



In the last year, thousands of individuals, family members, advocates, employees, and nonprofit providers have engaged in development of OPWDD's People First Waiver, a critical redesign of New York's service delivery system to:

- Empower individuals and families to have a stronger voice and more flexible services.
- Provide the most person-centered, integrated services possible.
- Ensure that all of an individual's needs are met in a coordinated way.
- Measure quality of care based on an individual's personal outcomes.
- Ensure effectiveness and efficiency in OPWDD operations.

Last winter, 251 organizations, groups, and individuals participated in OPWDD's Request for Information (RFI) regarding the kinds of system reforms needed to achieve the goals of the waiver. All stakeholders were invited to provide comments, suggestions, and constructive criticism on the key areas of:

- Assessment
- Care Coordination
- Effective Supports
- Fiscal, Administrative and Organizational Structure
- Quality

Continuing OPWDD's commitment to an open and transparent development process, this document provides an overview of the responses received in each of these areas—many of which align with the goals of the waiver. These responses have been incorporated into OPWDD's ongoing negotiations with the federal government.

Assessment

One of the most important functions within the OPWDD system is assessing the capacities and needs of individuals with developmental disabilities. Assessments—using standardized tools—help to identify the services and supports that will best meet someone's needs and are a critical foundation for proper person-centered planning.

Approximately one-half of all respondents answered all questions included in the assessment section of the RFI.

Self-advocates described key attributes of an effective assessment process as: transparency, equity, comprehensiveness, responsiveness to change, and independence from funders. In keeping with the intent of the People First Waiver, it was noted that the individual's whole needs must be considered, and the tool should use plain language. The appeals process, how resources are allocated, and perceived lack of independence in administering assessments were common concerns expressed about the existing process.

Additionally, it was suggested that no one existing tool could successfully accomplish true person-centered planned, and that components of many existing tools should be integrated; approximately 90 percent of respondents expressed a desire to help OPWDD test tools for the validity and predictive capacity of a new assessment tool.

Care Coordination

Care coordination makes use of the information gained through assessments; It is a person-centered interdisciplinary approach to addressing the full range of a person's needs, integrating habilitation, medical and behavioral health care, and support services. Continuous feedback ensures that the individual's needs and personal outcomes are being met, as they may change over time.

Approximately 65 percent of all respondents participated in the care coordination section of the RFI.

One component that respondents stated is essential is that circle of support or care coordination team meetings focus the service planning or care coordination process on the participant. It was suggested that other stakeholders, as desired by the individual, should be involved in planning services, and that all positive relationships and natural supports be clearly identified. Additional suggestions indicated that documents and materials related to the process be person-centered rather than based on specific programs or services. Respondents also highly recommended the use of plain language in service plans.

A recurring suggestion was that a common evaluation method, which is based on identified desired outcomes—not personal satisfaction, should be used to evaluate the efficacy of the person-centered plan.

Effective Supports

The RFI sought varied input from stakeholders regarding how to effectively provide supports and services, choice for individuals, and ensure sufficient service network capacity. The idea was to solicit ideas about how best to move away from a historically institutional model—not only in terms of residential opportunities, but also in how services (“care taking”) are provided and develop a truly person-centered model. Additional consideration was given for those individuals with more complex needs, such as dual diagnosis or medical needs.

Of the responses received, most frequent engagement came on questions concerning how to address the changing life needs of an individual receiving supports and developing naturally supportive relationships.

Respondents suggested periodic review of plans and regular surveys of individuals, family members, and advocates regarding their personal satisfaction with their supports and services and their attainment of goals, and not just relying on clinical evaluations alone. Respondents suggested providing maximum choice in selection of a Developmental Disabilities Individual Support and Care Coordination Organization (DISCO) and ensuring that the available options consider geographic accessibility and service opportunities.

Other common suggestions in this section included empowering individuals and families to have control over financial resources and hiring of staff, meeting not only the clinical needs, but the cultural needs of underserved populations, and the perceived importance of outside oversight entities.

Fiscal Administrative and Organizational Structure

Recognizing the importance of supporting quality service improvement, this section solicited input on how DISCO demonstration projects should be structured, given their primary responsibilities as care coordinators and fiscal intermediaries.

Respondents generally felt that DISCOs would need to provide services to “quite large” or “huge” numbers of people in order to be able to support individuals who have higher costs associated with their services. Several respondents recommended using the insurance industry as a model, including the idea that the smaller the pool of risk units, the larger the risk of exceeding capitated averages.

In terms of evaluating whether a DISCO demonstration project is sufficiently inclusive of services to meet every individual’s need, it was suggested that DISCO applicants provide education and training to service providers, meet designated requirements for person-centered planning, and that OPWDD develop a detailed list of services and supports that a DISCO would need, as well as standardized indicators to be measured in objective evaluations.

Respondents suggested that OPWDD could support DISCO demonstration projects by providing technical assistance, establishing clear guidance and protocols, delivering regulatory flexibility to allow for more innovation, and assisting with data and information technology.

Other responses included opinions on incentives for becoming a DISCO, the transition time permitted, how to manage risk, and safeguards.

Quality

Measuring quality in meaningful ways will determine if personal outcomes are being met and if they are truly based on an individual's interests and needs.

Approximately half of all respondents answered questions concerning quality in the RFI.

One fundamental shift the waiver will bring is in changing the focus of the service system, from one that is built around available services to one that incentivizes the development of new opportunities for individuals. When asked what would incentivize quality improvement, respondents commonly recommended financial support, the opportunity for increased responsibility, and changes to the oversight of services. Advantages and disadvantages to these recommendations, respectively, included:

- Being able to use funds to reward excellent employees, which risks placing the focus on funding streams instead of on person-centered, quality services.
- Motivating providers through positive recognition, which means there would be additional time and effort spent on proving quality, not improving care.
- Allowing OPWDD to focus more on agencies in need of assistance, which means a lack of consistent monitoring could cause high performing providers to slip.

It was also recognized that quality services cannot be achieved without a quality workforce. Respondents suggested many ways to ensure that direct support professionals (DSPs) are capable of providing care, including:

- Establishing core competencies for all DSPs.
- Requiring staff at all levels to meet annual training requirements.
- Promoting a culture of respect, support, mentorship, and trust in DSPs.

Focused Studies Opportunities

This section of the RFI was intended to solicit provider interest specific to participation in case studies. Due to its limited purpose, information was not summarized for inclusion in this document.