

**Managed Care Community of Practice
Stakeholder Engagement**

**Educational/Informational Needs of People with
Intellectual/Developmental Disabilities and Their Families**

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Matters



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Managed Care Community of Practice

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Background and Objectives

New York State is implementing a system of Medicaid Managed Care for people with intellectual and developmental disabilities (I/DD). The Managed Care Community of Practice, a project of The New York Alliance for Inclusion and Innovation (NY Alliance), is currently working to assist providers of services to people with I/DD in the transition to managed care. MCCOP provides informational updates, technical assistance, and support to providers to help prepare them to operate in a managed care system.

It is also vitally important to ensure individuals with I/DD, their family members and advocates have information about Medicaid Managed Care and what it will mean for their services to be provided through managed care. The New York Alliance has contracted with Medicaid Matters New York – the statewide coalition representing the interests of people who are served by New York’s Medicaid program – to undertake a stakeholder engagement component of the MC-COP to fulfill this need. Through the MC-COP Stakeholder Engagement project, the New York Alliance obtained important information to understand from individuals and families what they need and want to know about the transition to managed care, development and dissemination of informational materials about managed care, and ways they would like to receive information to best prepare them for this transition.

The New York Alliance and Medicaid Matters held focus group sessions with individuals and parents to collect this information. This provided the New York Alliance and Medicaid Matters qualitative data on the information and educational needs and wishes of people with I/DD and parents of people with I/DD.

Major conclusions include:

- ▶ Information about the transition to managed care to this point has not been sufficient to meet the needs of individuals and families;
- ▶ People generally receive or want to receive information in a variety of ways; there is no magic bullet for disseminating information in a way that will reach everyone;
- ▶ A variety of factors serve to further limit capacity to receive information, such as lack of access to the Internet and speaking a language other than English, for example;
- ▶ Dissemination of information must consider how to reach people where they are, using a variety of methods already in use or similarly in use for other purposes.

In addition to input on how people best receive information about system changes or new programs, participants provided feedback on experiences upon enrollment in Care Coordination Organizations (CCOs), the first step in the transition to managed care for the

majority of people with I/DD. While this was not the primary subject of the focus group sessions, a few questions were asked in this regard to take advantage of the opportunity to get this valuable feedback from individuals and parents. As expected, experiences with CCOs have been varied and range from very good (a self-advocate who reported having a very good relationship with her care manager and what she considered to be successful development of her life plan) to extremely negative (a couple of self-advocates who reported losing Medicaid enrollment because their Medicaid Service Coordinators used to take care of that for them and their new care managers did not). Feedback on experiences with the CCOs were recorded and will inform the MC-COP education and outreach efforts, as well as advocacy efforts outside the MC-COP.

Method and Demographics

The New York Alliance and Medicaid Matters contracted with a researcher in academia with expertise in doing research with people with disabilities to develop a focus group protocol. Amy Hewitt of the University of Minnesota wrote a protocol (attached) for use by the New York Alliance and Medicaid Matters and advised on focus group best practices.

Four sessions were held with a total 29 people in late spring 2019. Two sessions were held with individuals and parents, separately. To capture both urban and non-urban perspectives, sessions were held in New York City and Binghamton. Through subcontracts with Medicaid Matters, recruitment was done by representatives of the Self-Advocacy Association of New York State (SANYS) and Parent to Parent of New York State. At the researcher's suggestion, parent recruitment was targeted with the goal of having parents who are less connected to the system or less aware of educational opportunities. Participants were each offered a \$50 Visa gift card in recognition of their contributions to the project and the time commitment involved in participating in the focus group sessions. Invitees received an informational sheet describing the project, the purpose of the focus groups, including expectations of focus group participants (attached).

Ann Hardiman of the New York Alliance and Lara Kassel of Medicaid Matters conducted each of the sessions. Detailed notes were taken, as well as high-level notes on easel pads to demonstrate to participants the points they were raising were being captured. Blank index cards and pens were provided to allow participants to jot down feedback they would prefer not to provide in a public manner.

There were seven participants in the New York City focus group with parents of people with I/DD, including the Staten Island Coordinator for Parent to Parent of New York State. All were mothers of children under 21, with the exception of one mother of a 23-year-old young man. They live in four of five boroughs – Manhattan, Brooklyn, Bronx, and Staten Island. They were white (4), Latina (2), African-American (1), and Asian (1).

There were eight participants in the New York City focus group with individuals with I/DD. Two direct-support professionals accompanied the individuals with whom they work. One SANYS staff person attended and provided assistance to participants. Participants were white (3), African-American (3), and Asian (2). Their boroughs of residence were not noted.

There were six participants in the Binghamton focus group with parents, including Michele Juda, Executive Director of Parent to Parent of New York State. All were mothers of children under 21. One of them runs a respite program for a local agency, and one became a broker. They were all white, and all reside in or near Binghamton.

There were eight participants in the Binghamton focus group with individuals with I/DD. One direct-support professional accompanied the individual with whom she works. Two SANYS staff people and one staff person from Community Options, Inc. of the Southern Tier (the agency that hosted the focus group session) attended and provided assistance to participants. Participants were recruited by SANYS staff serving the SANYS Central/Northern region, which covers 20 counties. This resulted in participation from five upstate counties: Broome, Jefferson, Oneida, Onondaga, and Tioga.

The focus group sessions with parents were introduced by the representatives of Parent to Parent of New York State who were present at each session. The focus group sessions with individuals were introduced by Ann Hardiman, who has a long history in working with individuals with I/DD, including many years of service to SANYS as a board advisor. To facilitate discussion regarding informational needs on the transition to managed care, participants were asked to take a look at a brochure published by the New York State Office for People with Developmental Disabilities (OPWDD), titled *The Evolution of Supports and Services: Managed Care* (attached). No participants had yet seen the brochure, and feedback was provided regarding use and dissemination of such a brochure to provide information. The discussion grew from there, and much feedback was provided on the best ways to reach people and provide needed information. As reported above, questions were also asked about experiences with CCOs, including assessments and development of life plans.

Summary of Responses

As expected, there is great variability in how people receive or would like to receive information about important changes that will impact their or their children's lives. There is no singular way to effectively provide information to anyone, whether they have a disability or not. Participants did, however, report aspects of information sharing and dissemination that have, to this point, been lacking generally (not specific to the transition to managed care). To summarize:

- ▶ It has been their impression that OPWDD has relied heavily on regional forums that have not been accessible to everyone, due to their location and/or time of day;

- ▶ The OPWDD website is cumbersome and difficult to navigate;
- ▶ Parents rely on word-of-mouth because they have found other sources of information to be unreliable or non-existent;
- ▶ Parents reported there seems to be little attention paid to reaching people who are already marginalized, including people who lack access to smart phones and/or internet access, people who speak languages other than English, and people who live in historically underserved areas (both urban and non-urban);
- ▶ People often find out about changes after the fact or after an adverse event.

Consistent too, is feedback on the lack of sufficient information about the transition to managed care for people with I/DD, as well as Medicaid Managed Care generally. With the exception of individuals whose Medicaid Service Coordinators became their care managers within the CCOs, as well as individuals who were lucky enough to get highly-professional, highly-committed care managers, individuals and parents have had little or varying info about CCOs. Very few people seemed to know about choice and rights afforded them as CCO enrollees. Additionally, there is little information about how to reach CCO staff, and in particular, who to turn to for assistance.

Individuals and parents have varying degrees of understanding about what managed care is and how it may impact them. Managed care is something some people understand in concept (particularly parents who have private insurance coverage), but lack understanding of how it will work for people with I/DD and their vast array of service needs. Perceptions about managed care are largely negative, that it is restrictive and administratively burdensome. Most participants report getting little, if any, information about the transition to managed care, and no participants had ever seen the OPWDD informational brochure.

Recommendations

The qualitative data gleaned from the four focus groups allows the New York Alliance and Medicaid Matters to advance recommendations on the informational needs of individuals with I/DD and their families regarding the transition to managed care. Overwhelmingly, the most important and over-arching approach must be employment of a variety of methods to disseminate information about the transition to managed care. Assumptions about who will benefit from any one method must be avoided.

The following are specific recommendations to enhance and improve information about and understanding of the transition to managed care for people with I/DD:

- ▶ Engage individuals and their advocates in any and all discussions, planning and implementation activities regarding the transition;

- ▶ Provide information both through OPWDD (including the DDROs) and outside state auspices (through local organizations, community groups, statewide associations, and more);
- ▶ Meet people where they are; provide in-person, face-to-face, “high touch” opportunities in residential settings (including home visits with individuals who live with their families), at day and recreational programs, schools and school activities;
- ▶ Use a variety of electronic means/multi-media to disseminate information, such as:
 - Social media (Facebook and Facebook groups, Twitter, Instagram, Snapchat, and more)
 - YouTube videos (including videos produced by and featuring individuals with I/DD)
 - Media (TV, radio, news stories)
 - Live chats
 - An app
 - Webinars (both live and archived)
- ▶ Develop new and different informational materials, such as:
 - Visualizations, such as timelines, flow charts and organizational charts;
 - Frequently-asked questions (FAQs);
 - Matrix of what is provided across all insurance types (for individuals and families with a variety of coverage options); and
 - Charts comparing CCOs and managed care entities to show what each provides, their networks, and service areas.
- ▶ Empower individuals and parents to help inform their peers;
- ▶ Present information that is most relevant to individuals and parents; ensure people know what is changing, what is staying the same, that they have choices and rights, how to exercise their rights, and where to go for help.