International advances in self-direction: themes from a disability leadership exchange

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Abstract

Purpose – Self-direction–also known as participant direction, personalization and self-directed care–is a service delivery model that enables people to manage their personal budget and purchase services and supports tailored to their needs based on a person-centered plan. This paper, the outcome of an international learning exchange on self-direction, describes approaches across four countries' successful strategies, unresolved questions and recommendations to enhance self-direction globally.

Design/methodology/approach – The findings are a product of discussions at the 2019 International Initiative for Mental Health Leadership and International Initiative for Disability Leadership Exchange on Advances in Self-Direction. Participants included people who are self-directing, providers and caregivers who support people who are self-directing, advocates, fiscal agents and public managers who administer self-direction from the United States, England, Australia and New Zealand.

Findings – In all four countries, people who self-direct exercise high levels of choice and control and are able to individualize their services and supports to promote a good life in the community. The exchange also revealed challenges and possible solutions to improve and expand self-direction.

Practical implications – The results of the meeting provide guidance for public managers, providers and advocates for initiating and expanding self-direction.

Originality/value – This international meeting was a unique opportunity to compare self-direction across four different countries and across multiple perspectives, including people with disabilities, caregivers, providers and administrators.

Keywords Self-direction, Long-term support and service, People with disabilities

Paper type Technical paper

Introduction

Self-direction–also known as participant direction, personalization and self-directed care–is a service delivery model that enables people to manage their personal budget and purchase services and supports tailored to their needs based on a person-centered plan. Self-direction has long been considered an innovative and person-centered approach. In the era of coronavirus disease 2019 (COVID-19), this promise is amplified by the self-direction's flexibility, which allows people to minimize the number of supporters who enter their homes and compensate friends and family providing needed supports (Mahoney, 2020).

In September 2019, the Human Services Research Institute and Applied Self Direction hosted an International Initiative for Mental Health Leadership (IIMHL) and International Initiative for Disability Leadership (IIDL) Exchange titled *International Advances in Self-Direction* in Boston, Massachusetts. This two-day session, hereafter referred to as the Match, included people who are self-directing and their caregivers, providers, advocates, fiscal agents and public managers who administer self-direction from the United States, England, Australia and New Zealand.

This paper contains an overview of the four countries' self-direction approaches (data and perspectives provided by Match participants) and a summary of the lived experiences shared by Match participants who self-direct. Additionally, the paper outlines learnings from the Match including successful strategies, unresolved questions and next steps for the future of self-direction.

Overview of international approaches

The emergence of self-direction constitutes a shift in the delivery of long-term services and supports to people with disabilities and older adults. Instead of a pre-set menu of services, self-direction gives people a choice of providers and services and the ability to manage their budgets. In self-direction, professional roles are changed, and the balance of power is altered in favor of the person. Although there are some differences in self-direction components across the countries at the Match, there was general consensus that shared values of self-direction include the primacy of choice, trust that the person will do the right thing, the importance of relationships, the need to support people and families to self-direct and the maxim "nothing about us without us." [1] At the heart of self-direction is the human right of people to live independently.

Research has shown positive outcomes of self-direction. Multiple studies have tracked individual satisfaction and cost-effectiveness (Nerney *et al.*, 1995; Conroy and Yuskauskas, 1996; Conroy *et al.*, 2002; Taub *et al.*, 2004; Head and Conroy, 2005; Fenton, 2008; Croft *et al.*, 2018). One of the most influential studies, the cash and counseling demonstration and evaluation, used a randomized experimental design, found that quality of life and health improved, satisfaction with services was high and needs were substantially met for those self-directing (Carlson *et al.*, 2007). Another study found that people are being treated with more dignity and respect, made more decisions and received more flexible services than before they chose self-direction (Kimmich and Becker-Green, 2000). In the United Kingdom, an evaluation of the personalized budget initiative showed that those self-directing experienced positive quality of life outcomes and cost effectiveness and satisfaction (Personal Social Services Research Unit, 2012).

United States

According to a 2019 inventory conducted by Applied Self Direction, approximately 1.2 m people in the US are self-directing–up to 17% from 2013. Data from the National Core Indicators Survey (NCI, 2019) indicate approximately 13% of respondents with intellectual and developmental disabilities are self-directing. For people with mental health conditions, the numbers are small and limited to a handful of pilots around the country.

Self-direction in the US is not a national program with standardized requirements. Rather, the federal government offers aspirational and optional policies that encourage states to offer self-direction, such as language in the The Patient Protection and Affordable Care Act (2010). The shape and content of self-direction is determined at the state level. Every state offers at least one self-direction option in their long-term services and supports programs. Program requirements, structure, accessibility and eligibility vary by program within each state.

Self-direction in the US offers two options: employer authority and budget authority. With employer authority, participants can recruit, hire, manage and dismiss their support workers. A participant who has employer authority can receive support for "back room functions" such as authorized budgets, processing payroll and withholding state and federal taxes, from an entity commonly referred to as a fiscal intermediary.

When participants use budget authority, they can purchase a range of approved goods and services from nontraditional providers. Most states offer employer authority, and fewer

offer budget authority in combination with employer authority. Even fewer programs–primarily in mental health–offer budget authority only.

In both options, all payroll and approved goods and services are purchased through an approved service budget based on a service plan, preferably a person-centered plan created with the participant and support from their friends and family. Case managers/care coordinators are responsible for introducing self-direction to participants and helping them to understand their role, responsibilities and opportunities. Some states offer support brokerage to help to guide the participant through enrollment, choice of services and staff recruitment. Depending on the state, self-direction can be a complex process for staff as well as the individual–at least initially. Though questions have been raised regarding whether self-direction is an opportunity for fraud and exploitation, there have been few documented incidences.

England

In England, adult social care policy is set by the Department of Health and Social Care and implemented by locally elected councils. The roots of self-directed support are traceable to the 1970s and the independent living movement. Direct payments legislation, introduced in 1997, was a significant landmark, giving local authorities the power to make cash payments to people to organize their own care. Growing acceptance of personalization culminated in the Care Act of 2014, which enshrines self-directed support in law and requires councils to provide a personal budget for everyone meeting national eligibility criteria for long term community-based support (based on need and a means test). People can choose to take their budget as a direct payment, leave it to the council to manage or delegate to a third party through an individual service fund.

Although direct payments have been an option for over 20 years, enrollment remains limited. Of the 858,000 people receiving long-term support (latest figures at the time of the Match), an estimated 240,000 were using direct payments. Numbers vary significantly between councils, and there is also considerable variation amongst population groups: there are more working age adults (18–64) than older people (65+).

Each person with a direct payment has a care and support plan, setting out how their needs will be met, linked to the outcomes they wish to achieve, including the costs to be met by the council. People should be able to get assistance to help plan if they wish. Many local authorities provide this assistance directly, while others contract with the voluntary sector or organization managed by people with disabilities.

Each council sets its own requirements for calculating budgets, devising support plans and ongoing monitoring and review. Some are more permissive than others, and some providers are more supportive than others. Common concerns expressed by recipients are an overly bureaucratic process, restrictions on what the money can be spent on and excessive monitoring. Participants can also find it difficult to recruit personal assistants. Despite these difficulties, the evidence suggests that people with direct payments value them highly and prefer them to conventional services. Though established in policy and law, it will take time before self-direction is embedded in practice and routinely experienced by people. Other parts of the United Kingdom, such as Wales, Scotland and Northern Ireland, have similar direct payment legislation, but variations from those in England may result in different outcomes.

Australia

In 2013, the Australian Parliament passed sweeping reform of the social care system called the National Disability Insurance Scheme (NDIS), moving from a welfare model to an insurance model. NDIS integrates multiple social services into one unified funding source administered by the Commonwealth National Disability Insurance Agency. Initial funding

for NDIS was set at $22 bn. The aim of NDIS was to turn the service system on its head, putting funding in the hands of participants to purchase a wide range of services, equipment, adaptation and other needed supports. All regions except Western Australia have finished the three-year transition to the new service structure. At the time of the Match, 300,000 people had been enrolled, with an ultimate target of 467,000 participants. The target population is people with disabilities, including those with psychosocial disabilities that may arise from a mental health issue who have an ongoing functional impairment (National Disability Insurance Scheme, 2020). Since not all people with psychosocial disabilities have such impairments, many are not part of the Scheme and are supported through other programs.

NDIS participants have a plan that determines how the funding is managed. Participants choose between self-management, plan management and agency management. If participants self-manage their funds–the purest form of self-direction–they have the greatest flexibility in products and services. The plan is goal-driven and comprehensive, including assistive technology, transportation, supports for independent living, in-home support, capacity building and support for community participation and employment.

The number of participants choosing self-management is gradually increasing. At the time of the Match, 27.3% were self-managing. Of those, 15.8% were fully self-managing and 11.5% were partially managing their budget. People who self-manage tend to be younger, and they experience better outcomes than those who don't self-manage. While people who need more support can delegate self-management to a nominee, it appears that some of these individuals are screened out as candidates for self-management by the planner. Consequently, without intervention, only a small percentage of people opt to self-manage their budget. Some of this is not policy but misplaced judgment by the planner and can be challenged when people know their rights. Australian Match participants noted that since the introduction of the NDIS, self-management–though a positive step forward for many people– is still too small to drive changes in the system.

New Zealand

New Zealand's disability service system is small–about $1.7 bn NZD out of an overall budget for health and disability of $16.8 bn. Approximately, 34,000 people receive disability supports. Of that number, 17,000 receive community or home-based supports, and 6,732 receive self-directed supports. Currently, almost all who self-direct are under 65 with long-term disabilities. Older adults with disabilities and people with mental health concerns are funded by the district health boards (DHBs), and some of those DHBs enable limited numbers of people to self-direct. Those with long-term chronic conditions are also funded by the DHBs and are often supported to self-direct–especially medically fragile children.

New Zealand's transformation of disability services began in 2008. However, real change in self-direction began in 2012 with a demonstration called "The New Model" based on Individualized Funding and Local Area Coordination. Several transformational demonstration projects are now in progress. In the most significant project in 2017, people in a geographic region got personal budgets with complete control over how the money was used for supports. The range of disability services that can be purchased include community participation/day services, home and community support services, individualized funding, advanced home support, respite, vocational/day services and any other supports that will facilitate the person's goals.

The list of services and supports has evolved as funders have become more comfortable with risk. Though there was initial concern about fraud, it is negligible to non-existent. However, more recently, the self-direction program–which was envisioned to be flexible and person-centered–has been subject to more bureaucratic oversight. Rather than being able to choose from a wide range of options, people are being forced to choose from a more limited

menu. While it should be the individual who determines what their needs are, it often ends up being what the budget will allow.

Experiences of people who self-direct

To understand how self-direction was viewed by people receiving services, Match participants with lived experience and a panel of local self-advocates were invited to share their perspectives regarding how they heard about self-direction, how it shaped their lives, what was difficult about self-directing, and what would it take to engage more people in self-direction. One participant said that she decided to self-direct after "fights" with her case manager regarding her goals. "[I] hired my own job coaches and support service workers." She added that it is "a nice thing to choose your staff yourself. You don't have to deal with controlling people." Other participants commented on some challenges to self-directing:

(1) "Getting all the paperwork set up" is difficult.

(2) "Sometimes agencies try and talk you out of self-directing."

(3) "I was first at very confused. I did not really understand. I had someone help me with that for a while. Now I am pretty much doing it."

(4) "The process to hire people [was hard]. I needed help at first but mostly I do it myself now."

With respect to opportunities provided by self-direction, participants noted:

(1) "I wanted to be a song writer, and now I'm writing my own lyrics."

(2) "I own my own business."

(3) "I'm going to hire someone to me with marketing for my arts. I want to hire someone to help me setting up Etsy posting. I get help with art classes and supplies, gym membership etc."

(4) "My job coach [hired by the person] taught me many skills, computer, internet, etc."

(5) "It was confusing the learning the rules and budget codes. I had a first service coordinator who helped me."

Finally, many of the participants mentioned how important the support from their case managers was in deciding to self-direct:

(1) "I had a friendship with [my case manager] her, she was more than case manager. She supported me as a friend so that was a great help."

(2) "I have a good working relationship with my service coordinator who helps me along the way."

Best practices in self-direction: what we've learned

Using a World Café format (Bumble and Carter, 2020), Match participants came to consensus on best practices to ensure self-direction is implemented effectively and in alignment with the values of self-determination and social justice. These best practices, described below, are implemented to varying degrees across the world.

Equity in outreach

Match participants were concerned about ensuring self-direction is available to all who are eligible. Insufficient outreach results in inequitable enrollment in self-direction. For instance,

limiting outreach to people with fewer support needs denies the option to manage services to those with greater support needs. Concentrating on more "capable" families who are thought to be better able to manage self-direction excludes families with fewer resources or education. If targeted efforts are not mounted to inform diverse racial, ethnic and linguistic communities about self-direction, some will be unaware of the option. Finally, self-direction is very limited in mental health systems where medical treatment is still the primary model of support.

To attract people to self-direction, programs need to develop materials that explain participation criteria and relevant roles of the system and the person. Materials need to reach racially, ethnically and linguistically diverse populations, low-income communities and other underserved or underrepresented groups. Technology can facilitate access to self-direction through social media, videos of individual stories and on-line budget applications. Finally, making the process easier to manage could also increase uptake.

To enhance and expand self-direction, outreach should begin early. Some specific ideas for outreach included:

(1) Engage with communities surrounding people with disabilities and their families to identify resources and supports

(2) Make sure outreach materials are culturally competent and written in plain language

(3) Start with "low-hanging fruit" including individuals who are dissatisfied with current services

(4) Target young people and families before they opt for more conventional services

(5) Assume competence of the person at the beginning of the process to avoid gatekeeping

(6) Create a self-direction trial period where individuals can "try out" the option

(7) Make sure people have access to information, advice and support to assist decision-making

Person-centered planning
The person-centered plan is an important component of self-direction. The plan includes the person's vision of a good life, priorities, needs, services and supports that can be purchased and additional resources. Important considerations include:

(1) Outlining elements of the person-centered planning process in legislation, policy or regulation

(2) Striking a balance between flexibility and ensuring the process is somewhat standardized to avoid arbitrary and subjective judgments by others

(3) Reducing the administrative burden on the person and family

(4) Making the service "menu" and budget amount available prior to developing the plan

Role of self-advocacy, peers and peer-run organizations
Self-advocates and peers play an important role in self-direction. A self-advocate or peer is a person with lived experience of disability and/or self-direction who acts to promote self-direction at the policy, community/system and/or individual levels of society. Self-advocates or peers may be community activists, volunteer advisors or professional paid staff, depending on their role and focus. At the policy level, they advocate for expanded self-direction. At the community level, they advocate for capacity building to implement

self-direction. At the person level, they can help people and families understand the self-direction process by sharing their own experiences and providing guidance, mentoring and support. Once a person decides to self-direct, peers or self-advocates can assist the person during implementation (e.g. hiring and managing staff). In the current change to more self-directed, personalized model of social care in the UK, for example, Nind *et al.* (2020) found people with intellectual disabilities are leveraging peer support to learn about available options, make informed choices and plan activities and programs that are good fit for their daily lives.

To ensure peer and self-advocacy, the following issues should be taken into consideration:

(1) Include peer support in policy and regulatory guidance for self-direction

(2) Establish partnerships with peer-run and self-advocacy organizations

(3) Create funding mechanisms to sustain peer-run and self-advocacy organizations

(4) Provide training and mentorship opportunities for peers and self-advocates

(5) Compensate peers and self-advocates for their time

(6) Bring peers and self-advocates into discussions of self-direction policy and practice; when possible, they should lead or co-lead discussions

(7) Ensure peer supporters play a central role in self-direction

Use of data
Data on self-direction and experience of self-directing is important for quality improvement and oversight. Methods and measures should emphasize experience and the impact on quality of life (i.e. go beyond satisfaction). Cost and benefit data are also important to show the efficacy of pilots and generalize knowledge of self-direction across programs, systems and populations. Match participants identified the following best data practices:

(1) Involve people with lived experience in the design of quality improvement and evaluation efforts, including formulation of logic models, selection of measures and methods for data collection, analysis and reporting

(2) Make self-direction data available publicly

(3) Create a stakeholder forum to review the data and make suggestions for improvement

(4) Be wary of satisfaction surveys that may include sample bias or lack accuracy

(5) Make sure surveys include questions that address quality of life and other outcomes of importance to people and communities

(6) Provide stakeholders opportunities to share feedback beyond structured questions

(7) Employ multiple, accessible research methods

Adequacy of the direct support workforce
Many who are self-directing rely on the availability of direct support staff to hire. However, in many jurisdictions, workforce shortages result in substantial turnover. For self-direction to be more broadly available, it will be important to think about recruiting a more nontraditional workforce including neighbors and family members. Issues to consider include:

(1) Assist the person to recruit staff, customize training depending on the services to be managed, and manage the budget based on the person's capacity

(2) Ensure budgets include enough funds to attract capable staff

(3) Develop training about how to be an employer

(4) Give people the ability to use staff as job coaches

(5) Expand the pool of potential staff by exploring the person's circle of support

(6) Anticipate potential workforce unionization

System resistance to self-direction
A range of factors can influence the acceptance and scope of self-direction within a system. These include resistance from providers, policymakers and the public who question the capabilities of people with disabilities, fear about additional costs and concerns about fraud and misuse. Some strategies to respond to these factors include:

(1) Anticipate resistance and showcase the range of participants successfully self-directing

(2) Win support from policymakers and others by making the business case for self-direction, including both economic and quality of life benefits

(3) Be aware of the possibility of fraud but recognize that fraud/misuse is very low and develop proportionate responses

(4) Support the voices of participants and families demanding self-direction as a right

Future considerations and unresolved issues
Looking to the future, it will be important to evaluate different strategies to determine what works best for what approach. The following issues were identified as yet-to-be-resolved by Match participants.

Who should self-direct?
Data shows younger people, people who are dissatisfied with their current services, and those with autism are more likely to opt to self-direct (Bradley *et al.*, 2017). There is a suspicion that those who act as gatekeepers, including case managers, may make subjective, biased judgments about who should be encouraged to self-direct, thereby depriving those with more significant support needs the opportunity to self-direct. Case managers should be required to share self-direction information with all new enrollees.

Who should provide support?
Programs differ in who can and/or should be paid to provide support. Some programs pay family members and "legally responsible individuals," while some do not. Some programs allow participants to hire individuals who may have a criminal record. Some programs require extensive, standardized training for supporters, such as CPR and first aid. In other programs, requirements are minimal.

How should the plan and budget be developed?
Whether budgets should be developed before or after the planning process varies from program to program. There are arguments for both–putting the budget first means the participant has a realistic idea of what services and supports can be purchased; it is also more transparent. Leaving the budget determination to the end of the plan means the process may

be more spontaneous but also may generate unrealistic expectations and difficulty reconciling the plan with resources.

What should be funded?
Jurisdictions also vary on the scope of the menu of services and supports that can be purchased. There seems to be a tension between a desire to be flexible and creative and political concern about how the program may be regarded by taxpayers. This tension will probably grow if self-direction expands and becomes more prominent.

What type of support do participants need?
It is generally accepted that self-direction participants benefit from working with a case manager, support broker or other facilitator. Some jurisdictions use individual brokers, others contract with agencies, and some use public employees. Where support comes from may depend on local circumstances, resources and history. Case managers may have conflicts given their responsibility to be stewards of public funds, which may undermine their advocacy for the individual. Moving the support brokerage function to nonprofits and organizations managed by people with disabilities is one solution to this challenge. Additionally, there is variation in who pays for the cost of brokerage services, whether it comes from the individual's budget or not. Participants may need assistance to engage in self-advocacy to ensure their support needs continue to be met as they transition from traditional to self-directed arrangements.

Next steps for self-direction's expansion
To conclude the Match, participants discussed concrete steps to improve self-direction and expand the option to more people with disabilities.

(1) Communications should lay out self-direction's values and outcomes, including expanded relationships, employment and community membership. It will be important to demystify self-direction to demonstrate it is accessible to all.

(2) People who are self-directing should facilitate conversations and inform their peers as "ambassadors." Resources such as "Making it Real" (Think Local Act Personal, 2018), shared by Match participants from England, can serve as a template.

(3) Conferences, webinars and virtual discussion groups can be effective vehicles to spread the word about self-direction. Such meetings provide a means for people with lived experience to network and showcase the stories of people who are self-directing as well as the staff who are supporting them.

(4) To facilitate education and training for all stakeholders, it will be important to clearly spell out aspects of self-direction including development of the budget, the service model, fiscal intermediaries, facilitation support and what has worked and what has not.

(5) More work needs to be done to embed self-direction in the mental health system. Models, examples and research are needed.

(6) Self-direction should be a part of elementary and secondary school educational curricula to prepare students to self-direct when they make the transition to adulthood.

(7) IIDL/IIMHL should take the lead in crafting a universal statement on self-direction to reinforce the global value of self-direction and an international compact on self-direction. This statement can be reinforced through the organization of the IIDL/IIMHL at the national level.

Conclusion

The cross-national themes that emerged from the Match reinforce the benefits and opportunities that self-direction offers those receiving long-term services and supports. It also suggests that there is consensus regarding the key components of self-direction, emerging best practices and the challenges that remain. As health and social care systems recover from the disruption and isolation wrought by the global COVID-19 pandemic–and in some cases, as they reinvent themselves–these learnings may be particularly useful. Overall, the Match provided insights and suggestions that can form the basis for an ongoing campaign to expand and improve self-direction across the world.

Note

1. The term "nothing about us without us" is widely used in disability communities. One of the first use of this sentiment by self-advocates was at a ground-breaking gathering of people with intellectual disabilities in Malmo, Sweden in 1970. One of their assertions about how they should be treated was "We think we should be present when our situation is discussed by doctors, teachers, welfare workers, foreman, etc. (Nirje, 1972).

References

Applied Self-Direction (2019), "National inventory of self-directed long-term services and supports programs", available at: https://www.longtermscorecard.org/publications/promising-practices/2019-self-directed-ltss-inventory.

Bradley, V., Bonardi, A., Vorderer, L., Sartori, C., Croft, B., Li, H. and Mahoney, K. (2017), "Year one report evaluation of real lives legislation and self-directed services in Massachusetts", available at: https://www.hsri.org/files/uploads/publications/RealLivesEvaluation_Year1Report_092017.pdf.

Bumble, J.L. and Carter, E.W. (2020), "Application of the world café to disability issues: a systematic review", *Journal of Disability Policy Studies*. doi: 10.1177/1044207320949962.

Carlson, B.L., Foster, L., Dale, S.B. and Brown, R. (2007), "Effects of cash and counselling on personal care and well-being", *Health Services Research*, Vol. 42, pp. 467-487.

Conroy, J., Fullerton, A.Y., Brown, M. and Garrow, J. (2002), *Outcomes of the Robert Wood Johnson Foundation's National Initiative on Self-Determination for Persons with Developmental Disabilities*, Center for Outcome Analysis, Narberth, PA. Coalition for Collaborative Care. (n.d.).

Conroy, J. and Yuskauskas, A. (1996), "Independent evaluation of the Monadnock self-determination project", available at: https://www.researchgate.net/publication/228592650_Independent_evaluation_of_the_Monadnock_Self-Determination_Project/citation/download.

Croft, B., Simon-Rusinowitz, L., Loughlin, D.M. and Mahoney, K.J. (2018), "Mental health leadership perspectives on self-direction", *Social Work in Mental Health*, Vol. 16, pp. 381-399.

Fenton, M. (2008), "When individuals can choose, what do they choose?", *Paper Presented at the Home and Community-Based Waiver Conference, Minneapolis, MN*.

Head, M.J. and Conroy, J.M. (2005), "Outcomes of self-direction in Michigan: quality and costs", in Stancliffe, R. and Lakin, C. (Eds), *Costs and Outcomes of Community Services for People with Intellectual Disabilities*, Paul Brookes Publishing, Baltimore, MD, pp. 219-240.

Kimmich, M. and Becker-Green, J. (2000), "Evaluation of the Maryland self-determination initiative", available at: https://www.hsri.org/publication/evaluation_of_the_maryland_self_determination_initiative.

Mahoney, K.J. (2020), "Self-direction of home and community-based services in the time of COVID-19", *Journal of Gerontological Social Work*, Vol. 63 Nos 6-7, pp. 625-628, doi: 10.1080/01634372.2020.1774833.

National Core Indicators (2019), "In-person survey 2018-2019: final report", available at: https://www.nationalcoreindicators.org/survey-reports/.

National Disability Insurance Scheme (2020), "Mental health and the NDIS", available at: www.ndis.gov.au/understanding/how-ndis-works/mental-health-and-ndis.

Nerney, T., Crowley, R. and Kappel, B. (1995), "An affirmation of community: a revolution of vision and goals. Creating a community to support all people including those with disabilities", available at: https://arcmi.org/content/uploads/sites/15/2017/03/An-Affirmation-of-Community.pdf.

Nind, M., Coverdale, A. and Croydon, A. (2020), "Learning from each other in the context of personalisation and self-build social care", *Disability and Society*, pp. 1-21.

Nirje, B. (1972), "The right to self-determination", in Wolfensberger, W. (Ed.), *The Principle of Normalization in Human Service*, National Institute on Mental Retardation, Toronto, pp. 176-193.

Patient Protection and Affordable Care Act Patient Protection and Affordable Care Act (2010), *Pub. L. No. 111–148, 124 Stat.*

Personal Social Services Research Unit (2012), "Evaluation of the personal health budget pilot program", available at: https://www.phbe.org.uk/getFile.php?id=report.

Taub, S., Chiri, G., Astor, L. and Grotpeter, M. (2004), *Benchmarks and Trends in ISO Performance: Third Annual Quality Report*, Public Partnerships, Boston, MA.

Think Local Act Personal (2018), "Making it real: how to do personalised care and support", available at: https://www.thinklocalactpersonal.org.uk/_assets/MakingItReal/TLAP-Making-it-Real-report.pdf.

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