

What Would a Great Self-Direction Program Look Like?

Lynn Breedlove (March 2022)

A review of self-direction literature, statutes, policies and advocacy papers in the U.S. and other countries reveals a number of recurrent aspirations of the creators of these programs. Considering these themes as a whole makes it possible to generate a composite vision of a “Great Self- Direction Program”¹ with a number of discrete elements. This paper is an attempt at describing such an aspirational program, which (as far as I know) doesn’t exist anywhere (yet). It is intended to be a starting place for a conversation, not the last word on the subject. LB

1. Clear Self-Direction Definition and Values

Self-direction is clearly defined in statute, policy and/or regulations, and the core values are clearly stated and consistent with progressive views of self-direction (e.g. self-direction is intended to enhance community integration, a sense of belonging in the community, valued social roles, opportunities to participate in paid work, etc.).

2. A Strong Base for Self-Direction in Government

The agency or unit of government that oversees the self-direction program employs individuals with a solid understanding of self-direction and a commitment to it, including a recognition of how it is inherently different from other human service delivery models. This agency has strong ties and an active dialogue with people with lived experience of disability as well as organizations representing self-direction participants and their families, and is committed to continuous evaluation of how the self-direction program is working. The agency accepts responsibility to work with stakeholders to improve the self-direction program in relation to the elements in this paper, and to resist governmental actions which would erode self-direction. The agency also plays an active role in educating the public regarding self-direction and ensuring that people entering the long-term care system are given clear information on the self-direction option. Lastly, the agency actively promotes building the capacity of systems outside the paid services in the self-direction program which are important to self-direction participants, e.g. public/specialized transportation, affordable/accessible housing, etc.

3. Inclusive Eligibility Criteria

Whether a self-direction program is created to serve people with disabilities, people with mental illness, older adults, or all of the above, eligibility to self-direct one’s services within each population is broadly defined in order to affirm the principle that everyone can self-direct with appropriate support, and to ensure that no one is arbitrarily excluded from self-direction based on the level of a person’s disability or dementia, a person’s past track record of living independently, having a guardian, etc.

¹ This paper is focused on self-direction as relates to long-term supports and services for adults, not primary or acute healthcare.

4. Equity, Diversity and Cultural/Linguistic Competence

At all levels of a self-direction program, vigorous efforts are made to ensure that policies, procedures and practices do not intentionally or unintentionally exclude or under-serve potential self-direction participants because of their race, ethnicity, sexual orientation, economic status, primary language, reading/writing/verbal communication skills, or lack of active family to assist with self-direction. Information about self-direction is culturally and linguistically accessible. Support brokers, provider staff, and independent workers are culturally competent and practice cultural humility. The flexibility and creativity inherent in self-direction is leveraged so services and supports are responsive to participants' cultural backgrounds and preferences. There should also be safeguards to prevent the exploitation of undocumented or other workers providing services/supports to participants.

5. Transparent, Reliable and Adaptable Individual Budget-setting

The process for setting individual budgets: a) is transparent and understandable to participants and families, b) reliably generates an individual budget amount that is sufficient to cover the cost of the services/supports the person needs/chooses and the cost of fair wages and benefits, and c) includes a rapid review and approval process to modify the budget when a crisis necessitates a need for it.

6. Support for a Participatory Individual Planning Process

The process for creating individual self-direction plans offers ample time and support² for participants and families to focus on what the participant wants, enable the participant to make informed choices, and ensure that the participant is in the driver's seat for decision-making and plan development. The process also includes culturally inclusive language and processes, and appropriate accommodations.

7. Full Budget Authority

Participants and families have full control over a person's individual budget, as long as the funds are used for allowable goods or services as defined in statute, regulation and/or (in the U.S.) a state's Medicaid Waiver agreement with the federal government. Full budget authority means that a) government does not require prior authorization for an allowable good or service, and b) participants and families have complete freedom to negotiate rates of payment with various vendors and negotiate wages/benefits with independent workers.

8. Full Employer and Technology Authority

Participants and families have complete flexibility to choose the vendors for goods and the providers of their services, subject to criminal background checks³ for direct care workers. This flexibility includes the opportunity to choose from independent workers, neighbors, or family members⁴; established disability, mental health or aging provider agencies; and transportation, housekeeping, shopping or other services utilized by the general public. It also includes the opportunity to supplement or replace

² In various locales, this support is provided by people with job titles such as "facilitators", "support brokers", "independent brokers", "self-direction consultants", "peer counselors", "coordinators", "community navigators", "Bridge Builders", etc.

³ Background checks should be no more restrictive than those used in other human service programs.

⁴ Ideally, the program includes safeguards to ensure that family members are not exerting undue influence over participants to obtain employment for themselves.

services with appropriate technology of the person's choice, e.g. for scheduling, medication reminders, remote monitoring support in lieu of overnight staff, employment task prompts, etc.

9. Flexible Provider Agency Capacity

In every locale covered by the self-direction program, there is sufficient availability and choice of disability, mental health and/or aging provider agencies (depending on the population served) which are familiar with and supportive of the concept of self-direction, and sufficiently flexible in the provision of their services to accommodate the choices and cultural differences of participants.

10. Support for Successful Participation in Self-Direction

Participants and families have access to support⁵ as needed to: change individual plans; request changes in individual budgets; negotiate rates with vendors; effectively recruit, train and supervise independent workers; find new providers; develop backup plans; deal with medical, behavioral or other crises; develop appropriate health and safety protections, etc.

11. Participant-Friendly Processes throughout the Self-Direction Program

All of the processes⁶, mechanisms and forms associated with the administration of and participation in the program have been designed to be as simple, understandable and timely as possible, and are available in accessible formats as necessary. Red tape has been kept to a minimum. In comparison to managed-care or fee-for-service programs, participants and families are not experiencing extra "transaction costs"⁷ because they chose to self-direct their services.

12. Reliable Fiscal Intermediaries

The fiscal intermediary agencies which make payments to provider agencies and independent workers, handle payroll taxes and workers compensation, and generate spending reports for participants and families carry out these functions in a participant/family friendly manner, with a high degree of accuracy, transparency, timeliness and accessibility.

13. Training for Successful Self-Direction

Participants and families have easy access to free, high-quality training in a variety of formats to enable them to be successful in all aspects of self-direction. This training should include trainers with lived experience of disability and self-direction.

Lynn Breedlove is the former Executive Director of Disability Rights Wisconsin and a Past President of the National Disability Rights Network. He helped design Wisconsin's IRIS Self-Direction Program, which now has an enrollment of over 23,000 people with disabilities and older adults. He has done extensive writing, speaking and training on self-direction.

⁵ As with #5 above, depending on the locale this support is provided by "facilitators", "support brokers", "independent brokers", "self-direction consultants", "peer counselors", "coordinators", "community navigators", "Bridge Builders", etc.

⁶ This includes appeals and grievance processes.

⁷ In the context of self-direction, "transaction costs" refers to all the time, energy and stress associated with dealing with the mechanics of self-direction that is expended by participants, families and friends.