

Understanding Self-Direction for People with Developmental Disabilities: A Choice for Change in Illinois

Executive Summary

Self-direction is based on the idea that the people being served are in the best position to know what they want and need in order to connect to other people and resources in their community and live a quality life of their own making. Self-direction for people with developmental disabilities places the individual in control of a personal budget allocation and provides adequate support to the individual to plan and choose needed services.

Self-directed services have four key elements:

1. An **INDIVIDUAL BUDGET** controlled by the participant
2. A **SERVICE COORDINATOR** to help develop and monitor the Individual Service Plan and Individual Budget and ensure access to services
3. A **FISCAL INTERMEDIARY** to assist in financial management of employee payroll and taxes and purchased goods and services
4. **CHOICE OF SERVICES** from current providers and/or general services that are offered in the most integrated setting

Therefore, we recommend that Illinois develop a Self-Directed Supports Waiver for adults with developmental disabilities, which includes these four basic elements. We further recommend that the waiver include the following provisions:

- **Establish a Self-Directed Supports Waiver Advisory Committee made up of Self-Advocates and Stakeholders** – this committee would advise the state during the waiver development process and implementation of the self-directed supports waiver, with representation from self-advocates, family members, and stakeholders.
- **Offer a Flexible Individual Budget with Customizable Services** – participants should have a flexible enough budget that allows a true choice of services, including customizable goods and services that are not traditionally covered by Medicaid, while staying within funding limits.
- **Use an Effective Needs Assessment Tool** – the state should be utilizing the most effective needs assessment tool currently available for adults with developmental disabilities that determines a participant’s needs, goals, and individual budget, such as the Supports Intensity Scale (SIS).
- **A Fully Informed Participant** – the state should develop a method that lets the participant’s needs and goals dictate the individual budget and Individual Service Plan while fully informing the individual of limits to his or her funding and service options.
- **Use a Quality Fiscal Intermediary** – the state should commit to developing a Fiscal Intermediary capacity to manage fiduciary responsibilities associated with



a self-directed system, including management of employee payroll and taxes and purchases of goods and services as warranted. We believe that both ACES\$: Avenues to Consumer Services and \$upport and Public Partnerships have the potential to operate successfully under a new self-directed system in Illinois.

- **Use Quality and Independent Service Coordinators** – the state should develop a standard level of education, experience, and state-provided training in self-direction for Service Coordinators and either develop a new statewide Service Coordination Agency or modify the role of the Pre-Admission Screening (PAS) agents to ensure Service Coordinators remain independent of agencies that provide other services and offer a true choice to participants.
- **Establish an Additional “Support Guide” Role** – in addition to the Service Coordinator, the state should develop a position that can provide day-to-day assistance for participants, such as self-direction training, employee management education, community access, budgeting, and customized employment.
- **Develop Peer Support Network Opportunities** - the state should use self-direction to develop opportunities for people with developmental disabilities to connect with each other and their community, such as:
 - *Human Service Cooperatives* are governed by the members and their families to share resources and coordinate services and supports. Cooperatives would offer an opportunity to share information about self-direction among potential participants and develop a network of individuals and families to support one another as they begin self-directing their services.
 - *Peer Support Networks* would offer mutual assistance for individuals and their families to support one another and build community. These networks would not necessarily coordinate services like cooperatives, and could be organized by Service Coordinators to bring together individuals with similar interests and life experiences in a community.
- **Offer Different Levels of Self-Direction and Assistance** – the state should offer participants a range of options with varying degrees of self-direction and provider assistance. Options could include:
 - Participants have responsibility and control over services, staff, and the Individual Budget, with support from a Service Coordinator and Fiscal Intermediary. This option is typically called *Employer of Record*.
 - Participants recommend workers to be hired by a provider or leasing agency but retain control over the Individual Budget with the support of a Fiscal Intermediary. This option is typically called *Co-employment*.
 - Participants use staff and services from a traditional provider agency with an Individual Budget and input on how, when, where and by whom services will be delivered, placing more control and involvement on the service provider. This option is typically called *Agency with Choice*.

