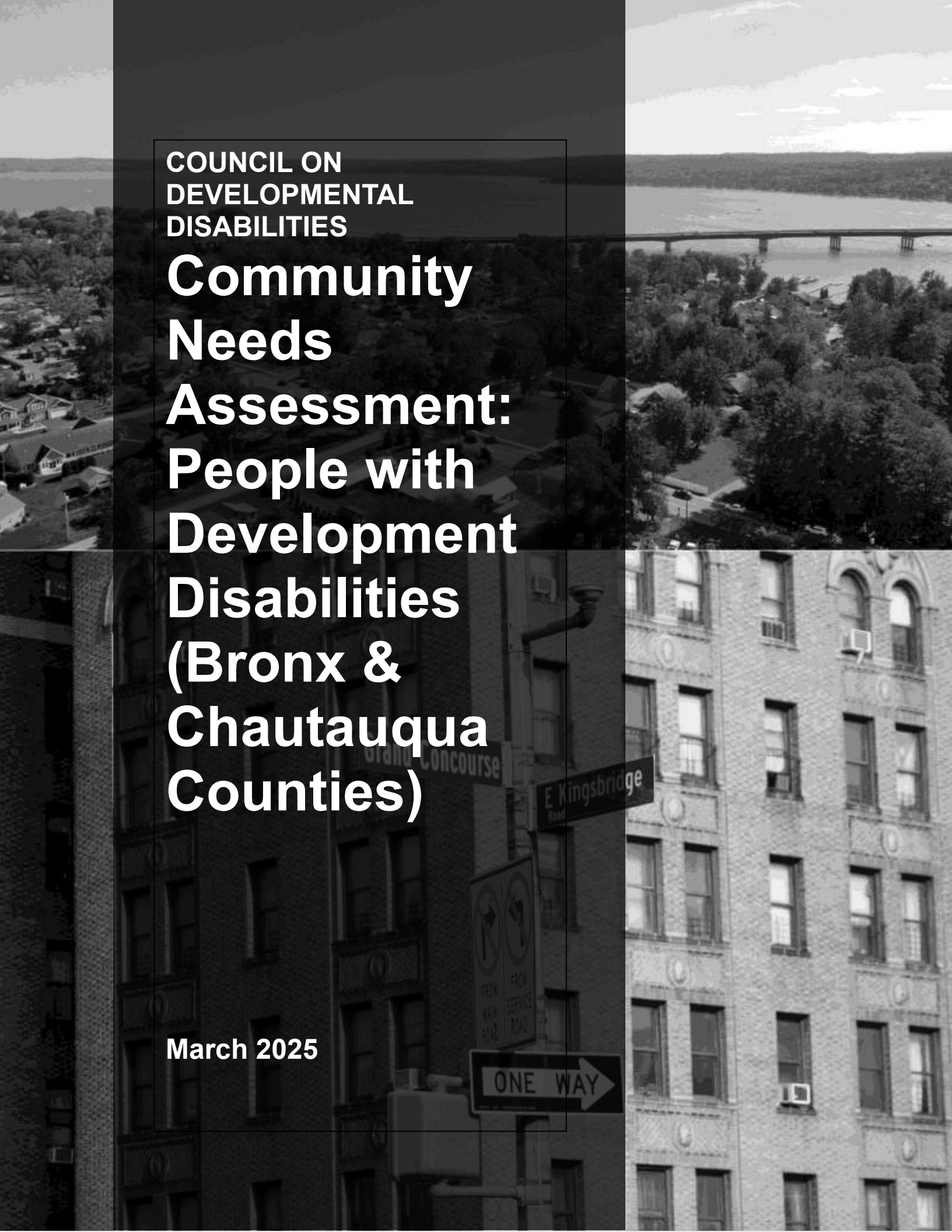


COUNCIL ON DEVELOPMENTAL DISABILITIES

Community Needs Assessment: People with Development Disabilities (Bronx & Chautauqua Counties)

March 2025

About the New York State Council on Developmental Disabilities
The Council on Developmental Disabilities' (CDD) mission is dedicated to enhancing the lives of New Yorkers with developmental disabilities and their families through programs that promote self-advocacy, participation, and inclusion in all facets of community life. CDD views disability as a natural part of the diverse human experience and prioritizes input from individuals with developmental disabilities and their families in decision-making processes.

CDD Core Values

- We view disability as a natural part of the diverse human experience.
- People with developmental disabilities and their family members are decision makers of agency initiatives.
- We seek input from people representing diverse perspectives and experiences to strengthen our initiatives.
- We promote equity in access to developmental disability services and resources and seek to drive positive change through a range of programs and projects.

About CSH
Corporation for Supportive Housing (CSH) is headquartered in New York City. As a national organization, CSH works to advance affordable and accessible housing aligned with services by advocating for effective policies and funding, equitably investing in communities, and strengthening the supportive housing field. Since 1991, CSH has been the only national nonprofit intermediary focused solely on increasing the availability of supportive housing. Over the course of our work, we have created more than 467,600 units of affordable and supportive housing and distributed over $1.5 billion in loans and grants. CSH has worked in more than 350 communities in 48 states, Puerto Rico and the U.S. Virgin Islands. As an intermediary, we do not directly develop or operate housing but center our approach on collaboration with a wide range of people, partners, and sectors. For more information, visit www.csh.org.

ACKNOWLEDGMENTS

We would like to acknowledge all those who participated in the discussions and activities that helped to shape this study and its associated strategies and recommendations.

We extend our gratitude to **the Council on Developmental Disabilities (CDD)** for issuing the grant**, the Rose F. Kennedy Center**, **individuals with lived experience, the Bronx DD Council, the Care Coordination and Health Services Committee, the Community Advisory Council Council, and the Strong Center for Developmental Disabilities.** This study reflects a collaborative desire to create a more equitable and supportive environment for individuals with developmental disabilities. Through shared knowledge, insights, and expertise, we can work together to drive meaningful changes in our communities.

EXECUTIVE SUMMARY

Background and Purpose

The Council on Developmental Disabilities (CDD) in response to the RFA awarded Corporation for Supportive Housing (CSH) funding to conduct a Community Needs Assessment. The purpose of the Community Needs Assessment is to help identify strengths, needs, key partners, and potential strategies to the CDD's identified targeted disparity.

The CDD established an internal targeted disparity workgroup that examined demographic data in New York at the intersection of socioeconomic status, disability, race, and location. Based on existing data, CDD identified two counties in New York that have very high levels of poverty: Bronx and Chautauqua Counties. CDD noted that Bronx County has the highest overall poverty rate in New York at 29.03%, the lowest overall household income at $13,718, and is also a federally designated poverty area. Additionally, Bronx County had the greatest poverty rate for people with disabilities at 43.4% (Disability Compendium, 2019). Among counties in upstate New York, Chautauqua County is one of the top five counties with the highest poverty rates. It also has the highest population of people with disabilities living in poverty, a total of 3,511 and the second highest poverty rate for people with disabilities at 33.5% (Disability Compendium, 2019).

CSH, a national leader in supportive housing and systems change, conducted this Community Needs Assessment in alignment with the CDD's Five-Year State Plan, to increase access to information, services, and support for low-income families and people with developmental disabilities, by creating opportunities for community-based initiatives that reduce barriers to access and use of developmental disabilities and community support. This report presents the findings from the Community Needs Assessment, offering insights into the current landscape of DD services, the most pressing challenges facing these communities, and opportunities for systemic improvements.

What is Developmental Disability?
Federal Definition of **Developmental Disability**
In general, the term "developmental disability" means a severe, chronic disability of an individual that:

1. is attributable to a mental or physical impairment or combination of mental and physical impairments;
2. is manifested before the individual attains age 22;
3. is likely to continue indefinitely;
4. results in substantial functional limitations in 3 or more of the following areas of major life activity:
    a. Self-care.
    b. Receptive and expressive language.
    c. Learning.
    d. Mobility.
    e. Self-direction.
    f. Capacity for independent living.
    g. Economic self-sufficiency; and
    h. Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized support, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

Types of Developmental Disabilities
CDC's National Center on Birth Defects and Developmental Disabilities has information on certain disabilities, developmental disorders, and related conditions.

Examples of Developmental Disabilities include:

- Autism Spectrum Disorders
- Cerebral Palsy
- Down Syndrome
- Fragile X Syndrome
- Intellectual Disabilities
- Language Disorders
- Learning Disorders
- Tourette Syndrome
- Traumatic Brain Injuries (TBI)

Rights of Individuals with Developmental Disabilities
The Americans with Disabilities Act (ADA) is the landmark federal legislation that prohibits discrimination against individuals with disabilities in many aspects of public life. Since the passage of the ADA, governments around the world have sanctioned similar laws that ensure people with disabilities have rights and accessibility to resources that support personal growth, independence, and expanded opportunities.

In New York State, the Human Rights Law prohibits discrimination based on disability and is enforced by the New York State Division of Human Rights (DHR). While the Americans with Disabilities Act (ADA) is enforced at the federal level, the Human Rights Law provides additional protections to ensure individuals with disabilities have equal rights and access to resources within New York State.

Systemic Change
The CDD plays a critical role in driving systemic change by increasing access to community-based DD services and ensuring individuals with disabilities and their families are at the center of decision-making. This report builds on the CDD's commitment to equity and inclusion by highlighting barriers to service access and providing actionable strategies to create a more sustainable and effective support system.

Next Steps
This report serves as a foundation for continued dialogue and action to improve DD resources and supports, community integration in two counties, Bronx and Chautauqua. The findings will inform policy decisions, funding priorities, and collaborative initiatives aimed at strengthening the DD service system in both urban and rural communities.

THE ISSUE

The New York State Council on Developmental Disabilities (CDD) is dedicated to enhancing access to services, resources, and opportunities for individuals with developmental disabilities (DD) and their families. However, disparities in service availability, affordability, and accessibility continue to affect low-income individuals, particularly those living in communities with high poverty rates and limited provider networks.

As part of its Five-Year State Plan, the CDD launched a targeted disparity objective to increase access to DD services for low-income families and individuals with disabilities. To support this effort, the CDD's Targeted Disparity Workgroup analyzed demographic data at the intersection of socioeconomic status, disability prevalence, and geographic location. This review revealed that Bronx and Chautauqua Counties experience some of the highest poverty rates among individuals with disabilities in New York State.

- The Bronx has the highest overall poverty rate in New York (29.03%) and the lowest median household income. It is also a federally designated high-poverty area.
- 43.4% of individuals with disabilities in the Bronx live in poverty, the highest rate in the state (Disability Compendium, 2019).
- Chautauqua County is among the top five counties in upstate New York with the highest disability-related poverty rates, with 33.5% of individuals with disabilities living in poverty (Disability Compendium, 2019).

These economic disparities directly impact access to critical services such as housing, healthcare, employment, and transportation.

While the Bronx has a higher concentration of DD service providers, individuals still face barriers such as long waitlists, Medicaid restrictions, and transportation challenges that limit their ability to receive care. In contrast, Chautauqua County has significantly fewer providers, requiring families to travel long distances to access even basic DD services.

“My service coordinator is very helpful and shares in my frustration with the system." Anonymous Participant

DATA COLLECTION AND METHODOLOGY

To assess the needs, strengths, and service gaps experienced by individuals with developmental disabilities (DD) in Bronx and Chautauqua Counties, this study utilized a mixed-methods approach that combined quantitative data analysis and qualitative community engagement.

Quantitative Data Collection
Quantitative data was gathered from state and local agencies involved in service provision for individuals with DD. Key data sources included:

- Demographic and economic indicators related to poverty, disability rates, and service accessibility.
- Service utilization metrics from DD providers, tracking the availability and distribution of resources.
- Housing and employment statistics to assess barriers to independent living and economic inclusion.

This data was used to establish baseline conditions, identify service gaps, and compare trends across the two counties.

Qualitative Data Collection
To gain deeper insight into the experiences of individuals with DD, caregivers, and service providers, qualitative research methods were employed, including:

- Surveys distributed to individuals with DD, caregivers, and service providers to collect firsthand perspectives.
- Focus groups that facilitated discussions on barriers to services, workforce shortages, and systemic challenges.
- One-on-one interviews with key stakeholders to explore community strengths, lived experiences, and potential solutions.

By integrating both quantitative and qualitative data, this methodology provided a comprehensive understanding of the systemic barriers and opportunities for improvement in DD services across urban and rural settings.

DATA ANALYSIS

The integration of both quantitative and qualitative data is essential for a holistic understanding of the needs in the community. An analysis of the collected information identifies trends, patterns, and correlations that help inform our recommendations. This analysis also supports the development of targeted strategies to improve access to services and resources for individuals with DD.

A review of data pertaining to the housing characteristics in the Bronx and Chautauqua Counties demonstrated that both regions face considerable challenges in the supply of affordable housing. Housing models that would be appropriate for individuals with developmental disabilities most commonly braid low-income housing with services. When the supply of housing in the broader affordable market is limited, the impacts are felt most by households experiencing poverty and with high service needs.

Housing affordability analyses commonly leverage two primary metrics – cost burden and household income. The housing cost burden is defined as the percentage of a household's income spent on housing costs, which includes rent or mortgage payments, as well as utilities, property taxes, and insurance. A household is considered "cost-burdened" if they spend more than 30% of their gross household income on these expenses. A household is considered "severely cost-burdened" when those expenses exceed 50% of a household's gross income. In the context of housing policy, household income is frequently considered as a percentage of the HUD Area Median Family Income (HAMFI). The HAMFI is calculated by the U.S. Department of Housing and Urban Development (HUD) to determine the median family income for specific geographic areas, such as metropolitan statistical regions or counties. HAMFI is adjusted to account for household size and is used to establish eligibility thresholds for affordable housing programs.

In the Bronx County, 79% of renter households with household income at or below 30% of the HAMFI are cost burdened and 62% of those households are severely cost-burdened. In Chautauqua County, 81% of renter households at or below 30% HAMFI are cost burdened, and 70% are severely cost burdened. Even among the 30% - 50% HAMFI range, housing costs account for substantial amounts of a household's income in both counties.

Bronx	**Total Renters**	**Cost burdened (>30%)**	**Percent cost burdened (>30%)**	**Severely cost burdened (>50%)**	**Percent severely cost burdened (>50%)**
<= 30% HAMFI	183,160	144,650	79%	112,720	62%
> 30% to <- 50% HAMFI	79,920	57,720	72%	18,030	23%
Chautauqua	Total Renters	Cost burdened (>30%)	Percent cost burdened (>30%)	Severely cost burdened (>50%)	Percent severely cost burdened (>50%)
<= 30% HAMFI	5,130	4,135	81%	3,575	70%
> 30% to <- 50% HAMFI	3,785	2,690	71%	525	14%

Also, analyses were conducted regarding the population of individuals with developmental disabilities in Bronx and Chautauqua counties, based on OPWDD service provision. Where possible, county-specific data was used. When county-specific data was not available, state-wide totals were utilized to estimate the need in Bronx and Chautauqua counties based on their relative share of the total service population within the state. OPWDD does not report county-level data for the Bronx, instead aggregating total data for New York City. To derive estimates for the Bronx, data from the 2020 decennial Census was used to calculate the share of individuals with a disability in the Bronx as a percentage of the total population of individuals with a disability across New York City's five boroughs. This ratio was then applied to the estimates on OPWDD data.

In 2023, approximately 7,942 individuals in the Bronx received services through OPWDD, and another 1,166 individuals received services in Chautauqua County. The average payment per person in the Bronx was $62,505.97, and the average payment per person in Chautauqua County was $66,786.50.

Assessing housing needs among this population is complicated, as an individual's level of service needs will inform the appropriate housing setting. Alongside these complications, for individuals that may be appropriately served while living independently in the community, the aforementioned strain on the supply of affordable housing severely limits the options available.

Statewide data and extrapolations were used to estimate the populations served in Chautauqua County and Bronx County with diagnoses most likely to align with service levels similar to those provided in supportive housing. The primary diagnostic categories driving this calculation are Mild and Moderate Intellectual Disabilities.

Intellectual disability diagnoses are classified as either "mild," "moderate," "severe" and "profound". For individuals with mild to moderate intellectual disabilities, the expected level of social and daily living skills, and level of support most closely aligns with a supportive housing model.

	Bronx (estimate)	**Chautauqua (estimate)**
Intellectual Disability – Mild	2,549	374
Intellectual Disability - Moderate	794	117

In developing the National Needs Assessment for supportive housing, CSH established estimated rates of need for PSH need among individuals with DD based on living situations. From that research, a rate of 33% was applied among individuals residing in Intermediate Care Facilities, Medicaid-funded group homes, and on state request lists for services and residential programs in order to estimate the population of individuals that could live independently in the community given affordable housing and services.

A comparison of primary diagnoses alongside the 33% rate applied to data on OPWDD service recipients by certified housing type suggests that an appropriate estimate for supportive housing need in this population likely sits in the range of 30 – 40%. Diagnoses with service levels aligned with supportive housing constitute 42.1% of primary diagnoses categories, and 32.9% of individuals fall into this category based on the National Needs Assessment after accounting for misaligned housing types. Based on the rate of need at 35%, it is estimated that there is a need for 2,780 DD-targeted supportive housing units in Bronx County, and 408 DD-targeted supportive housing units in Chautauqua County.

While these findings highlight critical disparities in access to housing, healthcare, and workforce support, addressing these challenges requires collaborative efforts across multiple sectors. No single organization or agency can resolve these systemic issues alone—meaningful change depends on partnerships between policymakers, service providers, advocacy groups, and community organizations. Throughout this needs assessment, cross-sector collaboration played a vital role in gathering data, identifying service gaps, and elevating the voices of individuals with DD and their families.

The next section outlines key partnerships that contributed to this study, their role in shaping the findings, and opportunities for continued collaboration to strengthen DD services statewide.

CROSS SECTOR PARTNERSHIPS: STRENGTHENING COLLABORATIVE EFFORTS

Addressing the challenges identified in this assessment requires collaboration across multiple sectors, including state and local agencies, advocacy groups, service providers, and community organizations. No single entity can resolve systemic gaps in housing, healthcare, workforce development, and service accessibility alone. Throughout this study, cross-sector partnerships played a key role in data collection, stakeholder engagement, and the development of recommendations.

“Kennedy Center was amazing my son received speech, physical, and occupational therapy a few times a week. It helped him so much.”

Bronx Developmental Disabilities (DD) Council
The Bronx DD Council played a central role in shaping this assessment through ongoing engagement, outreach, and direct collaboration. They actively assisted in survey distribution, focus group recruitment, and stakeholder connections, ensuring that families, service providers, and individuals with lived experience were represented in the data collection process. The council facilitated multiple discussions and presentations, offering real-time insights into emerging challenges, service gaps, and evolving trends in the DD community. Their support also helped connect the assessment team to key agencies, including the Bronx Borough President's Office, advocacy groups, and service providers. Additionally, the Bronx DD Council played a critical role in advisory conversations that shaped recommendations and ensured the assessment captured the realities faced by individuals and families navigating DD services.

Strong Center for Developmental Disabilities and the Community Advisory Council
The Strong Center for Developmental Disabilities, in partnership with the Community Advisory Council, contributed key insights into rural service limitations, transportation barriers, and provider shortages. Their engagement helped shape recommendations focused on expanding rural service models and increasing provider collaboration. They also facilitated key conversations with subgroups specializing in care management and service coordination, ensuring that the needs of individuals with DD in Chautauqua County were well-represented in the assessment.

Care Management Committee of the CAC
The Care Management Committee, a subcommittee of the Community Advisory Council, provided valuable perspectives from caseworkers and care coordinators who serve individuals with DD. Their expertise highlighted barriers to service navigation, workforce shortages, and policy constraints impacting care management systems. The discussions with this committee helped refine recommendations related to care coordination, provider accountability, and direct support workforce sustainability.

Targeted Disparity Workgroup
The Targeted Disparity Workgroup was the working group that developed the funding for this assessment. Members of the CDD team, who serve as funders and coordinators of this project, sit on the council and have been instrumental in advancing the assessment and its implementation. Additionally, because OPWDD team members are represented on the Council, they played a key role in facilitating access to OPWDD's system data and dashboards, ensuring that the most up-to-date information was incorporated into the findings.

In addition to the above partnerships, other organizations provided critical support in survey distribution, policy discussions, and community engagement. Inspired Community Project, New York Alliance for Inclusion and Innovation, The Resource Center, Disability Rights New York, and Advanced Care Alliance all contributed by sharing insights on workforce challenges, access to disability services, and regional service barriers. Some of these organizations are actively involved in ongoing projects with the CDD, allowing for continued collaboration, data-sharing, and discussions on best practices. Others provided key perspectives on service gaps and solutions, reinforcing the need for cross-sector partnerships that extend beyond this assessment.

Sustaining Cross-Sector Collaboration
These partnerships were essential to shaping this assessment and will remain pivotal as stakeholders work to implement solutions that address systemic service gaps. While this report marks the conclusion of the formal needs assessment, collaboration between agencies, advocacy groups, and service providers must continue to drive long-term improvements in DD services. Strengthening cross-sector coordination, securing sustainable funding, and aligning policy efforts with the needs identified in this report will be critical in ensuring that individuals with DD and their families receive the support they need.

By building these partnerships, stakeholders can advance more inclusive, effective, and accessible services for individuals with DD across Bronx County, Chautauqua County, and beyond.

VOICE OF THE COMMUNITY

Focus Group Insight into Barries and Opportunities
As part of the New York State Council on Developmental Disabilities (CDD) Community Needs Assessment, the Corporation for Supportive Housing (CSH) facilitated focus groups to gain deeper insight into the service needs of individuals with Intellectual/Developmental Disabilities (DD). These discussions provided an opportunity for individuals with DD, their families and caregivers, and service providers to share their experiences and perspectives on existing services, gaps in support, and potential areas for improvement.

Participants were given the option to engage in either a one-on-one discussion or a group discussion, allowing for a range of perspectives.

> *"We need better transportation for the people we serve. They need better doctors in our area, more understanding doctors."*

Service Needs in the Community
Participants shared mixed perspectives on the adequacy of services currently available to individuals with DD. While some described the level of services as moderate, others felt they were generally adequate. However, there was consensus that specific areas require significant improvement, particularly in terms of workforce support and long-term housing solutions.

One of the most pressing concerns raised was the shortage of qualified support workers. Participants emphasized the need for better recruitment and retention strategies, particularly through competitive wages and career development opportunities for Direct Support Professionals (DSPs). Currently, a pay disparity exists between DSPs employed by the state and those working for nonprofit organizations, making it difficult to sustain a stable workforce. A clear career path, along with standardized wages, was seen as essential to ensuring a consistent level of care for individuals with DD.

Housing was another major concern, with participants highlighting the need for individuals with DD to have access to stable, supportive housing that allows them to age in place. However, restrictive housing regulations often create barriers to making necessary modifications, and funding is insufficient to support long-term housing solutions. Participants also noted that greater investment in community resources, such as making DD-related information readily available in libraries, could help families navigate the service landscape more effectively.

Challenges with Policies and Programs
Participants expressed frustration with several policies and programs that they felt were not effectively meeting the needs of individuals with DD. The process for reporting issues, was described as intimidating for families, creating additional stress rather than offering meaningful support. Additionally, the process for securing housing and other essential services was viewed as unnecessarily lengthy and complex, with lease-up procedures and service applications creating significant barriers to access.

A lack of awareness was also identified as a key issue. Many parents struggle to obtain early diagnoses for their children due to limited guidance from pediatricians and schools, which in turn delays access to early intervention services. More widespread education and outreach efforts were seen as critical in helping families understand their options and advocate effectively for their loved ones.

Participants also called for increased parent education programs in communities, covering topics such as Social Security, long-term planning, and advocacy skills. These types of resources would empower families to navigate the system more effectively and ensure individuals with DD receive the services they need.

Experiences with Self-Direction Programs
The Self-Direction Program was generally viewed as a positive option, providing individuals with a wide range of services tailored to their needs. However, several challenges were noted, particularly related to administrative processes. Participants reported that reimbursement timelines could be unpredictable, creating financial strain, while excessive paperwork made the process difficult to navigate. Some also felt that the initial orientation for Self-Direction should be more comprehensive to better prepare families for managing the program.

Another significant concern was the program's exclusion of certain therapies. Participants felt that expanding coverage to include therapy services would greatly enhance the program's effectiveness. Additionally, the shortage of qualified support workers remains a major issue, making it difficult for individuals to fully benefit from the Self-Direction model.

Gaps in Services and Barriers to Access
Several gaps in services were identified, with transportation emerging as a major concern. Participants that parents have to fill in the transportation gap, including driving their children to school when other options are not accessible.

Housing remains one of the most significant gaps, particularly for individuals with DD who wish to age in place. Without a stable housing pipeline, many families struggle to make long-term plans for their loved ones. Participants emphasized the need for streamlined leasing and residential care processes, as well as policy changes that allow for greater flexibility in modifying housing to meet accessibility needs.

Another critical gap identified was the role of pediatricians and schools in supporting early diagnosis and intervention. Many medical professionals and educators lack sufficient knowledge about DD services, making it difficult for families to receive guidance on available resources. Participants suggested that increasing awareness and training among these professionals could lead to earlier diagnoses and better long-term outcomes for individuals with DD.

Strengths and Areas for Improvement Among Service Providers
Despite the challenges, participants praised the dedication and hard work of DD service providers. Many expressed appreciation for the commitment of staff members who go above and beyond to support individuals with DD and their families. Additionally, providers were

recognized for their strong advocacy efforts and their ongoing work to secure better funding and resources.

However, improvements are needed to ensure sustainability and effectiveness. Participants emphasized that increasing funding for managerial staff—who are often excluded from budget considerations—is critical to ensuring high-quality service delivery. Additionally, addressing workforce shortages and improving compensation for direct support staff would strengthen the overall system.

PERSONAL JOURNEYS

One-On-One Interviews for Deeper Understanding

As part of the DD Needs Assessment, the Corporation for Supportive Housing (CSH) conducted one-on-one interviews to gain deeper insight into the service needs of individuals with Intellectual/Developmental Disabilities (DD). These discussions provided an opportunity for individuals with DD, their families and caregivers, and service providers to share their experiences and perspectives on existing services, gaps in support, and potential areas for improvement.

Service Needs for Individuals with DD

The participants highlighted significant challenges in accessing resources tailored to individuals with DD. While some services exist, navigating them is often difficult, especially for families seeking support for children transitioning into adulthood. Housing options remain unclear, with confusion about available vouchers and independent living centers. Community-based programs, recreation services, trained medical providers, and day programs are all needed, but locating providers, especially specialized doctors - is a major hurdle.

Participants expressed a preference for programs that allow individuals more independence rather than requiring them to be tied to traditional program structures. Finding appropriate programs remains a struggle.

Policies and Programs That Are Working Well

Few programs were seen as highly effective. The participants noted that day programs have improved slightly, but they are still not ideal. Self-Direction was seen as beneficial, particularly in providing a budget for individualized needs. However, challenges remain in getting community classes approved and ensuring stability in services. The reimbursement process has improved, but more clarity and structure are needed to maximize its benefits. One area that was particularly helpful was respite services, especially overnight respite. The participants emphasized that respite of all types is essential for family mental health, providing much-needed relief for caregivers. Overnight respite services were especially valuable, allowing them to take a break and reset. Additionally, overnight summer camp respite was highlighted as a significant support, offering families the opportunity to step away and focus on themselves without worrying about their child’s well-being. These services played a crucial role in reducing caregiver stress and allowing parents time to manage daily responsibilities, work, and overall mental health.

Policies and Programs That Are Not Working Well

Accessing specialized medical care, especially in emergency rooms, is a major issue. ER staff often lack the training to understand and properly support individuals with DD, leading to a stressful experience.

Workforce shortages due to low pay for direct support staff create instability for individuals with DD. Frequent staff turnover disrupts consistency in care, making it difficult for children and families to form lasting relationships with caregivers. Eligibility barriers prevent access to

needed programs. Some individuals do not qualify for OPWDD services, and respite programs remain inaccessible due to strict reimbursement policies.

> *"Respite of all types has helped so much with my families' mental health. Overnight respite was very helpful to me and gave me the break I really needed." - Caregiver*

Accessing and Locating Resources
Many families rely on word of mouth, provider networks, newsletters, and community councils (e.g., Bronx DD Council) to learn about available resources. Those without personal connections often turn to helplines and nonprofit organizations for assistance.

Barriers to Services
Several key obstacles prevent families from accessing the support they need, including long wait times for services, lack of clear information on available programs, difficulty finding the right providers for specific needs, and no standardized eligibility one-pager to help families understand who qualifies for which programs.

The lack of provider accountability leads to inconsistent service interpretations and implementation and limited accessibility to providers via email makes communication difficult for parents managing caregiving responsibilities.

It was also expressed that language barriers are a challenge, while improvement has been made, it still creates access challenges for families who need interpretation services. The lack of awareness of available programs leaves many families uninformed about crucial services, and self-direction funding restrictions. Not all providers allow the use of fiscal intermediaries creating confusion around what expenses are reimbursable and what must be paid out of pocket.

Employment, Housing, and Community Life
Employers are not always knowledgeable about the existing incentives for businesses to hire individuals with DD. Many businesses hesitate to hire due to a lack of understanding about different levels of disability and accessibility needs. Social programs and school integration should be expanded to foster inclusive environments for individuals with DD. Job training during school years should be a priority to better prepare individuals for the workforce. SSI policies need reform, as individuals who earn above a certain threshold risk losing essential services and benefits.

Best Ways to Support Families and Individuals with DD

- Specialized training for service providers should emphasize recognizing individual behaviors and needs rather than applying a one-size-fits-all approach.
- Increased investment in community-based programs to ensure services are more widely available.
- A more inclusive approach to DD supports reinforcing that individuals with disabilities deserve to be fully integrated into society.
- Stronger advocacy efforts in schools particularly around Medicaid funding and how it supports school-based DD programs.

Source: World Health Organization

This discussion reinforced the urgent need for better access to specialized medical care, a more stable workforce, and greater clarity in navigating DD services. Families continue to face significant challenges in finding appropriate resources, and the lack of clear guidance on eligibility and funding structures adds unnecessary barriers. Expanding employment opportunities, strengthening provider training, and advocating for better policies in schools and Medicaid reimbursement processes are all essential steps toward improving the quality of life for individuals with DD and their families.

Participant Survey Demographics

70 total participants

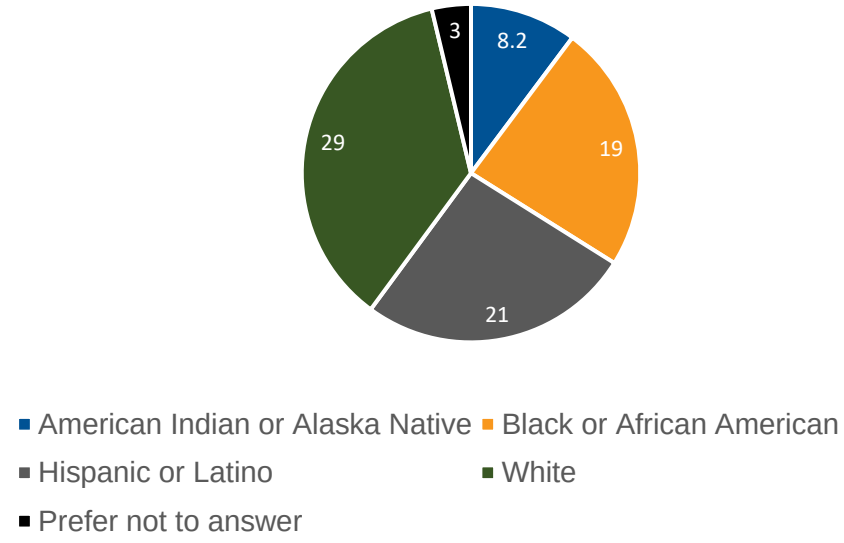
Participant Residence:

- Bronx County: 47
- Brooklyn: 1
- Chautauqua County: 23
- Rochester, NY: 1

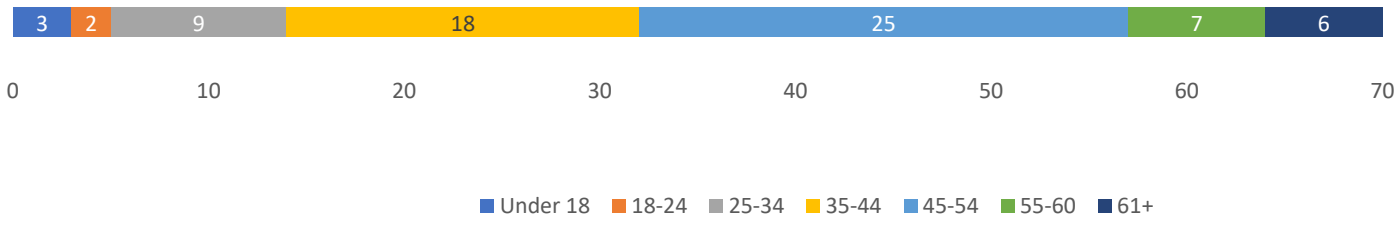
Who Completed the Survey:

- Family member or caregiver of a person with a developmental disability (DD): 57
- Person with a developmental disability (DD): 13

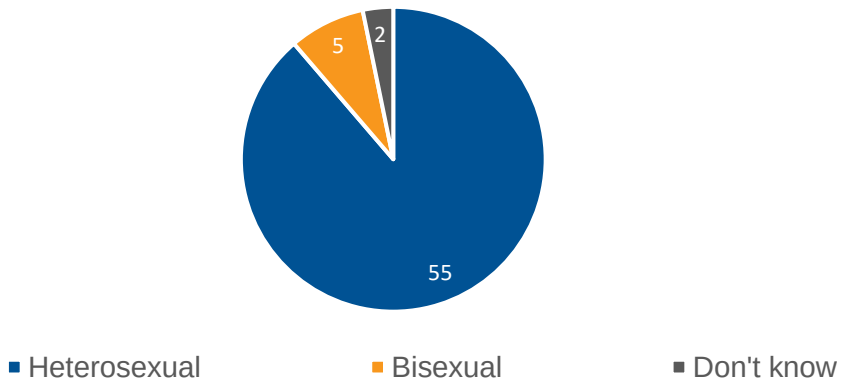
Race & Ethnicity



Age Groups



Sexual Orientation



Provider Survey Demographics:

- Total Providers: 37

Service Areas:

- Bronx: 9
- Chautauqua County: 28
- Westchester County: 1
- Cattaraugus County: 1

The survey was conducted to assess the needs, strengths, and service gaps experienced by individuals with intellectual and developmental disabilities (DD), their caregivers, and service providers in Bronx and Chautauqua Counties. The goal was to gather both participants, people with lived experience, and provider's perspectives on key areas such as healthcare access, housing, employment, community engagement, and transportation.

Participants included:

- Individuals with DD who provided firsthand experiences about their access to services and daily living challenges.
- Family members and caregivers who shared insights into available support, barriers to services, and ongoing challenges.
- Service providers who contributed perspectives on workforce shortages, funding limitations, and the strengths of the DD service network in both locations.

This section provides a breakdown of the survey's findings, highlighting key themes specific to Bronx and Chautauqua Counties, followed by recommendations to address the challenges identified.

KEY THEMES FROM THE SURVEY

The Bronx: Strengths and Challenges

Strengths in the Bronx
Availability of DD Services and Providers – Bronx County continues to have a higher concentration of DD service providers, clinics, and vocational programs compared to rural areas, providing individuals with multiple support options. Families noted that some providers, such as AHRC and BronxWorks, have been instrumental in helping individuals access services. Providers echoed this, emphasizing the broad availability of programs, though not always equitably distributed.

Strong Family & Caregiver Networks – Families described strong advocacy efforts and peer support networks that help them navigate complex systems. Providers recognized caregivers' dedication but noted that many struggle with exhaustion and a lack of respite services.

Community Engagement & Awareness – Families pointed to resource fairs and workshops as essential for staying informed about available services. However, both participants and providers highlighted the need for more culturally responsive and accessible outreach, particularly for non-English-speaking families.

Existing Healthcare Services – Some providers, such as YAI and Adapt Community Network, offer specialized healthcare for individuals with DD. While access is a challenge, many families felt these services were critical lifelines, especially for dental and therapy services.

Challenges in the Bronx
Healthcare Access Barriers – Many families reported difficulty finding medical professionals trained to work with individuals with DD, with long waitlists, insurance limitations, and a lack of Medicaid-accepting providers, particularly for dental care. Providers confirmed that staff shortages and low Medicaid reimbursement rates make it difficult to recruit DD-specialized healthcare professionals.

Housing & Independent Living Challenges – The high cost of living remains a barrier to securing affordable, supportive housing. Families expressed frustration over long waitlists and lack of emergency housing options. Providers noted that funding constraints and zoning regulations limit the development of additional supportive housing.

Employment & Workforce Gaps – Vocational training programs exist, but families emphasized that job placement and long-term employment support are still lacking. Many providers agreed, stating that businesses are not fully prepared to offer inclusive hiring practices or necessary accommodations.

Transportation Barriers – Public transportation is widely available, but broken elevators, unreliable paratransit, and inconsistent scheduling limit access to medical appointments and social activities. Providers acknowledged that transportation gaps make it harder for individuals to receive consistent care and called for stronger advocacy for infrastructure improvements.

Chautauqua County: Strengths and Challenges

Strengths in Chautauqua County
Tight-Knit Community Networks – Families in Chautauqua County rely on strong peer support networks. Informal advocacy efforts play a crucial role in securing care. Providers recognized that while services are limited, the community itself provides a layer of informal support.

Person-Centered Care from Providers – Despite limited provider options, those operating in Chautauqua County focus on highly individualized, person-centered care. Families expressed appreciation for The Resource Center, which offers a range of services despite staff shortages.

Community Collaboration – Both families and providers highlighted local partnerships between schools, small organizations, and faith-based groups as a strength. However, these efforts often struggle with sustainability due to limited funding and workforce shortages.

Challenges in Chautauqua County
Severe Shortage of DD Services – Unlike the Bronx, which has services but faces access barriers, Chautauqua County lacks essential DD service providers. Families often travel long distances for specialized care. Providers acknowledged that expanding services in rural areas is challenging due to funding limitations and workforce shortages.

Workforce & Staffing Issues – The shortage of Direct Support Professionals (DSPs) was one of the most pressing concerns across both families and providers. Families reported constant staff turnover and long hiring delays, while providers noted low wages and burnout as major barriers to workforce retention.

Transportation Barriers – Unlike the Bronx, where transportation is unreliable but available, Chautauqua County has minimal public transit options. Families reported that getting to appointments, jobs, or programs requires personal vehicles or expensive private transportation. Providers cited medical transportation inefficiencies and the need for expanded paratransit services.

Limited Employment Opportunities – Job training and placement programs are scarce. Families stated that employers often lack the knowledge or willingness to hire individuals with DD. Providers also pointed out that without targeted workforce programs, economic inclusion remains a significant challenge.

Lack of Social & Recreational Opportunities – Families highlighted the lack of inclusive social and recreational activities. Many individuals with DD experience isolation due to a shortage of accessible community engagement programs. Providers agreed, adding that budget constraints limit the ability to create and sustain meaningful activities.

Survey Findings Summary
The survey findings highlight critical gaps and strengths in both Bronx and Chautauqua Counties, emphasizing the need for targeted interventions that address geographic and systemic challenges while building on existing community strengths.

While the Bronx has a higher concentration of services, barriers such as limited provider availability, long wait times, and workforce shortages prevent effective utilization. Chautauqua County, in contrast, lacks basic DD services, forcing families to travel long distances and struggling with a workforce crisis that impacts service delivery.

By implementing strategic investments in workforce development, transportation, healthcare accessibility, and inclusive community programming, organizations and policymakers can work toward a more equitable and sustainable system for individuals with DD in both urban and rural settings.

RECOMMENDATIONS AND IMPLEMENTATION STRATEGY

The findings from this assessment reveal significant challenges in service accessibility, workforce retention, housing availability, and healthcare access for individuals with developmental disabilities (DD) in Bronx and Chautauqua Counties. Across multiple data sources, families, individuals with DD, and service providers identified gaps in direct support staffing, difficulties navigating eligibility processes, lack of affordable housing options, and limited community-based support services. Additionally, barriers in transportation, employment opportunities, and social inclusion programs continue to limit the independence and well-being of individuals with DD.

While Bronx County benefits from a higher concentration of service providers, systemic obstacles such as long wait times, limited Medicaid-accepting healthcare providers, and a lack of housing tailored for individuals with DD make service access difficult. In contrast, Chautauqua County faces a fundamental lack of DD services, forcing families to travel long distances for essential care while contending with severe workforce shortages.

To address these disparities, this report outlines key recommendations aimed at improving service delivery, strengthening workforce pipelines, expanding housing and transportation options, and enhancing overall system accessibility. These recommendations serve as a foundation for policy improvements, funding initiatives, and programmatic changes that will create a more equitable and sustainable support system for individuals with DD. While addressing these challenges requires collaboration across multiple agencies, the Council on Developmental Disabilities (CDD) can play a critical role in closing service gaps through strategic grant-making, program development, and policy influence.

The following recommendations outline priority areas for investment, followed by specific ways the CDD can provide targeted support.

Strengthening Workforce Development for Direct Support Professionals (DSPs)

A consistent and well-trained workforce is essential for ensuring that individuals with DD receive high-quality care. The shortage of DSPs has led to inconsistent care, high staff turnover, and disruptions in service delivery. Wage disparities between state-employed DSPs and nonprofit-employed DSPs have further contributed to workforce instability. This has made it difficult for many providers to retain skilled workers, resulting in reduced service availability and long waitlists for families.

To address these workforce challenges, it is recommended that CDD can develop a workforce grant program that supports DSP recruitment, training, and career advancement. Providing financial incentives such as tuition assistance, credentialing programs, and structured career pathways can encourage long-term commitment to the field. Additionally, funding policy research initiatives that explore ways to address DSP pay equity, ensuring competitive wages across service sectors. By making these strategic investments, CDD can help stabilize the DSP workforce and improve service consistency for individuals with DD.

Additional recommendations:

- Advocate for wage standardization across state and nonprofit providers to reduce workforce disparities.
- Develop credentialing programs and career pathways that provide DSPs with structured growth opportunities.
- Partner with community colleges, vocational schools, and workforce agencies to improve recruitment and retention.

Expanding Housing Options & Reducing Barriers to Independent Living

The lack of affordable, supportive housing for individuals with DD remains a major concern. Families continue to face barriers when seeking supported living arrangements, emergency housing options, and transitional housing programs tailored to individuals with DD. The need for more inclusive housing solutions has been a consistent theme throughout this assessment.

It is recommended that these challenges can be addressed by creating a grant program for DD-targeted supportive housing initiatives. Funding can be allocated to pilot programs that explore new housing models, such as integrated supportive housing developments and DD-specific rental assistance programs.

Additionally, funding to help service providers navigate zoning regulations and housing policy changes that often limit the expansion of DD-focused housing. By supporting capacity-building efforts among housing providers, it will increase affordable housing availability and long-term stability for individuals with DD.

Additional Recommendations:

- Expand state and federal funding opportunities to support DD-focused housing development.
- Simplify the leasing and eligibility process for DD-targeted supportive housing units.
- Advocate for policy adjustments that allow for home modifications and accessibility improvements.

Improving Access to Healthcare & Specialized Medical Services

Individuals with DD experience long wait times for medical care, limited Medicaid-accepting providers, and a shortage of DD-trained healthcare professionals. In both Bronx and Chautauqua Counties, families reported challenges in accessing specialists, receiving timely dental care, and finding emergency medical staff trained in DD-specific care. These barriers have resulted in delayed diagnoses, inadequate treatment plans, and poor overall health outcomes for individuals with DD.

doctors, dentists, and emergency room staff, ensuring that more medical professionals are equipped to serve individuals with DD.

Additionally, CDD can support telehealth expansion programs to increase access to DD-specific medical and behavioral health services, particularly in rural areas. Funding initiatives that strengthen Medicaid reimbursement for DD-related healthcare services can further help incentivize providers to expand their services to individuals with DD.

Enhancing Transportation Access for Individuals with DD

Transportation remains one of the most significant barriers to healthcare, employment, and community integration for individuals with DD, particularly in rural areas like Chautauqua County. The lack of reliable, ADA-compliant transportation prevents many individuals from attending medical appointments, participating in vocational programs, and engaging in community activities. Families often must cover the cost of private transportation, which is not financially feasible for many.

It is recommended that this challenge can be addressed by funding pilot programs that explore flexible, on-demand transportation options for individuals with DD. Collaborating with transit agencies and service providers, the CDD can help develop more reliable paratransit systems, accessible ride-sharing programs, and community-based mobility solutions. Additionally, funding transportation advocacy initiatives can help ensure that accessibility improvements remain a key priority for local and state transportation planning.

Expanding Community-Based Support for Families & Individuals with DD

Families and caregivers of individuals with DD experience high levels of stress and burnout, yet respite care options remain limited, underfunded, and difficult to access. Many families lack access to caregiver respite services, inclusive social programs, and DD advocacy resources. Parents and caregivers frequently report experiencing burnout and financial strain due to the lack of structured community-based support. Additionally, individuals with DD often have limited opportunities for social engagement, vocational training, and recreational activities, particularly in rural areas where programming is scarce.

financial resources to support weekend and overnight respite services can alleviate the stress placed on families.

It is recommended that community-based programs that promote inclusive social and recreational programs that promote community integration and peer support be expanded. Supporting local organizations in expanding DD awareness and advocacy initiatives can further help increase outreach and education efforts, ensuring that more families are aware of available services.

Implementation Steps:

- Advocate for increase state and local funding for overnight and summer respite programs.
- Develop simplified reimbursement processes to improve access to respite care services.
- Strengthen community partnerships to expand respite care offerings through local nonprofits and service agencies.

Ensuring Aging in Place for Individuals with DD

Aging individuals with DD face significant barriers to maintaining independence due to a lack of accessible housing options, limited long-term care planning resources, and insufficient home-based support services. Many families struggle to find stable housing solutions that allow individuals with DD to remain in their communities as they age.

Additionally, caregivers—many of whom are aging themselves—have expressed concerns about what will happen to their loved ones when they are no longer able to provide direct care.

It is recommended that the CDD consider funding aging in place by funding DD-specific aging support programs that help individuals maintain independence through home modifications, in-home support services, and assisted living programs tailored to DD populations. Grant funding could also support training for caregivers and direct support professionals on best practices for aging-related DD care.

It is recommended that the CDD advocate for policy adjustments that increase funding for home-based and community-based services (HCBS) and ensure long-term housing stability for aging individuals with DD.

Additional Recommendations:

- Develop financial assistance programs for home modifications and accessibility improvements to help individuals remain in their homes.
- Expand caregiver support programs that provide aging caregivers with respite care, legal guidance, and transition planning assistance.
- Strengthen partnerships with housing agencies and aging services providers to create integrated care models for individuals with DD as they age.

Enhancing Early Diagnosis and Intervention Awareness

Timely diagnosis and early intervention are critical for maximizing developmental outcomes and ensuring that individuals with DD receive the support they need from an early age. However, many families face delays in accessing screenings, misdiagnoses, or a complete lack of information about available resources. often the lack of training in recognizing early signs of developmental disabilities, leading to missed opportunities for early intervention.

It is recommended that funding early screening initiatives which improve access to developmental evaluations, family education programs, and school-based diagnostic services, will ensure families are receiving early diagnosis and care. Developing statewide public awareness campaigns can also help families identify early warning signs and connect with services sooner.

Additionally, it is recommended that the CDD support training programs for pediatricians, educators, and early childhood providers to increase awareness and referral pathways for DD services.

Additional Recommendations:

- Establish mobile screening units to provide early diagnostic services in underserved areas.
- Integrate early intervention training into medical and educational professional development programs.
- Expand outreach efforts through community health centers, schools, and childcare facilities to ensure families receive information about available early intervention programs.

Expanding Employment and Social Opportunities for Individuals with DD

Employment remains one of the most significant barriers to independence for individuals with DD. Many struggle to find jobs due to discriminatory hiring practices, a lack of inclusive training programs, and limited workplace accommodations. Even when employed, individuals with DD frequently experience job instability and underemployment, with few pathways for long-term career growth.

Additionally, there is a lack of social and recreational programs that provide meaningful community engagement, further isolating individuals with DD from peers and support networks.

It is recommended that the funding the expansion of employment opportunities through vocational training programs, inclusive job placement initiatives, and employer engagement efforts. Grants can support on-the-job training models that help individuals with DD build skills while working.

Additionally, advocating for policy changes increases wage protections for DD employees and provides incentives for businesses to hire and retain workers with disabilities. Expanding access to social and recreational programs can also help individuals develop peer networks, leadership skills, and community connections.

Additional Recommendations:

- Develop inclusive internship and apprenticeship programs in collaboration with businesses, workforce agencies, and trade schools.
- Increase state and federal funding for supported employment services, ensuring long-term job stability for individuals with DD.
- Strengthen partnerships with parks, recreation centers, and community-based organizations to expand inclusive social and recreational programs.

How the CDD Can Advance These Efforts

The scope of these challenges requires targeted intervention, and CDD is positioned to address service gaps through grant-making, policy advocacy, and technical assistance. By focusing on funding strategies that enhance workforce retention, housing accessibility, healthcare, transportation, and community-based supports, the CDD can drive long-term improvements in DD service delivery.

One key approach is the development of targeted grant programs that fund initiatives such as DSP workforce training, DD-specific supportive housing, healthcare provider education, and community engagement projects. These funding opportunities can help providers expand their capacity and address critical service shortages.

In addition to funding, the CDD can support policy, and systems change efforts by working with state and local agencies to advocate for Medicaid reimbursement increases, DD-friendly housing policies, and improvements in public transportation accessibility. By funding policy research and technical assistance initiatives, CDD can help drive systemic improvements that go beyond individual service grants.

Finally, CDD can play a critical role in technical assistance and capacity building by supporting service providers in developing best practices for workforce development, housing expansion, and healthcare access. Providing training resources and facilitating knowledge-sharing opportunities among DD providers can help strengthen the overall service system and ensure more effective, sustainable solutions.

Conclusion

By focusing on strategic grant-making, policy advocacy, and capacity-building initiatives, the CDD can effectively address service gaps for individuals with DD in the Bronx and Chautauqua Counties. While broader systemic change requires collaboration across multiple sectors, the targeted recommendations outlined in this report offer realistic, actionable strategies for improving workforce retention, housing access, healthcare services, transportation, and community-based support. Through continued investment in these priority areas, the CDD can help create a more equitable, accessible, and sustainable support system for individuals with DD and their families.

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