

Self-Direction Worldwide

Contrasting beliefs and their impact on practice

A DISCUSSION PAPER FROM THE CENTRE FOR WELFARE REFORM

Lynn Breedlove

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Contents

Summary	3
1. Introduction	4
2. Defining self-direction and its purpose	8
3. Critiques of the systems that preceded self-direction	14
4. Citizenship, human rights and community participation.....	16
5. Key values and principles of self-direction	18
6. The support necessary to successfully self-direct	23

Summary

People with disabilities, older people and their allies in many countries around the world are working hard to make self-direction a reality. We are all at different stages in this process and our strategies reflect the different cultural, political and economic realities of our respective countries.

However, we face similar challenges, and strategies that have worked in one locale may be applicable elsewhere. In other words, we can learn from each other. So it's worth the effort to notice our commonalities, our differences, our unique or shared accomplishments, and lessons learned that we can all build on.

This paper is intended to contribute to that global dialogue. It includes: different definitions and terminology for self-direction, critiques of the systems that preceded self-direction in various countries, prevailing values and principles of self-direction around the world, contrasting views regarding the link between self-direction and community participation, and examples of a wide variety of supports available to people in different locales designed to enable them to successfully self-direct.

I. Introduction

What does ‘self-direction’ mean to people and governments around the world?

In some places, it’s a new (or not so new) human service program. In other places it’s a funding mechanism or a way for the government to save money. Sometimes it only applies to a narrow slice of the services or supports people receive (e.g. only for hiring in-home workers). Sometimes it’s only available to a small portion of the older adults and people with disabilities (e.g. “the most capable”) who are eligible for publicly-funded long-term support services.

In contrast to these perspectives, there are some people and organisations who see self-direction as something much more fundamental to human beings and society. This is the view that self-direction is an essential element of citizenship, and consequently should be a core value in the relationship of government to its citizens.

So what?

Does it matter?

I believe it does.

‘Self-Direction’ is only one of many terms used for the same (or similar) idea, but that is the term I will use in this paper to subsume all the other terms, such as:

- self-determination
- self-directed care or support
- participant direction
- recipient-directed care
- consumer-directed care
- personalisation
- personalised care or support

- client-led care
- self-management
- personal budgeting
- individualised funding/budgets
- direct payments
- cash payments for care
- cash and counselling

If anything connects these ideas it is perhaps that they all seem to refer to a greater level of freedom from intrusion by government, providers, or professionals.

During the last 20+ years, self-direction projects and programs have surfaced in many different countries and every state in the U.S. Statistics issued by various governmental bodies suggest that a large number of people with disabilities and some older adults are currently self-directing their services and supports. For example all 50 states in the US reported some level of self-direction in 2016, but in 7 states the number of people engaging in self-direction was fewer than 1,000.

AARP, The Commonwealth Fund, the SCAN Foundation and many other organisations have cited a variety of studies that indicate that “people who self-direct their services are more satisfied with them, and experience equal or improved outcomes than people whose services are directed by an agency” (Edwards-Orr and Ujvari, 2017).

But the trends suggesting that a growing number of people are self-directing their supports require examination. How is ‘self-direction’ defined in these different countries? What and whom are these various governmental bodies counting? When people ‘choose to self-direct’, what do they think that will mean in their lives? When people with disabilities, older adults, families, and self-direction advocates promote the idea of self-direction, what are their motivations and rationales for it?

Evaluations of self-direction have generally shown that (compared to preceding models) it results in:

- higher consumer satisfaction
- higher worker satisfaction and job retention
- stronger interpersonal connections
- more community integration
- fewer out-of-home placements
- improved physical and mental health
- consumers using a greater diversity of goods and services
- improved access to home and community-based services
- good stewardship of public funding
- very few cases of fraud or abuse

[Alakeson, 2010](#)

As with any phenomenon which is evolving simultaneously in many parts of the world, it is not surprising that there would be substantial variation in the thinking of its originators and practitioners. In this paper, I will attempt to present some of that variety, so that people who are currently practicing or exploring the possibility of self-direction can reflect on their own views in relation to their self-direction comrades around the world.

To some degree, self-direction has been a major theme in my thinking and practice since I started in the disability field in the 1970s (although the term self-direction became popular later). The first person with significant disabilities whom I got to know well was a vivid exemplar of a life with virtually no chance for self-direction. He and I were the same age, which made the contrast between our lives all the more startling. He had spent most of his life in a series of state-run institutions. Even though he was living in the community when I met him, he had virtually no opportunity to decide where to live, whether to pursue an education, whether to work, what kind of job to prepare and apply for, etc. Being friends with a truly disempowered person gave me an enduring understanding of the indignity that powerlessness inflicts on a human being.

In the 1970s, in the era of normalisation and PASS (Wolfensberger and Glenn, 1978), we used terms in the U.S. like ‘autonomy’, ‘choice’, and ‘dignity of risk’, precursors to the self-direction movement which followed. But there was an important difference. Back then, we imagined a progressive disability

service system designed by right-thinking professionals within which people with disabilities would be offered some degree of choice and control.

Nowadays, many people with disabilities whom I know reject the notion that their lives will in any way be circumscribed by a ‘system of services’ designed by anyone other than themselves. In their view, true self-direction creates opportunities to chart individual life paths and invent ways to receive support that could not accurately be described as ‘systems’ and might be surprising to ‘enlightened professionals’.

In the USA (and perhaps in some other countries) many people view the growth of self-direction as a logical next step after normalisation and social role valorisation, and a phenomenon which is consistent with the values of person-centred planning, community integration, school inclusion, and competitive employment. But some would say that it is also an outgrowth of the independent living movement pioneered by people with physical disabilities. It also represents a distinct paradigm shift from the normalisation era, given that it is based on a serious contention that people with disabilities (with or without the help of family and friends) are actually better positioned to decide the most effective and efficient use of public dollars in their lives than case managers, social workers, government officials, provider agency staff, advocates or anybody else.

However it’s also important to note that self-direction has not always grown out of noble intentions and aspirations for people with disabilities or older adults. In some instances in the USA and elsewhere, government decided that the fee-for-service system was too expensive; the solution appeared to be “Let’s cut the funding but give people more control over how it is spent.”

2. Defining self-direction and its purpose

Here are some examples of a variety of statements regarding the definition and/or purpose of self-direction, along with my comments noting some interesting features in these statements.

Definitions that focus broadly on the whole life of the person

Self-directed support is the process of taking control of your life and any support you might need to live it.

Duffy, 2010

Self-direction aims to empower individuals by providing them with more choice and control.

Barczyk and Lincove, 2010

Self-determination is the process of defining one's own direction.

Brugnaró & Timmons, 2007

Self-direction is having choices to make and taking responsibility for those choices. Self-direction is in the act of an isolated individual imposing their will on the world... Effective self-direction emerges from constructive interdependence... Self-direction refers to the capacity to align the assistance that a person requires with a life that they want to live.

O'Brien and Mount, 2015

Note: The idea that a self-directing person must/should take responsibility for his/her choices is only occasionally mentioned in the self-direction literature.

Self-determination means running my own life and directing my personal care assistants on how best to assist me in my personal care ... (it) doesn't mean you have to do everything yourself, but it does mean you have to be in charge of your life to the fullest extent that you possibly can be... What I consider to be self-determination for people with disabilities is to work collectively, with the person with a disability at the top."

Kennedy, 2019

Note: Kennedy a) sees self-direction of his services as integral to being in control of his entire life, not just his services, and b) he acknowledges that each person's capabilities may limit the degree of self-direction that particular person can realistically achieve, which underscores the importance of having allies.

The objective of self-direction (and a key objective of citizenship) is to diminish the number of decisions that impact your life that are made by people who don't know you.

Duffy at the Self-Direction & Citizenship Retreat, Wisconsin, October, 2018

Note: This unique perspective leads us to reflect on who makes the decisions in most people's lives and how that differs from the experience of many people with disabilities and older adults.

Self-determination means:

- making your own choices
- speaking up when you're not happy about something
- having control over your own life
- being willing to try new things
- figuring out what you do and don't like
- asking for help when you need it
- knowing the whole story,
- and taking responsibility for your decisions

Winnick and Bear, 2003

Note: This definition includes a reference to the person's responsibility and it implies that self-direction is a lifelong, evolving learning process.

Self-Determination is the right of all people with disabilities (with their chosen allies) to make choices and direct all aspects of their lives, including how they are supported; and to control the funding to pay for that support. Or, in the words of a person with a disability: 'I, the people I care about, and those who care about me making a life that is good for me'.

Survival Coalition, 2006

Note: The mention of 'chosen allies' as part of the equation.

Sometimes proposals ["proposals" refers to proposals for self-determination systems change initiatives in the U.S, submitted to the Robert Wood Johnson Foundation in 1996] talk about self-determination as an opportunity: the person will have choices about who provides what service and when. Sometimes they talk about self-determination as a competency to be acquired: the person will participate in training delivered according to a self-determination curriculum devised by experts.

O'Brien, 1997

We understand self-determination to refer to a characteristic of a person that leads them to make choices and decisions based on their own preferences and interests, to monitor and regulate their own actions and to be goal-oriented and self-directing.

National Gateway to Self-Determination, 2019

Self-determination was not some form of rugged individualism, but rather recognition of our inter-connectedness and shared vulnerability.

Nerney and Crowley, 1994

Definitions that focus primarily on paid services and supports

Self-directed support is about people being in control of the support they need to live the life they choose.

[In Control England, 2019](#)

Self-directed care is an alternative way of delivering services that seeks to empower participants by expanding their degree of choice and control in selecting services.

[Alakeson, 2010](#)

Self-directed support allows people to choose how their support is provided to them by giving them as much ongoing control as they want over the individual budget spent on their services.

[Self-Directed Support Scotland, 2019](#)

Note: This is one of the only definitions that includes the concept that people should be given the level of control they want over their individual budget, which could be total or partial control.

Self-direction helps people of all ages, with all types of disabilities, maintain their independence at home by choosing the mix of services and supports that work best for them. Self-direction is built on the belief that the individuals receiving the services and supports know their needs best and are in the best position to plan and manage their own services.

[Applied Self-Direction, 2019](#)

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.

[Fernhill Solutions, 2017](#)

Self-direction is a service model that empowers public program participants and their families by expanding their degree of choice and control over the long-term services and supports they need to live at home.

Crisp, 2010

Note: The mention of families here, which is missing in most of the other definitions.

Self-Determination is NOT a model or a program with a predetermined menu of available services and a set way of delivering them ... (people) are free to ‘order off the menu’, including those services they desire to be provided in ways that meet their needs.

National Resource Center on Supported Living and Choice, 1998

Self-direction includes “budget authority” (control over one’s individual budget) and “employer authority” (control of the decision whom to purchase one’s services from).

Wisconsin’s IRIS Program

[IRIS (I Respect, I Self-Direct) is Wisconsin's Medicaid-funded self-direction program, currently serving 20,000+ people with intellectual/developmental disabilities, people with physical disabilities, and older adults.]

REFLECTION #1

In locales where self-direction is defined in terms of citizenship, human rights and a person's whole life, self-direction appears to be more of a foundational societal value, belief or ideology, i.e. something bigger and more important (and potentially more lasting) than the typical lifespan of a human service program.

In locales where self-direction is defined solely in terms of the person's control over services and support, it is unclear whether government or self-direction advocates see it as pertaining only to the recipient-of-paid-services part of the person's life, or as something which is integral to the person's overall autonomy as a citizen.

REFLECTION #2

Is self-direction something you have to do by yourself? Is that what people are (mistakenly) referring to when they talk about 'true self-direction'?

What if your capacity to make big life decisions is limited? What if you are at the beginning of your learning curve in making big life decisions? Does that mean you shouldn't self-direct your services? Or, that government should exclude the option of self-direction for you?

In some locales, family, friends and allies are explicitly included in the definition of self-direction. In other locales, they aren't mentioned. What does that mean about self-direction in those places?

3. Critiques of the systems that preceded self-direction

In many countries, the impetus to proceed toward self-direction clearly came (at least in part) from dissatisfaction with the status quo in disability or ageing services at the time. Here are some examples of that:

The reason to reform services in line with the principles of self-determination is to increase the control people with developmental disabilities have over the conduct of their own lives, to remove the power that service systems have to dictate such fundamental matters as where and with whom they live and who assists them, and consequently to decrease the opportunity that service workers have to rule over those they assist by imposing their opinions and inclinations as a rule of conduct.

[O'Brien and O'Brien, 1999](#)

The current service provision across New Zealand tends to be task-based, rigid, non-responsive and un-targeted... The current approach to delivery of (home and community-based) services 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.

[Fernhill Solutions, 2017](#)

Service organisers (buyers of services) are communicating with service providers (sellers of services) directly. This often results in that voices of people with disabilities (service users) remain unheard... Service systems tend to narrow the choices for support for persons with disabilities down to traditional, somewhat rigid services... Person-centered planning is not enough, if... there are no real choices.

[Choices: A Platform on Supported Decision-making – Finland, 2019](#)

The implementation of self-directed support legislation in Scotland was largely driven by professionals critical of the welfare state and its ability to promote independent living.

[Pearson et al, 2018](#)

A goal of the NDIS (National Disability Insurance Scheme in Australia) is to get younger people with disabilities out of aged care homes.

[Taleporos, 2018](#)

Note: The self-direction literature rarely mentions people living in institutions, and in many countries these people are ‘carved out’ i.e. excluded, from self-direction programs.

[With regard to the demand for self-direction from people with disabilities and their families] Those who make this demand identify many current service models and practices as the biggest barriers to greater choice and control... There is an awareness that the system has grown in ways that structure in some unnecessary expenditures and create incentives that drive up costs without a corresponding rise in benefits to people with developmental disabilities.

[O’Brien, 1997](#)

[Self-determination addresses] the pernicious effects of... poverty: isolation, lack of real friendships and relationships, and lack of disposable income, i.e., income that all Americans use to enhance the quality of their lives... Poverty has become a residual entitlement as well as a precondition for receiving support... Of those (people) who do work, their hours and employment opportunities are significantly constricted by... program eligibility guidelines, income limitations, asset limitations and human service configurations.

[Nerney, 1996](#)

4. Citizenship, human rights and community participation

Beyond the stated or implied rationales for self-direction inherent in the self-direction definitions cited above, the self-direction literature includes additional reasons that people with disabilities, older adults, and advocates are enthusiastic about self-direction:

Self-directed support is a new way of organising support to people with disabilities and families in order to better respect their human rights ... (it) is about organising things so that people are not passive, instead they are active citizens, able to control the assistance they receive, in control of their own lives, and able to play an active part in community life.

Duffy, 2018

Note: Duffy emphasises a) that self-direction is a direct manifestation of citizenship and a human right, and b) that participation in community life is an essential goal of self-direction.

The goal of self-determination has remained 'crafting a meaningful life deeply embedded in one's community'.

Nerney, 2003

Note: In many writings about self-direction, the person's connection to community life is not mentioned, which implies that it is either not a goal of the designers or implementers of self-direction in those locales, or only a goal for some people.

The central goal of self-direction is to maximise an individual's opportunities to live independently in the most integrated community-based setting of his or her choice.

Gettings, 2013

[In referring to several of the Robert Wood Johnson proposals] In exchange for greater choice, people and their families and friends are asked to assume an increased share of the work and risk that has been assumed by service providers for those people in 24-hour services.”

O'Brien, 1997

Note: O'Brien makes explicit the often implied but unspoken transfer of work and risk from the system to the person/family.

Self-Directed Support is organised around a different Citizenship Model:

1. Citizens are in control of their own lives
2. Citizens live as part of a community
3. Citizens have entitlements to support
4. Citizens shape the support they need

Duffy, 2018

REFLECTION #3

Can self-direction be a vehicle for enabling or confirming segregation in a person's life? In those locales where self-direction writings are silent on community participation, the answer could unfortunately be Yes.

Without a clear and forthright statement regarding this goal of self-direction and the importance of truly informed choice (which results in most people choosing community participation if they can see it happening for someone else and they believe they will be supported in it), it is possible that (so-called) 'self-direction' could be used to facilitate segregation. Self-direction advocates need to develop safeguards to prevent that.

5. Key values and principles of self-direction

To guide the development of self-direction in their respective locales, various individuals and governments have identified certain values or principles of self-direction which they hope will undergird the approach in their state or country.

Four key components of self-directed support include participant control, participant responsibility, participant choice, and avoidance of conflict of interest.

Cook et al, 2010

Values supported by Self-Determination include:

- Respect (people deserve to be treated with respect)
- Choice (from the same array of choices most people enjoy)
- Ownership (of your life – the person has the final say)
- Support (the person chooses his/her circle of support)
- Opportunity (to explore all the possibilities that are present in the person's community)

National Resource Center on Supported Living and Choice, 1998

The purpose of self-directed support is to offer people the six keys to citizenship:

1. Self-determination - making our own decisions, in control of our life
2. Direction - having a meaningful life that suits us and the kind unique person that we are
3. Money - being able to pay our way and to decide how we will meet our own needs
4. Home - having a place of our own where we are safe, where we belong

5. Support - getting help when we need it to do the things we really want to do
6. Community life - playing an active part in our family, our circle of friends and our community

O'Brien and Mount, 2015, citing the ideas of Simon Duffy

Guiding Principles of Self-Determination:

- Dignity and Respect
- Choice and Control
- Relationships
- Giving and Community (everyone deserves an opportunity to give to their community)
- Dreaming and Planning
- Fiscal responsibility (to live within a budget)
- The Role of Professionals (to become partners with the people who hire them)
- Choice Has Limits (public funds will not be used to support choices that are illegal or harmful to the person)
- Self-Determination is Not Abandonment (of the person to live/work in an unsafe situation)
- Whatever it takes (a commitment to help people achieve their dreams)"

Winnick and Bear, 2003

Self-Direction requires collaboration, teamwork and relationships. Real relationships include responding to the voice of the person receiving support. Self-direction can't just be transactional.

John O'Brien at the Self-Direction and Citizenship Retreat, Madison, Wisconsin, October, 2018

Note: 'Transactional' means (according to Google) relating to the conducting of business.

You can choose whether you would prefer to get support from a service provider such as a voluntary organisation or care agency, or by employing personal assistance, or a combination of both.

[Self-Directed Support Scotland, 2019](#)

A person must have as much involvement as the person wishes in relation to the assessment of the person's needs for support or services, and the provision of support or services for the person.

A local authority (involved in arranging self-directed support) must take reasonable steps to facilitate the following general principles – that the right to dignity of the person is to be respected, that the person's right to participate in the life of the community in which the person lives is to be respected.

[Social Care - Self-Directed Support, 2013](#)

In order to relieve consumers of the... administrative responsibilities in... a self-directed model... fiscal intermediary organisations are often used for the financial responsibilities associated with managing support services.

[Scherzer et al, 2007](#)

If you self-manage your NDIS funding you will have:

- choice (to choose your supports, who and how they are provided)
- flexibility (to use any provider)
- capacity (to employ staff directly or have someone employ staff on your behalf)
- ability (to negotiate the cost of your supports)
- control over (and responsibility for your NDIS funding)

[National Disability Insurance Scheme – Australia, 2013](#)

Principles (of any effort that claims to offer self-directed support for citizenship):

- Right to Independent Living
- Right to a Personalised Budget
- Right to self-Determination - I have the authority, support or representation to make my own decisions)
- Right to Accessibility
- Right to Flexible Funding
- Accountability Principle - I should tell people how I used my money and anything I've learned)
- Capacity Principle - Give me enough help, but not too much; I've got something to contribute too)

O'Brien and Mount, 2015

Self-Determination takes the position that the purpose (of public funding) must be related to a person with a disability having a purposeful life, having the ability to seek the same goals that all others have related to personal relationships, membership in the community, and establishing an economic and spiritual future.

Nerney, 2004

Note: Nerney is one of the only writers on self-direction who raises a concern about poverty and cites the goal of people having an “economic future”. Even though the majority of people with disabilities who are self-directing their supports are living in poverty, presumably this is not their life choice.

[Regarding the role of guardians in self-direction] Marge (Sheri's mother and guardian) says that she has always acted on the belief that Sheri has far more far more capacity than others, including Marge herself, can see. Marge understands her guardianship not so much as making substitute choices that remedy Sheri's incompetence than she understands being a guardian is finding ways to actively represent Sheri's potential to know and to do and to control more than anyone, including Marge, now thinks she can.

O'Brien and O'Brien, 1999

6. The support necessary to successfully self-direct

In some locales, the description of self-direction makes little or no reference to the need for some people with disabilities and some older adults to be supported by paid individuals (above and beyond unpaid family and friends) in their quest to have control over their lives and services. [In this context 'support' does not refer to in-home or vocational support but the support you might need to understand self-direction, to identify and comprehend the choices available to you, to make informed decisions, and to problem solve around difficulties as they arise.] In places where the need for self-direction support is acknowledged, here are some examples of what has been said about it.

The Scottish Government believes everyone should be in control of their life. Some people need support to lead an independent life and advocacy to be empowered to make important decisions about their life.

[Self-Directed Support Scotland, 2019](#)

A person must be provided with any assistance that is reasonably required to enable the person

- to express any views a person may have about the options for self-directed support, and
- to make informed choice when choosing an option for self-directed support.

[Social Care - Self-Directed Support, 2013](#)

Participants in the 'I know what I want' project were offered training, consultation, and peer group activities to support them during the (individual planning) process.

[Choices: A Platform on Supported Decision-Making – Finland, 2019](#)

One thing I learned is that you can't be afraid to ask for help when you need it. Asking for help is self-determination, too.

[Kennedy, 2019](#)

We are going to live self-directed lives and we need all of you to help us do it!

[Tia Nellis, then President of SABE \(Self-Advocates Becoming Empowered\) addressing an international audience](#)

Quality support should be based on: “an authentically implemented culture of person-centered care and planning; ongoing and mutually respectful relationships; the principle that (supporters) 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.

[Otmann et al, 2009](#)

There is evidence that in some areas of the UK people with learning disabilities are ‘self-building’ their own networks of support... (which includes) developing their own personal networks and local venues, facilitated community networks, circles, catalysts, micro-enterprises... advocacy groups, gig buddies and friendship clubs.

[Hall et al, 2018](#)

An Independent Facilitator is a person selected and directed by the participant to assist in the development and execution of a person-centred plan and to assist the participant in making informed decisions about the participant's choices regarding self-determination.

[An Act Relative to Real Lives, 2014](#)

Independent facilitation (supports) the individual... to take up his citizenship and make his or her contribution alongside others... The role is fundamentally derived from a social justice perspective... Where there are no existing family connections, (independent facilitators make an) effort... to recognise those people who love and care for the individual and who are prepared to stand by them over time... The foundation of the work is relational.

Ontario Independent Facilitation Network – Canada, 2019

Local Area Coordinators (LACs) (in support of NDIS participants in Australia):

- work with their local community to make it more inclusive for all people with a disability
- link you to information and support in the community and mainstream services
- work with you to develop your plan, help you implement it, and monitor how your plan is going and undertake your Plan Reviews

Scope Australia, 2019

Supported Decision-Making is a series of relationships, practices, arrangements and agreements designed to assist an individual with a disability to make and communicate with others decisions about their life.

Disability Rights Maine, 2019

Less restrictive means of decision-making supports should be tried... before use of guardianship... is considered... The appointment of a guardian... limits an individual's autonomy... and transfers the individual's right of autonomy to another individual/entity.

National Resource Center for Supported Decision-Making, 2019

Older people need to receive simple, clear informational aids (available in multiple formats) to help them understand their program options and responsibilities and to help them develop and implement their care plan.

[Fernhill Solutions, 2017](#)

A ‘circle of support’ program as well as peer and volunteer support should be considered when care recipients prefer less agency involvement.

[Fernhill Solutions, 2017](#)

The purpose of Community Navigator Services is to promote self-determination, support the individual making life choices, provide advocacy and identify opportunities to become a part of their community... provide support in developing social networks... and promote and coordinate the use of generic resources.

[North Carolina Division of Medical Assistance, 2016](#)

It is common for (self-direction) programs to ... provide participants with a counselling service to advise them how to use their individual budget, about the types of choices available, and how to plan for emergencies.

[Alakeson, 2010](#)

IRIS consultants:

- Listen to what you want your life to be.
- Help you figure out how to meet your goals.
- Help you design a plan that fits your budget.
- Make sure all required paperwork is done.
- Assist you to update your plan.
- Help you find workers, service providers and items.

- Assist you in completing...paperwork.
- Help you find places to buy equipment and...supplies.
- Help you explore job opportunities.
- Assist you to develop a backup plan to help keep you safe.
- Measure how well your plan is working.
- Help you understand your responsibility to stay eligible for Medicaid and IRIS.

Wisconsin Department of Health Services, 2018a

A Support Broker is an individual who assists participants in planning, securing and directing self-directed supports.” (IRIS Service Definition Manual, 2018) Examples of tasks performed by Support Brokers include:

- helping participants navigate systems which can be daunting to them (e.g. establishing eligibility for public funding, accessing nutrition programs, using affordable housing programs)
- assistance in coordinating a complex array of medical, behavioral, residential, and vocational services
- helping participants identify vendors and other contractors for home modifications and other adaptive equipment
- assisting participants in designing the role for their participant-hired workers and recruitment of such workers

Kevin Keisling, Executive Director, Avenues to Community, Madison, WI – USA, 2019

Bridge Builders...help a person build a bridge into community life... Bridge Builders are paid staff that support (people with disabilities) to identify personal interests, set goals, and make lasting, natural connections in community settings... Bridge Builders are community connectors, assisting members to self-select what they want to do and where they want to do it.

LOV Dane, 2019

REFLECTION #4

Acknowledging the need for paid support for self-direction makes sense if one acknowledges the reality that some people have limits in their intellectual capacity or memory, some people are worn down by life or the service system, and some people don't have family or friends who can provide unpaid support for self-direction. Without support:

- some people will be unsuccessful in self-direction, i.e. they will face life or service-related difficulties they can't overcome, their choices will be manipulated by people who have undue influence over them, or the administrative aspects of self-direction will be overwhelming, and
- the view that “some people aren't capable of self-direction” will be reinforced



Figure 1. Various models of infrastructure for self-directed support

REFLECTION #5

Looking around the world, it is interesting to note the variety of supports which are available to help people be successful in self-direction. It appears that certain models of support fit the local history and culture better than other models.

Certain models could also be complementary, i.e. it could be worthwhile to have more than one model of support available in a locale. By showcasing some of the kinds of support that have developed in various places, my hope is that we can learn from each other and have more cross-pollination of these good ideas around the world.

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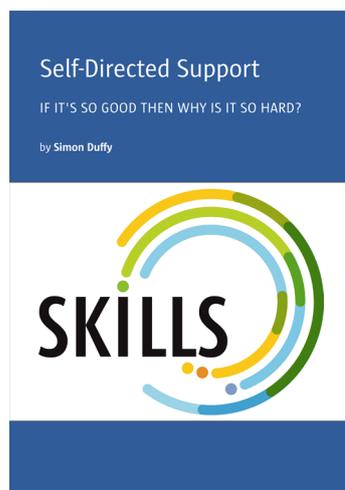
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ABOUT THE AUTHOR

Lynn Breedlove was the Executive Director of Disability Rights Wisconsin from 1980 to 2011. He is a Past President of the National Disability Rights Network in the United States. He is a board member and Past President of In Control Wisconsin (www.incontrolwi.org), an organization formed to promote and defend self-direction in Wisconsin. He was also involved in the design and implementation of Wisconsin's IRIS self-direction program.

Email: lynnbreedlove.wi@gmail.com



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This paper is available to read at: www.centreforwelfarereform.org

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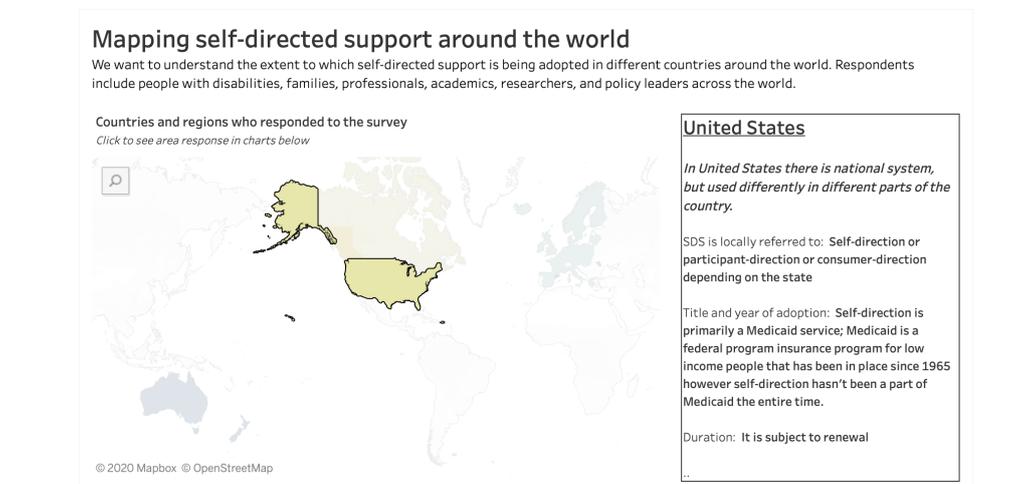
In 2017, with support from the European Union’s Erasmus+ programme, we created a network for learning about self-directed support called the SKILLS project. The SKILLS project developed a range of resources to help countries develop systems of self-directed support. In 2019 we were awarded a further 3 years of funding to strengthen and extend this network and to advance self-directed support across the whole of Europe.

The project is led by KVPS and is managed in partnership with the Finnish National Agency for Education. However, although the hub is based in Europe, we welcome membership from leaders on self-directed support from around the world. Our network is made up of organisations who are leading work in their home country or region on self-directed support, particularly those working alongside people with intellectual disabilities and their families. Our goal is to work in partnership with other important European and International bodies, especially those led by disabled people, and to help ensure we can achieve citizenship for all.

To find out more go to: www.selfdirectedsupport.org

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