

THE PENNSYLVANIA DEVELOPMENTAL DISABILITIES COUNCIL

POSITION PAPER

Participant-Directed Services and Supports

Participant-directed services and supports are a system in which people with disabilities, and their chosen family, friends and allies, choose how their services and supports are designed, put into place, and funded.

PDSS are home and community-based services in which a person has the authority to:

Develop the array of formal and informal services and supports which meet her/his needs

Directly recruit, hire, train and manage the people that support him/her and

Make decisions about how the funding to support him/her is spent.

Participant-directed services are about choice and control.

Philosophy

The PA Developmental Disabilities Council believes that all people with disabilities should have the option to design, control and direct their own services and funding. Participant-directed services can provide these options. People directing their own services report increased satisfaction and better life outcomes, and experience in other states has shown that in some cases, when people with disabilities direct their own supports, they use less money than if the services had been prescribed for them¹. CMS describes PDSS as having the “potential for cost effectiveness”.²

¹ Dale, Stacy B., and Randall S. Brown. "How does Cash and Counseling affect costs?." *Health Services Research* 42.1p2 (2007): 488-509.

Dale, Stacy B. and Randall S. Brown. "Reducing Nursing Home Use through Consumer-Directed Personal Care Services." *Med Care* 44.8 (2006): 760-7.

Dale, S., Brown, R., Phillips, B. Schore, J. and Carlson, B. (2003). The effects of cash and counseling on personal care services and Medicaid costs in Arkansas. *Health Affairs: Data Watch*. November 19, 2003.

Carlson, Barbara Lepidus, et al. "Effects of Cash and Counseling on Personal Care and Well-Being." *Health Services Research* 42.1 (2007): 467-487.

Fleming-Castaldy, Rita P. "Are Satisfaction with and Self-Management of Personal Assistance Services Associated with the Life Satisfaction of Persons with Physical Disabilities?" *Disability & Rehabilitation* 33.15-16 (2011): 1447-1459.

Powers, Laurie E., Jo-Ann Sowers, and George HS Singer. "A Cross-Disability Analysis of Person Directed, Long-Term Services." *Journal of Disability Policy Studies* 17.2 (2006): 66-76.

Young, Heather M., and Suzanne K. Sikma. "Self-Directed Care: An Evaluation." *Policy, Politics, & Nursing Practice* 4.3 (2003): 185-195.

² Centers for Medicare and Medicaid Services. Teleconference with Pennsylvania PDSS Coalition (9/16/2013).

Combined with good person-centered planning³, participant-directed services can offer excellent opportunities to focus on outcomes, achieving goals held by all people, like enjoyment of full citizenship; full participation in their chosen communities; and engaging more naturally with friends and family.

Participant-directed services are a critical part of empowering people to develop the variety of community supports and community engagement needed by full members of societies. By their very nature, participant-directed services make it more likely that people are receiving support to participate in non-disability specific settings and from non-system resources.

Principles for Success⁴

Freedom to plan a real life. The ability for a person with a disability, along with freely chosen family and friends, to plan their own lives, with necessary support, rather than purchase a one size fits all program.

Authority over resources. The ability of a person with a disability to control the dollars needed to purchase supports.

Support for building a life in a person's community. The arranging of resources and personnel — formal and informal — that will assist a person with a disability to live a life in the community that is rich in friendships, work, family and community associations.

Responsibility to give back to the community. Taking a valued role in a person's community through competitive employment, organizational affiliations, spiritual development and general caring for others in the community, as well as accountability for spending public dollars in ways that are productive and effective.

Recommendations

To ensure that people have the opportunity to direct their own services, the Council believes that all waiver participants and other Pennsylvanians supported by disability service systems must be provided with information to make an informed choice about how their services and supports are created and delivered. Information provided must include: descriptions of all of the services that can be

³ The process is directed by the individual, with assistance as needed or desired from a representative of the individual's choosing. It is intended to identify the strengths, capacities, preferences, needs, and desired measurable outcomes of the individual. The process may include other persons, freely chosen by the individual, who are able to serve as important contributors to the process. (Centers for Medicare and Medicaid Services).

⁴ Adapted from the Robert Wood Johnson Foundation's National Program Office on Self-Determination for Persons with Developmental Disabilities (1998).

self-directed; supports that can be created and maintained in the non-formal, natural community, and descriptions of the supports available to assist people to self-direct.

The Support Broker system should be enhanced and empowered to work in a PDSS system, and the Support Broker model should be available to all people with disabilities in all Commonwealth systems of service and support.

People with disabilities must be meaningfully involved in efforts to redesign systems for Person Directed Services and Supports. Potential recipients of person directed services should form the majority of the stakeholders involved in such systems redesign and implementation.

Equally, support must be given in the financial management of these services, and the ongoing assessment of the programmatic supports provided in both formal and informal communities. Power to change supports must be available, and the opinions and choices of the person with the disability supported.

- Lastly the state must establish and maintain a system for the evaluation of the new changes. This should involve the programmatic, life outcome and financial aspects of the changes conducted, ideally, by people with disabilities and their chosen allies along the model of the IM4Q⁵ program. Such evaluation should be conducted on a statewide basis and the results compiled and distributed widely amongst stakeholders.

Adopted by Council 4/16/2015

⁵ A program in which people with disabilities and their chosen allies conduct interviews with people in the ODP system to determine and measure their life outcomes, preferences and needs.