

Thank you for your time and participation in the managed care townhall sessions. Approximately 1,000 people participated in a session. Below is an overview of the sessions and the feedback we heard from participants.

## Townhall Discussion Feedback

Guidehouse is evaluating the New York State’s Office for People With Developmental Disabilities (OPWDD) service delivery system to provide recommendations regarding a potential transition to managed care or another service delivery system that could help OPWDD better support people with developmental disabilities. To understand how people are being supported now, Guidehouse held townhall discussions with providers and Care Coordination Organizations (CCOs) and with people with developmental disabilities, their family members and other natural supports. Table 1 highlights the sessions that were held with people with developmental disabilities, family members and natural supports.

**Table 1: Six sessions with People with developmental disabilities, Family Members and and Natural Supports**

Sessions	# of Participants
October 2 (Day)	135
October 2 (Evening)	118
October 6 (Day)	129
October 6 (Evening)	65
October 10 (Day)	178
October 10 (Evening)	148
<b>Total</b>	<b>773</b>

Table 2 provides an overview of common feedback received from participants during the six sessions with people with developmental disabilities,, family members and natural supports.

**Table 2: Feedback from people with developmental disabilities, Family Member and Natural Supports**

### Current Supports and Services

Access to Services	<ul style="list-style-type: none"> <li>• Difficulties in accessing care             <ul style="list-style-type: none"> <li>• Lack of trained providers, appointment availabilities, wheelchair accessible offices and office equipment</li> <li>• Accessibility is worse for those with complex needs and/or those living in rural areas.</li> <li>• Difficulties traveling long distances to access specialized care and assistive technology</li> </ul> </li> <li>• Providers who can serve people with developmental disabilities do not always accept Medicaid, so people have to pay out-of-pocket for services, specifically for specialized care.</li> </ul>
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	<ul style="list-style-type: none"> <li>Some people have had a positive care management experience because they were able to find a care manager that met their needs and supported them for a long period of time.</li> </ul>
Medical Care	<ul style="list-style-type: none"> <li>Difficulties finding a consistent provider for medical care (both adults and children) <ul style="list-style-type: none"> <li>People have been denied hospital care due to their disabilities.</li> </ul> </li> </ul>
Specialized Care	<ul style="list-style-type: none"> <li>Difficulties accessing specialized care such as dental care, speech therapy, physical therapy and mental health services</li> </ul>
Behavioral Health Services	<ul style="list-style-type: none"> <li>Concerns about access and quality of mental health services and a lack of trained providers <ul style="list-style-type: none"> <li>Need for more therapists with experience serving people with disabilities.</li> </ul> </li> <li>Difficulties in finding behavioral health services and specialists</li> <li>People have been denied care due to high behavioral needs.</li> </ul>
Dental Care	<ul style="list-style-type: none"> <li>Concerns about access to dental care, long wait times and travel times for people with complex needs.</li> <li>Need for properly trained staff to ensure that dental care can effectively meet the needs of people with complex needs.</li> </ul>
Therapy	<ul style="list-style-type: none"> <li>Concerns about access to physical and speech therapists</li> </ul>
Medical Equipment	<ul style="list-style-type: none"> <li>Difficulties accessing medical equipment and long wait times to be approved for equipment</li> </ul>
Day Habilitation	<ul style="list-style-type: none"> <li>Concerns about how long it takes to get into day habilitation programs</li> </ul>
Housing	<ul style="list-style-type: none"> <li>Increased housing shortages and lack of affordable housing</li> <li>Need for better support for those living in non-certified housing</li> <li>Need for housing close to caregivers</li> </ul>
In-Home Assistance	<ul style="list-style-type: none"> <li>Need for in-home assistance with daily activities like dressing, bathing, cooking and cleaning</li> <li>Concerns about inadequate support for people living at home, with a call for fair compensation for family caregivers</li> <li>Challenges in finding residential placements that match the person's needs and the need for more options and providers</li> <li>Concerns about how managed care contracting impacts the reimbursements of home health services</li> </ul>
Respite Care	<ul style="list-style-type: none"> <li>Concerns about access to respite care</li> <li>Low payment rates for respite care providers are a challenge.</li> </ul>
Self-Direction	<ul style="list-style-type: none"> <li>Most people are happy with their self-direction supports and services.</li> <li>Concerns about long wait times for service approvals</li> <li>Concerns about changes in self-direction if there is a transition to managed care</li> </ul>
Supported Employment Program	<ul style="list-style-type: none"> <li>Lack of supported employment programs</li> <li>People have a hard time finding and getting a job.</li> </ul>
Transportation	<ul style="list-style-type: none"> <li>Concerns about access to transportation in rural areas and the use of public transportation in cities</li> <li>Challenges in finding rides to work and medical appointments</li> <li>Calls for compensation for transportation expenses</li> </ul>
Fully Integrated Duals Advantage for Individuals with Intellectual and	<ul style="list-style-type: none"> <li>Negative experiences with the current managed care pilot program <ul style="list-style-type: none"> <li>Lack of access to services, trained professionals and poor coordination of services</li> </ul> </li> </ul>

Developmental Disabilities (FIDA-IDD)	
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**Workforce**

Finding and Retaining Staff	<ul style="list-style-type: none"> <li>Challenges in recruiting and retaining qualified and trained staff</li> <li>Concerns about how a managed care system could put providers out of the network for people with developmental disabilities.</li> </ul>
Training Among Staff	<ul style="list-style-type: none"> <li>Lack of properly trained staff to support people with developmental disabilities has negatively impacted the care people receive.</li> <li>Need for self-direction staff training and a general orientation</li> <li>Lack of training for people with complex needs, specifically in specialized care</li> </ul>
Staff Payment Rates	<ul style="list-style-type: none"> <li>Lower payment rates are a key problem impacting the workforce.</li> <li>Need better pay for Direct Support Professionals (DSPs) and better support for staff working in the field.</li> <li>Complex needs are not supported as part of the provider rates.</li> <li>Concerns about how capping rates in a managed care system will not help the staffing problem</li> </ul>
Aging Parents of Individuals with IDD	<ul style="list-style-type: none"> <li>Concerns about who will provide care to and advocate for their children when parents are unable to               <ul style="list-style-type: none"> <li>As parents/caregivers age, there is difficulty around accessing services that the parents/caregivers have historically provided.</li> </ul> </li> </ul>

**Care Delivery Model**

Managed Care	<ul style="list-style-type: none"> <li>Do not believe that a managed care service delivery system is going to improve services and supports</li> <li>Managed Care Organizations lack the skills, experience and expertise to support people with developmental disabilities.</li> <li>Concerns that Managed Care Organizations will not focus on the needs of people with developmental disabilities</li> <li>Concerns that capped rates in a managed care system will not support the complex needs of people with developmental disabilities</li> </ul>
Value-Based Care and Shared Savings	<ul style="list-style-type: none"> <li>Need to implement value-based care and shared savings before implementing managed care</li> <li>If local providers meet target outcomes, providers will benefit from shared savings.</li> </ul>

**Data and Communication Transparency**

Data Transparency	<ul style="list-style-type: none"> <li>Need for better communication and timely updates on services</li> </ul>
Communication and Transparency	<ul style="list-style-type: none"> <li>Need for access to data for better understanding of the services provided</li> </ul>
Community Involvement	<ul style="list-style-type: none"> <li>Community involvement and support from OPWDD for meeting people's basic needs is important.</li> </ul>
Non-English Speaker	<ul style="list-style-type: none"> <li>Lack of resources for people who do not speak English</li> </ul>

**Administrative Burden**

Bureaucracy	<ul style="list-style-type: none"> <li>Concerns that managed care will increase bureaucracy and worsen current administrative barriers to accessing care</li> </ul>
Administrative Process	<ul style="list-style-type: none"> <li>There is a lot of paperwork that needs to be completed to access OPWDD services.               <ul style="list-style-type: none"> <li>OPWDD application and approval process takes a long time.</li> </ul> </li> <li>People have waited years for service approvals.</li> </ul>

**Appendix A – People with developmental disabilities, Family Members and Natural Supports Discussion Questions**

Below are the questions that were used to guide conversations.

1. What is working well with the services and supports you and/or your loved one receives?
2. What would you change about the **Long Term Supports and Services** you and/or your loved one receives?
  - a. Long Term Supports and Services include:
    - i. In-home help with getting dressed.
    - ii. In-home help with bathing
    - iii. In-home help with cooking
    - iv. In-home help with cleaning
    - v. Help with finding a job
    - vi. Help with finding rides to work
3. What would you change about the **Medical Care** you and/or your loved one receives?
  - a. Medical Care includes:
    - i. Primary Care (Finding doctors to meet you or your loved one’s needs; making doctors’ appointments; attending doctors’ appointments)
    - ii. Special Care for illnesses (For diabetes, high blood pressure, or cholesterol)
    - iii. Getting help when you or your loved one has a health emergency
4. What would you change about the **Non-Medical Services** you and/or your loved one receives?
  - a. Non-Medical Services include:
    - i. Mental Health services (For anxiety, depression)
    - ii. Dental Services
    - iii. In-home Nursing Care
    - iv. Getting wheelchairs, walkers and/or other medical equipment
    - v. Case Management services (Care Coordination Organizations)
    - vi. Respite Care (A break from taking care of your loved one while someone else takes care of them)
5. What would you change about the **Basic Needs** you and/or your loved one receives?
  - a. Basic Needs include:
    - i. Transportation
    - ii. Housing

iii. Food

6. Please tell us how much you know about managed care.
7. If you are comfortable sharing, what are strengths and opportunities for improvement of Managed Care?
8. Is there anything else you want to tell us about how you or your loved one receive services?