

Issue:

DDAN ISSUE REPORT: PERSON-CENTERED SELF-DIRECTED SERVICES

Issue Description:

It has become apparent to families that the state of New Jersey does not share their view of what constitutes “person-centered planning”. While the state seems to view this concept as a simple matter of meeting certain criteria on a checklist, individuals and families desire thoughtful planning that actually helps individuals with intellectual and developmental disabilities (I/DD) to achieve their life goals. For true person-centered services to be achieved is it vital that the state is on the same page as advocates.

Toward that end, it is important for state support coordinators to be well trained and empowered to assist individuals and families. As positive outcomes in obtaining services demand support coordinators with the knowledge and skills to create true person-centered service plans, improved training and accountability is needed. Restrictions should be softened to allow Support Coordinators to assist people and families in areas where HIPPA laws have previously prevented them from getting involved. And coordinators should be instructed and empowered to move away from cold and impersonal terms for people with I/DD, such as “consumer” or “client”, toward the use of more person-centered terminology.

One of the most pressing and persistent challenges currently faced by families who seek personalized support services is the state’s recent changes to the Self-Directed Services (SDS) system. Since the state’s move to appoint Public Partnerships, LLC (PPL) as its new fiscal intermediary, the whole system has been thrown into disarray. Families strongly feel as though the very concept of self-direction is being actively discouraged by the state. The state’s move from Easter Seals to PPL as the SDS fiscal intermediary has caused a sharp rise in confusion and hardship among families, and the state’s decision to place families as employers of record leaves families vulnerable in the event of legal disputes with self-directed employees. Families and self-advocates fought very hard for years to achieve self-directed services. Yet recent changes have drastically restricted, rather than expanded, the freedom, choice, and control to address individual needs that families once had.

1. Person centered planning is a process of continual listening, and learning. It focuses on what is important to and important for someone now, and in the future; and acting upon this in alliance with their family, friends and service providers (<http://helensandersonassociates.co.uk/person-centred-practice/>).

As the system transition to the Fee for Service, many individuals and families in Self-Directed Services have experienced the erosion of self-direction, and the very concept of Person-Centered Services is being actively discouraged by the state. A series of changes has caused a sharp rise in confusion and hardship among families. Families and self-advocates fought very hard for years to achieve self-directed services. Yet recent changes have drastically restricted, rather than expanded, the freedom, choice, and control to address individual needs that families once had.

2. With multiple statewide changes, the role of Support Coordinator has become more important than ever. Individuals and families desire thoughtful planning that actually supports individuals with intellectual and developmental disabilities (I/DD) to achieve their life goals. It is vital for Support Coordinators to be well trained, supervised and empowered to assist individuals and families. The high turnover rate and burnout of Support Coordinators negatively affect the lives of individuals and families.

Issue Action Items: (Include if the Action is at the Federal/State/Local Government/Community or Media Level)

1. Increase focus on the Person-Centered planning in policy making and accountability practice
 - a. DHS to include individuals, families, Support Coordinators, and service providers at a table from the beginning of discussion, not after the policies/guidelines are drafted (State/Local Government)
 - b. DHS to schedule regular dialogue sessions with individuals, families, Support Coordinators and service providers for interactive planning and collaboration to ensure the smooth running of the system as a whole.
2. Increase choice of Self-Directed Person-Centered Service System
 - a. Offer both Employer of Record and Agency with Choice system (State)
 - i. Ensure individuals and families to change their choice without service disruption
 - b. Offer two Fiscal Intermediary (FI) models for processing payments for services rendered (State)
 - i. FI to simply process payments for those persons in the SDS program that wish to have total control over their needs.

- ii. A fiscal agent with Choice who will be the “Employer of Record” who offers comprehensive full-time DSP benefits such as medical, dental, life insurance, sick time, paid-time off and paid vacation. A package similar to that enjoyed by DDD personal and other state employees.
 - iii. DHS to improve its flexibility of Medicaid billing (up to 60 days) in order to prevent service disruption caused by unforeseen circumstances (such as approval delays due to State IT issues)
 - iv. DHS to use state-only dollars to cover services when service disruption happens due to unforeseen circumstances beyond individual and families’ control
 - c. Expand the definition of Support Brokerage to include not only management of Self-Directed Employees but also agency-hired staff so that they can assist individuals in federal, state, and local programs such as Supplemental Nutrition Assistance Program (SNAP, formerly called Food Stamp), housing and utilities assistance and Medicaid.
- 3. Ensure and enhance freedom of choice
 - a. Include state-only dollars for specialized services and allow time-limited service duplication or extension of approval under special circumstances such as hospitalization and vacation
 - b. Increase the provider capacity in rural, city and any underserved areas (Local Government/Community)
- 4. Make robust and comprehensive plan to solve the Direct Support Professional (DSP) workforce crisis (Federal/State/Local Government/Community/Media)
 - a. Increase the wage for DSP and restore comprehensive benefits for all full-time DSP including medical, dental, life insurance, sick time, paid-time off and paid vacation (Federal/State/Local Government/Community/Media)
- 5. Increase the quality of Support Coordination Services
 - a. Streamline the documentation so that Support Coordinators can focus and facilitate Person-Centered Planning and Services in collaboration with individuals, families, providers and other stakeholders (Federal/State/Local Government/Community)

- b. Make a robust support and training system to reduce turnover and prevent burnout (Federal/State/Local Government/Community)
- c. Utilize innovative international and national recognized leaders in person centered planning to provide evidence-based training (State/Local Government/Community)
- d. Offer substitution of relevant experience for required education for Support Coordinators (State)
- e. Create a separate code by Department of Labor in order to collect data such as service request, provision and utilization rate (Federal)
- f. Improve the mechanism to qualify new Support Coordination Agencies and disqualify those that do not meet quality standards.

Next Steps:

1. Recruit more members, especially younger parents and individuals, to the Committee
 - a. Committee members will speak to other families and individuals
 - b. The list of prospective members will be submitted to DDAN for review.

¹ 2015 DDD Quality Improvement Stakeholder Report (https://www.state.nj.us/humanservices/ddd/documents/stakeholder_input_report_on_quality_improvement.pdf)

² CQL – 5 Factors of Quality (<https://c-q-l.org/files/2017Documents/CQL-Personal-Outcome-Measures-Factors-And-Indicators.pdf>)