

The 2021 Self-Direction Virtual Conference Series

#SDseries2021



SELF-DIRECTION WORLDWIDE

WHAT CAN WE LEARN FROM EACH OTHER?

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Wisconsin

The Self-Direction Virtual
Conference Series

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SELF-DIRECTION HAS MANY NAMES AROUND THE WORLD

Personalisation

Self-determination

Personal budgeting

Individualized budgets

Participant-directed care

Consumer-directed care

Client-led care

Self-management

Direct payments

Cash payments for care

Cash and counseling

WISCONSIN'S IRIS SELF-DIRECTION PROGRAM – CREATED IN 2008

People with “intellectual or developmental disabilities”	8,000
People with physical disabilities	9,000
“Frail elderly” people	5,000
TOTAL in 2021	22,000



AN EXAMPLE OF A “CONTROL YOUR WHOLE LIFE” DEFINITION OF SELF-DIRECTION

“Self-Determination is the right of all people with disabilities (with their chosen allies) to make choices and direct all aspects of their lives.”

(The Survival Coalition of Wisconsin Disability Organizations, 2006)



Andy Thain, Thorp, Wisconsin, U.S.

A DEFINITION OF SELF-DIRECTION FOCUSED ON A PERSON'S CONTROL OF SERVICES

"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."

(V. Alakeson, "International Developments in Self-Directed Care", 2010)



SOME PEOPLE SAY SELF-DIRECTION IS AN ESSENTIAL PART OF CITIZENSHIP

“Self-directed support is organized around a Citizenship Model that says:

- Citizens are in control of their lives
- Citizens live as part of a community
- Citizens have a right to support
- Citizens shape the support they need”

Simon Duffy, Centre for Welfare Reform, England



DISSATISFACTION WITH THE SYSTEMS THAT PRECEDED SELF-DIRECTION



- “The current system (is) task-based, rigid, and non-responsive” (New Zealand)
- “Service organizers (i.e. case managers) communicate with service providers directly...voices of people with disabilities (are) unheard...service systems tend to narrow the choices for people.” (Finland)
- The implementation of self-directed support was largely driven by criticism of the welfare state and its inability to promote independent living.” (Scotland)
- (The impetus for self-direction is the desire) “to remove the power that service systems have to dictate such fundamental matters as where and with whom people live and who assists them.” (U.S.)

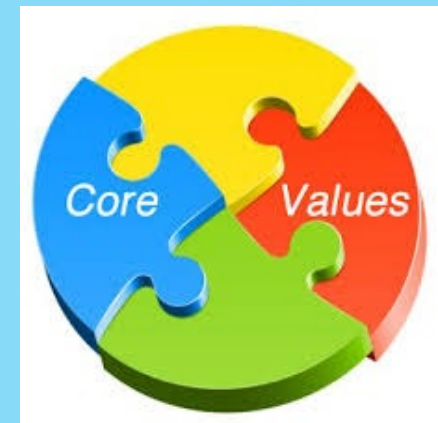
OVERALL POSITIVE EVALUATION RESULTS OF SELF-DIRECTION WORLDWIDE (COMPARED TO PREVIOUS SYSTEMS)

- Higher consumer satisfaction, worker satisfaction and worker 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 services
- Good stewardship (i.e. responsible use) of public funding
- Very few cases of fraud or abuse



THE VALUES OF SELF-DIRECTION: RECURRENT THEMES AROUND THE WORLD

- Respect for people receiving services
- Ownership of your life and your relationships
- Maximum choice
- Opportunity to explore and pursue all the possibilities that life offers
- Right to custom-design your supports to fit your culture and lifestyle
- Professionals are partners, not overseers
- Community integration and participation



HOW DOES SELF-DIRECTION RELATE TO COMMUNITY INTEGRATION?



SOME PEOPLE SAY COMMUNITY PARTICIPATION IS **ESSENTIAL** TO SELF-DIRECTION

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

The System of the Future, Tom Nerney, 2003



OPINIONS VARY WITHIN SELF-DIRECTION CIRCLES: WHAT DO YOU THINK?



Is community participation:

- A goal for everyone in self-direction?
- A goal only for those people who bring it up and affirmatively identify it as a goal?
- A possible goal we should raise with people to ensure they have an informed choice to embrace it or not?
- A goal we should assume applies to everyone unless they tell us it isn't?

QUESTIONS OR COMMENTS?



SHOULD PEOPLE HAVE ACCESS TO PAID SUPPORT TO SUCCESSFULLY SELF-DIRECT?

“The Scottish Government believes that ... 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)



EXAMPLES OF SUPPORTS TO HELP PEOPLE SELF-DIRECT



"SELF-BUILDING SOCIAL CARE" ENGLAND & SCOTLAND

THE BACKDROP:

- Self-direction and Personal Budgets have been popular in the UK for some time
- Substantial cuts in "social care" (human services) \$ in the UK in recent years, resulting in cuts in day services and employment supports, tightening eligibility, and loss of adult education programs
- Growing interest in "Co-Production" (local citizens, professionals and providers working collaboratively at the local level to create new exciting projects custom-designed to fit the local community)
- More info: **Selfbuildingourlives.org**



“SELF-BUILDING SOCIAL CARE” – WHAT IS IT?

- **“Self-build social care” = people with disabilities co-constructing local networks from the local resources and relationships available to them**
- Involves a merger of individualized supports and “collectivized forms of support” created and controlled by people with disabilities
- Examples: facilitated community networks/circles, micro enterprises, peer advocacy groups, friendship clubs, and “gig buddies” (people with disabilities and volunteers with similar interests attending concerts and other events together)
- Strong emphasis is placed on working with people to identify what they care about and what interests them



ANSWERS TO
"WHAT IF THERE IS NO
SUPPORT FOR S-D?"

FROM WI SELF-DIRECTION
FACILITATORS - 2021



- People won't know what choices are available, and/or won't get the services/supports they need
- Missed opportunities for creative, cost-effective solutions
- Deteriorating health and safety for participants; increased risk of institutionalization, homelessness and even death
- Many participants will retreat to managed care
- Participants will feel overwhelmed, anxious, frustrated, ignored, and isolated; increased need for mental health services as a result
- Increased burden on families

QUESTIONS OR COMMENTS?



THE MAJOR OBSTACLES TO SELF-DIRECTION



A. The Squeeze



B. Rising Transaction Costs



C. Exclusion

A. THE SQUEEZE

ENCROACHING ON THE SPACE WITHIN WHICH
PEOPLE CAN SELF-DIRECT



B. RISING TRANSACTION COSTS



“Transaction costs” are defined as:

“the costs incurred as a result of participating in a market”

or

“the costs incurred in overcoming market imperfections”

C. EXCLUSION FROM SELF-DIRECTION

If government believes the only people capable of self-direction are those with a proven track record of high self-reliance, then:

- a) some people will be discouraged from choosing self-direction,
- b) the decision-making reins will be handed over to families, or
- c) people will be “screened” for eligibility for self-direction



A FEW THOUGHTS ON OVERCOMING THE OBSTACLES:

1. In general...
2. The Squeeze...
3. Transaction Costs...
4. Exclusion from Self-Direction...



LINK TO SUMMARY AND FULL PAPER ENTITLED

***"SELF-DIRECTION WORLDWIDE:
CONTRASTING BELIEFS
AND THEIR IMPACT ON PRACTICE"***

-LYNN BREEDLOVE (2020)

<https://centreforwelfarereform.org/library/selfdirection-worldwide.html>

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QUESTIONS