

DDAN ISSUES REPORTS: Person-Centered Services Committee

Issue:

The Developmental Disability Advocacy Network (DDAN) Person-Centered Services Committee firmly believes that person-centered thinking is the most important overarching principle for the service delivery system for people with Intellectual or Developmental Disabilities (I/DD).

Issue Description:

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. Person-centered planning pioneers, such as Learning Community for Person-Centered Practices and the University of Missouri-Kansas City, have created various tools to implement their definitions and framework¹ in people's lives. In the last over 10 years, NJ's Service delivery system has experienced multiple changes. In recent years, NJ has made some progress such as the creation of the Division of Developmental Disabilities (DDD)'s [Office of Education on Self-Directed Services \(OESDS\)](#), joining the National Community of Practice Supporting Families, and completing the National Center on Advancing Person-Centered Practices and Systems (NCAPPS) Self-Direction Learning Collaborative. Many advocates believe that more robust collaborations are needed to further infuse the concept of person-centered planning into practice, including freedom, choice, control, contribution, flexibility, and budget authority for all. The Committee emphasizes for all including those who choose provider-managed or self-directed services.
2. Philosophy and values that drive person-centered thinking/planning need to be reflected and written in all the policies and put into practice regardless of the choice of their service delivery model. Considering the Home and Community-Based Settings Rules unequivocally put individuals in the driver's seat, individuals and families must be at the table to create and revise policies, not after they are finalized.
3. Adequate housing is a human right and a key social determinant of health. However, numerous research studies confirm that individuals with disabilities often face significant challenges in accessing both stable housing and essential supports and services. In New Jersey, the shortage of affordable housing and limited flexibility in managing or budgeting staff within their own homes continue to be major obstacles for individuals with I/DD seeking to live in the community.
4. Support Coordination plays a critical role in making person-centered thinking and planning a reality. It is vital for Support Coordinators and Supervisors to be well-trained, mentored, and empowered in person-centered thinking, planning, and facilitation skills to assist individuals and families; however, the current training and certification process

¹ The Learning Community for Person Centered Practices, <https://tlcpcp.com>; and Charting the LifeCourse developed by the LifeCourse Nexus, University of Missouri- Kansas City, <https://www.lifecoursetools.com/>

may not necessarily cover all aspects of person-centered planning and increase their competency. In addition, many Support Coordinators expressed that a significant amount of paperwork prevents them from providing quality and meaningful engagement with individuals and families, which is an essential part of the working relationship. Support Coordination Agencies are struggling with a high turnover rate and burnout due to the aforementioned barriers.

5. Direct Support Professionals (DSP), including Self-Directed Employees (SDE), are the backbone of the I/DD service delivery system; however, their salary is far from the living wage. It is commendable that the wage for DSPs steadily increases every year; however, due to New Jersey's annual minimum wage raise as well as the recent steep inflation rate, it has a limited effect on resolving the DSP workforce crisis. People who self-direct their services report that the \$25 hourly wage cap for SDEs negatively impacts the recruiting, hiring, and retaining of competent staff. Especially for people with acuities, these regulations have been a barrier to choose their own staff as nursing credentials are now mandated in order for SDEs/DSPs to have an increase in wages. Individuals and families who chose the traditional agency delivery model fear that eliminating the cap would further exacerbate their staffing issues. This Committee is concerned that the advocacy work that focuses on one group unintentionally hurts the others, while all agree that DSP's salary should reflect their invaluable roles and skills. As this Committee represents the whole DD Community, we urge leadership and all stakeholders to collaborate to pursue a solution for all, rather than divide ourselves.
6. Aging parents/family members struggle to find and train their successor(s) who are willing and capable of "carrying the torch" to support their loved ones with disabilities. Fortunately, the OEOSDS within DDD is actively working with stakeholders, accessing multiple resources and tools for adult individuals with I/DD and their aging families to prepare for the change of primary caregiver (often called succession or future planning). There currently is a committee working on systemic and generational sustainability throughout adulthood. Some individuals and families, especially those who rely on paid staff, express their desire to learn and use tools to help them prepare for care succession planning. Many expressed to learn from and with other individuals and families with similar lived experiences (peer-to-peer support and education).
7. Support Brokerage is expected to assist Self-Directing individuals and families. The number of Support Brokerage is increasing and more people are aware of such services. Though the recent rate increase of Support Brokerage may entice more providers to offer this viable support, the state should assess the unintended consequences on individuals and families as some people have to give up this critical support due to budget constraints. In other states, such as Pennsylvania, Supports Brokerage does not impact the individual's budget. The service delivery is also limited and people who live in a provider-managed setting are unable to receive Support Brokerage even if they choose to direct their support and activities during the day.
8. Since the onset of the pandemic of the COVID-19, the restriction of hiring family members as paid staff has been eliminated. The Committee applauds the State's swift

response and appreciates increased flexibility. While we hear numerous success stories, we also started to hear about some questionable practice. This issue is stemmed from multi-layered issues including but not limited to lack of quality care, long waitlist for services, DSP shortage and high turnover. Individuals with acute needs struggle to establish non-family support and services. The Committee respectfully requests that the I/DD community and state leadership acknowledge these unintended consequences and collaboratively work to create a mechanism to assure the quality of services, financial transparency, and accountability of paid family staff, without jeopardizing the flexibility and trust of family support.

Issue Action Items:

1. Increase focus on person-centered planning tools and approaches for all people in the DDD Adult System, in policy-making and accountability practice
 - a. Expand the role and mission of the Office of Education on Self-Directed Services (OESDS)
 - i. OESDS to work with not only self-directing individuals and their families but also all who receive the DDD-funded services and support
 - ii. Lead the community engagement in all work around self-direction, working on the challenges of sustainability, futures planning, aging caregivers, and championing person-centered thinking, planning, best practices and living by staying on the cutting edge of national trends, using and sharing several practices, tools, methods and continue to actively work to pursue growth in these areas within the system with stakeholders.
 - iii. Change the name to the Office of Person-Centered Best Practices to reflect its expanded roles and objectives to serve all
 - b. DHS/DDD to include individuals, families from both the Self-Directed and Provider managed models of support, Support Coordinators, and service providers at a table from the beginning of discussions, not after the policies/guidelines are drafted (State/Local Government).
 - c. DHS/DDD to resume quarterly dialogue sessions, as we have in years past “Dialogue with the Division,” to include individuals and families from both the Self Directed and Provider Managed models of support with individuals, families, Support Coordinators, and service providers for *interactive* planning and collaboration to ensure the smooth running of the system as a whole. A strong focus should be made on discussing person-centered practice and planning.
 - d. OESDS and DDD to collect both quantitative and qualitative data through the above-stated groups and share the results with the public.
 - i. Data collection includes but are not limited to: the number of people who self direct and barriers to achieve their goals
2. Increase choice of person-centered planning and approaches in all DDD Service System

- a. DHS/DDD to monitor the upcoming Fiscal/Employer Agent provider changes and provide additional support to individuals and families as needed.
 - b. Allow individuals and families to change their choice without service disruption between two Fiscal Intermediary (FI) models for processing payments for services rendered
 - i. FI to simply process payments for those persons in the SDS program who wish to have total control over their needs.
 - ii. FI to simplify the hiring and onboarding process.
 - iii. DHS to improve and simplify its flexibility of Medicaid billing for Goods & Services (currently up to 60 days) approval to be within 7 business days in order to prevent service disruption caused by any unforeseen circumstances.
 - iv. DHS to use state-only dollars to cover services when service disruption occurs due to unforeseen circumstances beyond individual and families' control.
 - c. Expand the availability of Support Brokerage to all who need extra support and make it accessible without worrying about constraining their budget
 - i. Extra support may include but is not limited to:
 - 1. Assist individuals/families in applying for federal, state, and local programs such as the Supplemental Nutrition Assistance Program (SNAP, formerly called Food Stamp), housing, and utility assistance
 - 2. Coordinate person-centered supports, services and activities along with individuals who reside in a licensed provider-managed setting and choose to individualize their weekday (Traditional Day Program Hours)
 - ii. Establish separate funding for Support Brokerage, not out of individuals' budget.
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.
 - i. Direct Support Professionals should be paid when they accompany individuals to hospitals to communicate on their behalf, relay important medical history, and provide emotional support ("Retention pay").
4. Reinstate full budget authority to all individuals and families who are self-directing their services and make a robust and comprehensive plan to solve the Direct Support Professional (DSP) workforce crisis
- a. Remove the wage cap and honor true budget authority and freedom of choice for individuals to determine their SDE's wage, give raises, build longevity, and continuity of care, and respect the role of their employees

- b. Establish a “provider-assisted self-direction” option where individuals and families can remain active in choosing their staff and services, while agencies assume responsibility for providing administrative support (e.g. paperwork).
 - c. Increase the wage for DSP and restore comprehensive benefits for all full-time DSPs including medical, dental, life insurance, sick time, paid time off, and paid vacation for all Fiscal Intermediaries.
 - d. DHS to continue to promote the [Jobs that Care New Jersey](#) and launch targeted outreach to potential or future DSPs and those who are interested in working with people with disabilities (e.g. college students).
 - e. Create a Standard Occupational Classification (SOC) for DSP in order to collect data such as service requests, provision, and utilization rate (Federal).
5. Increase the quality of Support Coordination Services
- a. Increase the rate for Support Coordination Services.
 - b. Reduce and consolidate the documentation (paperwork) so that Support Coordinators can focus and facilitate person-centered planning and services in collaboration with individuals, families, providers, and other stakeholders (“People over Paper”).
 - c. DDD and Support Coordination Agencies to utilize innovative international and nationally recognized leaders and various tools in person-centered planning to provide evidence-based training.
 - d. Allow substitution of relevant lived experience for required college education for Support Coordinators.
6. Further empower individuals and families to take charge, and create steps to put assurances in place to support the sustainability of their loved one’s Person-Centered life.
- a. Provide navigation and planning support for individuals and aging caregivers to sustain person-centered planning and practices
 - b. Expand the definition of “families” and welcome individuals’ circle of support especially those who closely assist their loved ones to customize their services.
 - c. Open OESDS’s peer and family networking meetings to all, including those who use the traditional provider-managed service model, so they can learn about person-centered practices. They can also learn about the options available to people living in licensed settings who may want to discover the options of planning a person-directed day by exploring local, non-disability specific community activities with support.
 - d. DHS/DDD to increase support and flexibility to support individuals and caregivers during the transition phase when the aging parents/caregivers become unable to carry out their role. Consider using state funds temporarily for someone who has been self-directing to continue to remain in their home and community of choice. This will create an opportunity for supports to be re-established to avoid chaos and trauma by uprooting the person and their life.

7. Create additional support and tools for all staff, both family and non-family staff, to ensure the quality of care and embrace person-centered practice
 - a. Convene a workgroup to create a mechanism to ensure financial transparency, accountability, and quality of support and services
 - i. Support Coordinators and DDD to monitor the quality of support rendered by all DSPs, including paid family staff
 - ii. Design tailored training and support for paid family staff to improve their skills and ensure financial transparency and accountability
 - iii. Collect data to identify barriers, concerns, and promising practices
 - iv. Facilitate a long-term care coordination planning with individuals and family caregivers to prevent crisis, trauma, and disruption as well as plan for life changes
8. Create a robust housing support framework
 - a. Eliminate the cap on Supportive Housing Connection subsidy, or boost equivalent resources, for adults with I/DD. This change ensures that more individuals who choose self-directed services have more housing stability close to those residing in licensed, provider-managed settings. By removing the cap or increasing resources, we create a level playing field, empowering individuals with I/DD to pursue the housing option that best suits their needs, regardless of the service model they choose.
 - b. Empower individuals and families with full budget authority. Grant individuals and families full budget authority to sustain self-directed services and supports. In licensed settings, all funds are typically spent. To promote equity, those choosing to direct their services in their own homes should have comparable financial access, including flexibility and full authority to coordinate and access all necessary services, including their overnight care.
 - c. Implement ongoing evaluation and quality improvement measures. Integrate robust monitoring and evaluation systems to ensure that the housing support framework is effective, sustainable, and aligned with person-centered needs. Regular feedback from participants and providers will help refine processes, promote accountability, and guide continuous improvement initiatives.