

## **DEVELOPMENTAL DISABILITIES ADVOCACY SURVEY** **For Families and Self-Advocates**

The purpose of this survey is to enable families and self-advocates to help set the advocacy agenda for 2015. Results of the survey will be used to identify the top advocacy priorities across New York State. These priorities will be shared with providers and provider associations and will be front and center of our statewide advocacy campaign to OPWDD and our elected officials to fight for what is needed!

Professionals should complete this survey only if they are family members or self-advocates. Please do not complete more than one survey.

If you have not yet completed the survey, please use this link to do so:  
**<https://www.surveymoz.com/s3/1831455/DEVELOPMENTAL-DISABILITIES-ADVOCACY-SURVEY>**

If you have not yet completed the survey and do not have access to a computer, please complete this survey and **RETURN IT TO THE REGISTRATION TABLE** or mail it to the address below.

**What are the 3 MOST IMPORTANT unmet needs in your region? Keep in mind that they may or may not be your own family's most important needs. Please write "1" next to your top priority; write "2" next to your second priority; and write "3" next to your third priority.**

- Out-of-home residential services with 24-hour staffing
- Out-of-home residential services with part-time staffing
- Employment services
- Pre-employment services
- Center-based adult day services (day habilitation)
- Community-based adult day services (day habilitation without walls)
- In-home caregiving (respite)
- In-home skills building/caregiving (community habilitation)
- Help managing challenging behaviors
- Afterschool programs for children
- After-program recreation for adults
- Weekend recreation
- Caregiving during a family emergency (emergency respite)
- Other – please specify \_\_\_\_\_

---

In the next few years, people with developmental disabilities will be required to join a managed care organization.

- The managed care organization will have a network of service providers, and people will have to get their services from network providers.
  - The managed care organization will get a monthly payment for all its clients.
  - The goals of managed care are to improve care coordination and to save money.
- 

**What are your 3 MOST IMPORTANT concerns about managed care?  
Please write "1" next to your top priority; write "2" next to your second priority; and write "3" next to your third priority.**

- If managed care organizations do not receive sufficient funding:
  - needed services may be limited or denied
  - people with intense (and costly) needs may not receive all the services they need
  - staffing, training, and supervision may be inadequate, causing the quality of services to decline
- Managed care organizations may not provide people with enough choices of providers and may not allow individuals to keep their current providers
- Managed care organizations try to keep costs down and may be unwilling to provide much needed higher salaries for direct support staff
- Managed care organizations are expensive to run. Costs for running these organizations should not be deducted from the money available for services
- Other — please specify

**RETURN COMPLETED SURVEY TO THE REGISTRATION TABLE**

or

**Mail Completed Survey To:  
Margaret Puddington  
562 West End Ave., 2A  
New York, N.Y. 10024**