



Introduction

As OPWDD transitions New York State's developmental disabilities service system from a fee-for-service structure to a managed care structure, new policies and procedures will effect individuals' selection and enrollment into Developmental Disabilities Individual Support and Care Coordination Organizations (DISCOs), the rights enrolled DISCO members will have in receiving services through the DISCO, the process afforded them to resolve any concerns and complaints, and how they access independent advocacy at any point in the service system process – in person-centered planning, during service delivery, or when filing and following through on a grievance. Making sure that individuals who are receiving services are involved in a meaningful way, are provided the kind and level of assistance they require to represent their needs and desires, and are fully informed about how the system will operate to meet their needs all require critical consideration as OPWDD prepares to begin system reforms through pilot DISCOs. Through this report, the work team, made up of self-advocates, family members, provider agency representatives, a county government representative, and OPWDD leaders and staff members, provides needed direction around these important topics.

The People First Waiver Access, Enrollment & Advocacy Work Team held six meetings between August 7 and September 25, 2012. At these meetings, members:

- reviewed current required protections for individuals receiving services through managed care in New York State;
- discussed further provisions they wished to recommend regarding particular aspects of the pilot DISCOs: individuals' involvement in setting policy within their DISCO, the rights of enrolled members of a DISCO, an effective grievance and appeals process, and independent advocacy for enrolled individuals; and
- identified key issues that will require further exploration.

Existing Protections

Managed Care operations in New York State are governed by Public Health Law Article 44 and NYS Department of Health regulations, Subpart 98-1, as well as NYS Social Services Law Section 364-J and federal managed care regulations contained in Part 438 CFR. OPWDD's establishment of specialized managed care organizations known as DISCOs will comply with these statutes and regulations and require additional specialized provisions to be effected through OPWDD regulation and the DISCO contract. In addition, DOH and OPWDD will work closely together in DISCO applicant readiness review and DISCO oversight.

The existing managed care laws and regulations provide many protections for individuals enrolled in managed care. In many ways, these provisions assure a strong voice for individuals and quality service delivery. These provisions describe how managed care organizations must demonstrate their ability to provide quality care, how they are to communicate with members, the kinds of information they must make available, how they may market their services to potential enrollees, and the kinds of language

that needs to be in their members handbooks. They spell out specific enrollee rights such as the right to be free from restraint used as a means of coercion, convenience or discipline, and the right to be treated with respect and consideration for dignity and privacy. They also prescribe how organizations must make services available in a timely manner, provide a process for grievances and appeals, and monitor their own operations. They prescribe how managed care organizations must comply with the federal Americans with Disabilities Act, how they are to contract with individual service providers, and how states must actively assess and continuously improve the quality of the managed care services provided.

Still, OPWDD and its stakeholders have worked together for more than 30 years to improve supports and services for people with developmental disabilities. In moving the service system under these existing managed care provisions, it is important that OPWDD and its stakeholders ensure that the DISCOs benefit from the expertise and understanding that now define the current system. The DISCOs will not be typical managed care organizations, but rather, will be specialized organizations that provide the kinds of supports and services that are needed to support a rich life – not simply improved health. This distinction is critical and required the Access, Enrollment and Advocacy Work Team to consider how existing law and regulation will affect the DISCOs and what kinds of unique procedures or provisions might be needed to ensure the specialized system of support envisioned, particularly in the pilot phase within which OPWDD will evaluate the effectiveness of DISCO policies. What follows is a summary of the team members’ insights and recommendations regarding the four topics they examined.

Involvement of Individuals Served - How are individuals involved in the development of the DISCO’s policies?

Background Materials Reviewed:

- Summaries of Public Health Law provisions and Department of Health regulations regarding managed care organizations in New York State.

The team noted the following insights and issues:

- The Request for Applications should specify that the InterRAI Assessment Suite will be phased in over time for all individuals’ assessments.
- All people eligible for OPWDD services should be eligible for DISCO enrollment. DISCOs should not be able to discriminate against certain individuals through a prohibitive definition of the service population.
- OPWDD may want to specify which policies individuals and advocates can be involved in creating.

The team makes the following recommendations:

- There must be clear involvement of individuals with developmental disabilities in the DISCO's policy-making, with 1/3 of the DISCO's board membership made up of individuals with developmental disabilities, advocates or parents.
- There must be an effective mechanism for communicating to DISCO members how they can be involved in making DISCO policies.
- OPWDD must be able to ensure that DISCO members are involved in DISCO policy making.
- DISCOs must be clear in describing service eligibility standards for their members.

Rights of Individuals Served – What rights do DISCO members have and how are they communicated to DISCO members?

Background Materials Reviewed:

- Summary of member rights in NYS Managed Long-term Care Plans (MLTCPs) as articulated in the MLTCP model contract.
- Summary of rights provided individuals with developmental disabilities by OPWDD regulation Part 633.4.
- "Know Your Rights" by Jack Kaylie, Consumer Advocate - a May 2008 consumer advocate informational booklet prepared to help assure that people with developmental disabilities and their families understand what is available to them under the law in New York State.

The team noted the following insights and issues:

- OPWDD may want to further define "timely" in the DISCO contract list of enrollee rights so that people don't have to wait a long time for services and waitlists can be avoided.
- OPWDD will need to establish and define the duties of enrollment brokers to assist people to understand how, when and where to get the services they need from the DISCO.

The team makes the following recommendations:

- The Developmental Disabilities Advisory Council should develop a simply worded, plain-English statement of rights for individuals with developmental disabilities enrolled in DISCOs. In doing so, the Council should examine existing rights documents and update language used in OPWDD regulations 633.4 as needed to reflect current policy direction of meeting individuals' needs. (The OPWDD managed care service system will also comply with existing requirements in managed care law and regulation regarding specific rights of enrolled individuals.)
- OPWDD should consider updating Part 633.4 Rights and responsibilities of persons receiving services to reflect current policy direction in service provision related to provision of services in the most integrated settings, community-integration, and meeting individuals' assessed need.

- Statements of members’ rights in DISCO contracts should specifically reference rights ensured by the New York State Olmstead Plan, OPWDD’s Language Access Plan; the Americans with Disabilities Act, HIPAA, and OPWDD Regulation Part 633.4.
- Statements of rights contained in DISCO contracts should reference “supports and services” rather than “treatment,” “care” or “health care” as is the current language in New York’s MLTCP contracts.
- Specifically, statements of rights contained in DISCO contracts should reference the DISCO member’s right to:
 - Development of a person-centered plan that relates to and meets all areas of assessed need and the provision of supports and services to meet those needs;
 - Update plans of care as needs and preferences change;
 - Self-direct services and supports;
 - Get information on available supports and services in simple, everyday language conveyed in a manner and language you understand, including the use of sign language and communication devices as needed;
 - Assistance in understanding information necessary to give informed consent;
 - Request an advocate to assist with decision-making;
 - Access medical and other records via health information technology;
 - Lead (not simply “take part in”) decision making about health care and other supports and services;
 - Receive personal hygiene services from a member of the same gender¹;
 - Receive instructions on how to change DISCOs;
 - Access an enrollment broker to assist with DISCO enrollment and disenrollment;
 - Complain, without fear of reprisal, to New York State DOH, OPWDD, local Departments of Social Services, the NYS Justice Center, and an independent ombudsman;
 - Know the financial impact on the member, if any, of choosing to use out-of-network providers; and
 - Have a person of his or her choice help facilitate their choice of supports and services.

Grievance and Appeals Processes – How do DISCOs provide for members to lodge complaints and have those complaints resolved?

¹ The existing OPWDD Administrative Memorandum, (ADM #2009-03) on gender specific assignments states, “When a preference is expressed, or upon the recommendation of the clinician, the individual’s program planning team shall assess the advisability of requiring intimate care by staff of a specific gender. In the event that the team determines that the individual requires such intimate care by a specific gender, it shall communicate such determination to the supervisor(s) responsible for setting staff work assignments in the residence or service. In these situations, providers must make every effort to assign staff of the appropriate gender to deliver intimate care services to that individual. OPWDD recognizes that in unforeseen circumstances, it may be not possible for intimate care services to be provided by staff of the preferred gender. Agencies must take appropriate steps to minimize the provision of intimate care services by someone who is not of the preferred gender.”

Background Materials Consulted:

- Overview of NYS's Managed Long-term Care Plan grievance process as described in public health law, regulation and the DOH Managed Long-Term Care Model Contract.
- Comparison of current OPWDD grievance process contained in OPWDD regulation Part 633.12 and current managed care grievance process in Public Health Law Article 44.

The team noted the following insights and issues:

- OPWDD may want to create an ombudsman to assist individuals with the DISCO grievance process and make the ombudsman accessible via a hotline.
- A culture in which people feel they are free to make complaints without reprisal is essential.
- Grievance processes should be "No Wrong Door" – meaning a person can report a complaint in a variety of places and it will get funneled into the correct process for resolution.
- Grievance and action reviews are best done by a team of reviewers that includes peer and independent reviewers.
- The more complex OPWDD makes the DISCO grievance process, the more overwhelming, costly and ineffective the process becomes for individuals.
- OPWDD oversight of the effectiveness of the DISCO grievance processes is critical.
- OPWDD should make sure the expedited review timeframes are sufficiently brief to protect safety and health.
- Individuals may need to be able to appeal the findings of a needs assessment.

The team makes the following recommendations:

- In developing the Request for Applications and reviewing submitted applications for pilot DISCOs, OPWDD should encourage the following best practice provisions with respect to a pilot DISCO's grievance process:
 - An informal process to assist in resolving complaints up-front before a grievance is filed.
 - Availability of an independent ombudsman with experience with individuals with developmental disabilities for assistance in the grievance process. Use of a hotline for access to the ombudsman.
 - A means of ensuring the correct level of assistance is provided to meet a person's true need for assistance in the grievance process.
 - Use of existing outside developmental disabilities related advisory councils (e.g. Family Support Councils, DD Councils in New York City) to help individuals and families through the grievance process, educate individuals and families about the grievance process, and review the effectiveness of the DISCO's grievance process.

- Opportunity for individuals and family members to submit satisfaction surveys regarding the DISCO's grievance process.
- OPWDD should use the following metrics to determine if each pilot DISCO has an effective grievance process in place:
 - The DISCO measures individual satisfaction with the grievance process and reports a high rate of satisfaction.
 - The DISCO is meeting or exceeding the timeframes established under New York State law (Article 44) for grievance and appeal processes.
 - Analysis of all the grievances filed at each pilot DISCO, noting how many were resolved at the provider level, how many grievance decisions were appealed, how many actions were appealed and how long resolutions of both grievances and appeals took.
- OPWDD should expand the list of parties who can file a grievance on behalf of an individual to reflect the list of parties who can make complaints under current OPWDD regulation: adult persons receiving services, parents, guardians, correspondents, and advocates of persons receiving services, and the Mental Hygiene legal Service.
- OPWDD should use peer review format or existing advisory councils to review DISCOs' grievance practices and identify best practices and system-level issues or concerns.
- People with experience in service coordination should participate in evaluating DISCO grievance processes.
- OPWDD should use advisory councils to provide information to DISCOs regarding the needs of individuals and families.
- In selecting pilot DISCOs, OPWDD should review applying provider agencies' history in addressing grievances.
- Continuation of supports and services for an individual who is filing a grievance should be automatic throughout the duration of the grievance/appeal process. Individuals should not have to request that services and supports continue.

Independent Advocacy – How does the managed care system provide individuals with developmental disabilities advocacy that is independent from the DISCO?

Background Materials Consulted:

- Overview of advocacy functions within OPWDD's current Medicaid Service Coordination program
- Westchester County Ombudsman Program, Westchester County Department of Community Mental Health

- Self-Determination Coalition Draft Position Paper “Preserving the Rights of People with Developmental Disabilities in the People First Waiver”
- Overview of the advocacy function in county government, as presented by a representative from Westchester County
- Overview of the potential structure of advocacy in a managed care environment, as presented by a representative from the Westchester Institute for Human Development

The team noted the following insights and issues:

- Ongoing, independent advocacy should:
 - Assist individuals to access and engage in their community, not just to access supports and services from the DISCO.
 - Be provided according to the individual’s need for advocacy; one size does not fit all.
- OPWDD will need to define the role of its regional offices in assisting, in a consistent fashion across the state, with resolution and filing of grievances and appeals.
- There must be significant public education for individuals and their families regarding the grievance process and the availability of independent advocacy.
- Outreach to self advocacy organizations, school districts, Special Education PTAs, family organizations, disability advocacy organizations, etc. is the most effective way of educating the broad stakeholder base and improving the process for individuals, families and providers and recruit volunteer ombudsmen.

The team makes the following recommendations:

- OPWDD needs to strive to create a culture within DISCOs that empowers and views the care coordinator as an advocate for individuals.
- OPWDD Regional Offices should continue to serve as a resource to individuals and families, but should not be the only source of advocacy.
- Independent advocacy of the most personal type for individuals and the most formal type outside the OPWDD system is available from many parties, including but not limited to:
 - Self-Advocates of New York State
 - Independent Living Centers
 - The federally required Protection and Advocacy Program
 - Local and regional advocacy organizations such as, GROW – Advocates for People with Developmental Disabilities in Westchester County
- Similarly, ongoing, independent advocacy can and should be available from many parties in the system.

- OPWDD should establish or designate an oversight group to evaluate the provision of ongoing, independent advocacy within the pilot DISCOs and provide advocacy training to advocacy entities.
- Independent advocacy must exist at two levels (system and individual) and be coordinated by one statewide advocacy (Ombudsman) organization that is:
 - independent from OPWDD, the DISCO and providers;
 - legally empowered;
 - professionally staffed;
 - accountable; and
 - engages a mix of professional and lay people; and
 - accessible to all individuals in the system (including those in institutional settings).
- The independent advocacy organization should fulfill consistent core functions (e.g. policy analysis) across the state, but provide access for individuals at the local level to existing advocacy organizations via contracts and/or relationships with these organizations.
- New York’s Protection and Advocacy Agency or the Justice Center, whether acting directly or sub-contracting to public interest law firms/organizations in the state, would be a good candidate for fulfilling this statewide/locally accessible independent advocacy function.
- Local Governmental Units may provide a good structure for making and overseeing the local connection for individuals to advocacy provided by local organizations or volunteers.
- There must be clear standards for independent advocacy and a rigorous system of state level oversight to be sure that the advocacy system is truly working for individuals.

Funding Independent Advocacy and Advocacy Training

- Funding for the advocacy organization should derive from:
 - the federal advocacy funds that used to flow to the Commission on Quality of Care and Advocacy for Persons with Disabilities (and may in the future be used for NY’s designated Protection and Advocacy program through the Justice Center legislation).
 - OPWDD’s budget
- OPWDD should fund, develop and implement an Ombudsman training program for the statewide advocacy organization and local volunteer advocates.
- The advocacy training curricula should be consistent and well developed.
- Training curricula could derive from the Partners in Policymaking Program (funded by the DDPC and administered by Cornell University), technical assistance and training from the University Centers for Excellence in Developmental Disabilities, Support Parent training from “Parent to Parent,” the Self Advocacy curriculum from SANYS, and existing training resources at OPWDD.

DISCO Responsibilities for Independent Advocacy

- DISCOs should assist individuals to establish a circle of support that includes people who are not paid to provide supports.
- DISCOs should be required to disseminate information regarding availability of independent advocates and/or agencies, to connect individuals to independent advocates if they so request, and to document regular follow ups (e.g. at least quarterly or whenever there is a change in individual's ISP) to track the status/progress of individual requests for advocacy.
- DISCOs should demonstrate that they will cooperate with advocates, provide advocates access to records, files, facilities, and personnel.
- As a best practice, the DISCO should include representation from the advocacy organization in an internal review board that reviews program outcomes and satisfaction data.
- Ideally, individuals in the system would have a choice of outside, local advocates, just like they have a choice of DISCOs and providers.

Team members also expressed the following suggestions that were not endorsed by the entire team:

- DISCOs should be required to provide Community Engagement Coordinators whose job it will be to help the person receiving services work with the DISCO to develop the Life Plan and then to do the things that will make the plan a reality.
- Requiring advocacy to be completely independent also requires that individuals and their families must have a relationship with yet another staff member or volunteer. There are already many layers in the system that require the development of a relationship including, assessment, DISCO with care coordination, and one or more provider agencies. Adding a separate layer for independent advocacy may lead to too many relationships to manage. A system for when an individual or their family does not trust the organization already is available. To create more adds confusion.

Additional Key Issues

The work team identified a few related key issues:

- How will OPWDD ensure that a sufficient workforce exists to meet individuals' needs?
- Education of individuals and families about their rights, the grievance and appeals process, and independent advocacy is very important and needs to be provided to each individual in a clear, understandable way.
- OPWDD needs to articulate a vision of what life will be like for people with developmental disabilities when it moves into Managed Care.

Additional References Consulted

- *Keeping Watch: Building State Capacity to Oversee Medicaid Managed Long-term Services and Supports*, AARP Public Policy Institute, July 2012.