities such as an advisory board or dedicated officer or administrator can ensure that accurate information is available to service users (Harkes *et al.* 2014b, Lombe *et al.* 2016). Such entities may provide accessible information to service users, carers and staff through a dedicated help-line, and it is expected this would likely reduce the burden on parents, guardians or friends who provide support. For example, close to eighty

percent of participants within the study by Lombe *et al.* (2016) indicated that the help of a resource consultant supported their budgeting decisions. In addition to dedicated staff providing advice, a support broker (Timberlake *et al.* 2014) may also directly co-ordinate and hire professional support on behalf of the service user and their family. Timberlake *et al.* (2014) found that some families saw the use of a support broker as of great impact on their decision making and planning process. Families benefitted from the support broker and felt as though it supported them in making inquiries and addressing issues that had arisen throughout their son or daughter's life. Given the importance of advocates, support services and an individual's network in terms of an individual's ability to participate in a self-directed system, social workers and other professionals have an important role in to play. Specifically, social workers and other professionals can support decision-making processes by linking people with disabilities and their families to entities that provide support including non-government organisations and advocacy groups (Mitchell 2014b).

Access to support and reliable information also affects informed decision making for people with disabilities (Mitchell 2012c, Harkes *et al.* 2014b, Mitchell 2014a, Mitchell 2014b). Seeking advice and input from trusted people, for example parents (Mitchell 2012c, Mitchell 2014b) or people with similar circumstances, has been identified as an important factor in facilitating choice (Mitchell 2012c, Mitchell 2014a). These trusted people can support decision making by providing information and advice, and emotional support throughout the process (Mitchell 2012c, Mitchell 2014b).

Trusted people who demonstrate confidence in the service user can also positively influence that person's sense of agency and ability to make choices. Adopting a strengths based perspective where the interests and competencies of those requiring support are accounted for and become central to the decision making process may encourage positive outcomes (Mitchell 2014a). In particular, having a family member, carer, friend, or colleague who is competent and that can negotiate effectively may encourage positive outcomes for service users and result in them receiving the services that they desire (Mitchell 2012c). Having access to knowledgeable support has also been identified as a factor that can affect the ability of people with disability to participate in self-directed programs. Harkes *et al.* (2014b) sounds a note of caution for adults with intellectual disabilities for whom self-directed

support is being considered, particularly people without family and friends, and without the capacity to self-direct on their own. They observe that ‘someone close to them must have knowledge of SDS [or] accessing it will be almost impossible...’ (Harkes *et al.* 2014b p. 98).

Developing and fostering experiential knowledge, such as taking the time to visit service providers to learn about their process, has been identified as an important factor contributing to informed choice (Mitchell 2012b, Mitchell 2014a, Mitchell 2014b, Timberlake *et al.* 2014). Mitchell (2012b) aimed to ascertain factors contributing to parents’ ability to encourage their young son or daughter with learning disabilities to make choices. Findings included that the opportunity for young people to ‘experience different options constituting a choice facilitated [their] increased levels of involvement’ (Mitchell 2012b p.1564). Specifically, young service users’ ability to visit a facility or place of study provided them with a better knowledge to make their choice, while also encouraging their parents to acknowledge their opinion and discretion in making a choice. For some service users, experiential knowledge gained through self-directed programs contributed towards their independence, and affected their feelings of confidence favourably (Junne & Huber 2014). Experiential knowledge is also important for the parents or guardians of service users. For example, experiential knowledge has been integral for parents and guardians of children with autism in informing their selection of service providers (Timberlake *et al.* 2014). Parents’ observations of support staff interactions and support towards their children with a disability was identified as a factor in their decision making process and, at times, is given greater importance than the support staff’s qualifications (Timberlake *et al.* 2014).

Inhibiting informed-decision making

The literature also identified a variety of factors that inhibit informed-decision making for parents, carers and service users. Limited access to accurate information and advice has been repeatedly highlighted as a barrier to informed decision-making and service selection amongst service users, family members and support staff (Mitchell 2012a, Dew *et al.* 2013, Harkes *et al.* 2014b, Mitchell 2014a, Mitchell 2014b). For example, in a secondary analysis of qualitative data from young people

with disabilities and their parents, Mitchell (2014b) found that most professional advice provided to service users was inaccurate and conflicting. Some service providers have yet to adapt their information in accessible ways (Harkes *et al.* 2014b, Mitchell 2014a). Inaccessible information can be problematic as it can result in service users making poor decisions about funding due to a lack of information, or inaccurate information and this can result in service users spending resources unnecessarily (Dew *et al.* 2013). Unfortunately, even when information is developed in accessible formats, some service users find that the information is not useful and suggest that experiential knowledge remains more effective (Mitchell 2014b).

People with self-managed packages who live in rural and remote areas face greater barriers and complexities than their metropolitan counterparts, impacting their ability to make informed decisions (Dew *et al.* 2013, Mitchell 2014a). Barriers include inadequate information, limited local services, higher costs (for example, those incurred by additional travel expenses, which are not always adequately compensated), and the complexity of self-managing their packages (Mitchell 2012a, Dew *et al.* 2013). For example, Dew *et al.* (2013) found that the option of flying in specialist staff to rural and remote areas has high costs pushed onto the service users. Furthermore access is made more difficult, and a legitimate form of informed decision making not possible when service users within remote settings find their choices are limited to services on a government 'approved provider' list (Dew *et al.* 2013).

Parents, guardians and carers, and many other support staff involved in self-directed support programs assume several roles which may have a considerable impact on the service users' decision-making processes and outcomes. Given the significance of those decisions and the closeness of some of the relationships, internal conflicts—including family conflicts—can be a barrier to quality decision making (Mitchell 2012a). For example, conflicts may arise if a service user believes their parents are not listening to their wishes about choices and decisions that affect their life (Mitchell 2012c). Additionally, the expectations of service users may differ from their parents or guardians, which in turn affects family relationships (Mitchell 2012a). A 'best practice' approach to resolve the question of who has choice and control within the family using self-directed services (Mitchell F., 2012a) is

needed. Similarly, conflicts of interest may also potentially arise between service providers on the one hand and service users or their family and carers on the other hand (Espiner & Hartnett 2012). For example, the providers of services and supports may also be involved in the planning of service users' support (Espiner & Hartnett 2012). This dual role of service planning and delivery by support personnel presents a barrier to authentic, autonomous decision making by the service user. The impact of this potential conflict of interest can be alleviated by having an independent staff member who works specifically with service users and their families to plan and organise the services they need (Espiner & Hartnett 2012).

Discussion and conclusions

This review aimed to provide an improved understanding of the engagement and decision making process of service users within a self-directed support framework. This is particularly timely given not only the 2016-2019 roll-out of the National Disability Insurance Scheme—which is based on the principles of self-direction—across all States and Territories in Australia, but also because of the underlying yet ambiguous assumptions associated with self-direction, choice and control. Review findings were categorised into either: (i) key areas that have an impact on service-user engagement within self-directed programs or (ii) aspects that contribute to informed decision making among service users engaging within a self-directed system. In the first category, findings provide some insight into service users' experiences and perspectives about the prevailing 'choice' models of self-direction. Specifically, findings provide insight into the specific key areas that contribute to service users' successful engagement with self-directed programs that aim to support their health and social care decisions. Largely, findings suggest that self-direction has the potential to provide people with disability more choice and control to align their services in keeping with their needs and aspirations. Self-budgeting as a characteristic of self-directed programs has the ability to ensure service users make their own decisions concerning their health and social care and this may result in favourable health and wellbeing outcomes for service users. However, self-budgeting may occasionally inhibit successful engagement as estimated budgets may not adequately meet the need of participants and result in their hiring of staff who are underqualified and potentially perform at a lower calibre than

desired. Successful engagement among service users with self-directed programs requires a cultural shift across service providers. In particular, it is important that service users and their families are regarded as central; that service users are viewed as being able to make choices concerning their health and social care; and that resources used to engage service users are accessible.

This review identified a variety of aspects that support and inhibit decision making among service users engaging with self-directed programs. Service users and their families made decisions based on their level of comfort with a service provider and service provider competence. Decision-making was also affected by the level of support or social capital that service users had. Independent third party advisors concerning budgeting or hiring were viewed as supporting informed decision making among service users. Additionally, experiential knowledge was viewed as strongly informing how service users made decisions concerning their health and social care. Sources also highlight the difficulties in navigating the complexities of self-managed funding, which in turn negatively affects service users' capacity to make effective choices and decisions. This review suggests that decision making by service users are inhibited by a variety of factors, including access to accurate information, family and professional support, geographical location, and socio-economic status. Additionally, as service users, family members and professionals working with self-directed programs often undertake multiple roles with differing priorities, conflicts of interest can potentially affect decision making among service users.

Importantly, this review identified that access to self-directed funding packages does not necessarily precipitate people's capacity for self-determination. People who are systematically disengaged from the sector for many years will not suddenly feel the will or ability to engage in a new service model simply because of its promise of 'greater choice'. This is particularly so for service users residing in remote communities, who may incur greater costs than those in urban settings (Dew *et al.* 2013) and receive fewer benefits from such models. Deeper insights into engagement and motivation to use systems are required to understand the institutionally disengaged people and families. Service users and families need external support if they are to successfully navigate self-directed systems and, plan

and manage their budgets, and determine how they will allocate their funded resources among their choice of supports and services.

It was apparent from the studies reviewed that self-directed models of services were implemented in different ways in different settings, with variations in the extent to which service users and their family members or guardians assert complete control over their funding budgets and self-directed services (Mitchell 2014b). This flexible approach to self-direction is important, as can be seen in Australia's *National Disability Insurance Scheme* where a tiered approach to self-direction is promoted. Specifically, there are four options for self-direction, one of which involves employing an organisation to provide advice for families using self-direction, or make decisions about budgets on behalf of service users (National Disability Insurance Scheme [NDIS], 2014). While the results of such approaches in Australia have yet to be comprehensively evaluated, early reports from the trial sites look promising in their ability to support service users and their families to achieve positive outcomes.

The review focused on the evaluation of self-directed approaches for people with disabilities and their families. Six (Mitchell 2012a, Mitchell 2012b, Mitchell 2012c, Mitchell 2014b, Mitchell 2014a, Timberlake *et al.* 2014) of the eleven original research articles explored the perspectives of service users and guardians concerning the implementation of self-direction policy for young people. As such, the findings provide unique insight into the perspectives of young people concerning their health and wellbeing. Guardian perspectives have been included in these studies as a representation of the opinions and best interests of young people engaging in self-directed programs. While the authors recognise the benefit of guardian perspectives, there is the potential that some of the perspectives of service users have remained absent. As a result, it is important that further research aim to continue to consider the perspectives of young people and their families concerning self-directed programming, in an attempts to ensure that the entirety of their perspectives are considered.

Implications for research

It would be useful for future research not only to evaluate the effectiveness of these approaches but also to explore more deeply the perspectives of service users, their parents, guardians and carers, together with the perspectives of service providers. It is also important that future research explore the impact of external supports in a variety of realms including budgeting (who does it, to what degree and how is it monitored) and service choice processes for participants within self-directed models. These propositions could be tested using theoretical frameworks such as self-determination theory to examine the degree of internal versus external motivation required for people to engage in user-direction services, and what factors promote or hinder their levels of motivation to participate. Finally, future research and evaluations could consider service-user concerns such as quality of life (health and wellbeing), impact (including levels of social and economic inclusion as measured by access to housing, education and work), and sustainability (determining who qualifies and why within the context of long term costs and outcomes) (Gross *et al.* 2013). Such research might identify ways to either improve self-directed models of supports and services, or design better approaches to ensure that people with disability can participate fully and inclusively in their mainstream societies.

Ends

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