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Guidance Document from the Member and Family Perspective

Reopening Services and Supports In
New York State (NYS) for Individuals with
Intellectual and/or Developmental Disabilities (I/DD)

Purpose of this Document:

The purpose of this guidance document is to introduce the individual and family perspective to inform organizations supporting the NYS I/DD community in shaping the reopening decisions regarding services and programs during the COVID-19 pandemic.

*Please note this document has not been approved or reviewed
by the NYS Office for People With Development Disabilities (OPWDD)*

Service Regions: Long Island • Queens • Staten Island • Brooklyn • Manhattan • Bronx • Lower Hudson Valley
Upper Hudson Valley • Capital District • North Country

Background

The NYS Governor has begun to focus on policies for reopening the State.

It is critical that individuals with I/DD and their families be at the center of discussions around what the “new normal”, and hopefully the re-imagining, of I/DD services will look like. Additionally, individuals and families continue to seek information related to service provider preparation efforts for future “waves” of COVID-19, as anticipated by government and public health infectious disease experts.

Individuals, families, advocates, Care Coordination Organizations/Health Homes (CCO/HHs), fiscal intermediaries (FIs), providers, the New York State Office for People with Developmental Disabilities (OPWDD) and the Department of Health (NYSDOH) will need to work collectively to define a future post-COVID-19, that promotes the health and well-being of New Yorkers with I/DD and their families as they return to inclusive lives in our communities.

Re-opening Plans must be person-centered and responsive to individual needs:

The development of an I/DD service reopening plan must include the engagement of those directly impacted, namely individuals and families. Individuals and families are continuing to provide valuable input through their experiences of the service delivery system during the public health crisis; identifying strengths and weaknesses for the service delivery provider’s reopening plan.”

Above all, individual and families from the NYS I/DD community assert that the reopening process of I/DD service must emphasize a person-centeredness approach as a shared top priority along with health and safety priorities. Discretion and flexibility must be given to individuals and families as to the services they choose, the medium by which the services are delivered (i.e. virtual vs. site-based), where they are delivered, and comfort levels with regard to health, safety, and well-being of individuals served.

Critical Areas for Consideration

Feedback from individuals and families continues to be garnered through various forums throughout the pandemic. Individuals with I/DD, and the people who support them, continues to raise critical questions and concerns around key areas that must be addressed by government, providers, CCOs and FIs prior to and during the I/DD service system reopening. Several common themes have emerged as a result of these discussions:

- Safety and infection control practices at residential, day, and community services including transportation of individuals.
- Equity in determining how services will be delivered, especially for those individuals with more intensive needs and/or behavioral challenges.
- Implications for self-directed services.
- Mental Health needs post-pandemic and potentially trauma-induced behavioral changes.
- Communication, transparency and collaboration amongst individuals, families, CCOs, FIs, and service providers.

Safety and infection control practices at residential, day program, and community habilitation services

The COVID-19 crisis presents numerous complexities around how safety and best practice infection control practices can be appropriately maintained within the residential, day program, and community habilitation settings. While individuals and families understand that current practices and protocols were implemented with very little lead time, there is now an opportunity to pause, reflect and plan for the “new normal” of future service delivery mechanisms. Thus, the following areas are key considerations that individuals and families deem critical to safely reopen services from infection control and safety standpoints:

- Current residential visitation policies must be reviewed and revised to safely allow families and other (limited) members of the individual's circle of support to visit on a regular frequency.

Safety and infection control practices at residential, day program, and community habilitation services (cont.)

- Plans must be developed for how social distancing can occur in residential, day program, and community habilitation settings, including transportation. Subsequently, individuals and families will require in-depth training and discussion around how this can be implemented in a manner which is sensitive to individuals' understanding of what social distancing is and why it is important to preventing the spread of infection.
- Similarly, attention should be given to the concept of individuals' with I/DD wearing personal protective equipment (PPE) and under what circumstances this will be necessary. Generally, it is difficult to require an individual with I/DD to use PPE for extended periods of time (if at all). As such, requirements for individuals should be limited to only essential safety circumstances
- Consideration should be given, with input from individuals and families, as to which services will re-open on-site as opposed to services that should continue to be offered virtually.
- Individuals and families should be offered flexibility as to when and whether they will return to site-based services upon reopening, considering uncertainty factors that may exist related to risk of infection, anxiety about infection, and other important factors. This needs to be addressed through engagement of the collective I/DD service provider community
- Concerns around how transportation will be managed during the reopening period continues to be a priority for individuals and families. Plans to develop transportation protocols should be vetted with individual and families to ensure the new processes address these concerns.
- While service providers and CCOs will take initial lead on developing infection control plans for their respective workplaces and staff, individuals and families should have the opportunity to review those plans and provide questions/inputs as appropriate, to ensure the health and safety of themselves or their loved ones.

Safety and infection control practices at residential, day program, and community habilitation services (cont.)

- Individuals and families will need to be kept informed as to the mechanism for regular testing of both individuals and staff and how testing will be used to prevent and monitor the spread of infection.

Implications for self-directed services

For individuals who self-direct, special considerations need to be addressed collectively between individuals, service providers, and FIs to ensure individuals have flexibility to make necessary changes to their budget, so that services can be provided to meet the needs of the individual. Coming out of the COVID-19 pandemic, individuals may experience additional health and/or mental health needs that were not previously anticipated. As such, creativity and flexibility in budget and services must be offered. The I/DD community awaits further guidance from OPWDD on this critical issue.

Mental Health needs post-pandemic and potential for trauma-induced behavioral changes

Statistics related to the I/DD population and mental health project that individuals with I/DD, approximately 30% have co-occurring mental health conditions. The COVID-19 public health crisis has only enhanced the need for mental health supports for the I/DD community in NYS, as a result of limited and/or no social interaction, isolation/quarantine, loss of friends or family, and a decrease in overall group-based services. Individuals and families seek collaboration with providers, CCOs, and FIs to identify mental health services for individuals with I/DD that can be delivered through a variety of mechanisms.

Additionally, some individuals may experience behavioral challenges caused by the confines and constraints of the pandemic; individuals and families recognize the need for alignment between individuals' interdisciplinary care teams to appropriately assess, treat, and support individuals in addressing these needs.

Communication, collaboration and transparency among individuals, families, CCOs, FIs, and service providers:

Amidst these challenging and rapidly evolving situation, it is critical for the NYS I/DD community to work together as the decisions on the future of I/DD services post-COVID-19 are enacted at the Federal, State, and local levels. To help facilitate communication, providers, CCO/HHs, and FIs will develop communication and feedback channels for individuals and families. Even in the absence of detailed guidance from State or Federal entities, providers and other organizations working with individuals and families need to ensure forums are frequently scheduled for discussion, critical-thinking, and problem-solving.

These communications channels might include web-based forums, question and answer sessions, organizational newsletters with comprehensive information and guidance with the opportunity to review and provide input to draft plans or other guidance/policy documents.