

# Statewide Family and Provider Care Mapping Report



## Children and Youth with Special Health Care Needs in New York State



Department  
of Health

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## Children and Youth with Special Health Care Needs in New York State – Statewide Family and Provider Care Mapping

Children and youth with special health care needs (CYSHCN) and their families have needs for care and support beyond those experienced by other children generally. According to the National Survey of Children's Health (NSCH), more than 765,000 (18%) of New York's children age 0-17 have a special health care need. Almost half of CYSHCN live in households with income below 200% of the federal poverty level. CYSHCN are more likely to have their daily activities greatly affected by their health condition(s), to miss 11 or more school days in a year, and to have trouble making or keeping friends. Families of CYSHCN report higher out-of-pocket medical expenses, have trouble paying medical bills, spend more time coordinating their child's health care, and report reducing or stopping work due to their child's health. Only 11% of New York State (NYS) caregivers of CYSHCN reported that their child received care in a well-functioning system and only 15% reported their adolescent with special health care needs received services needed for transition to adult health care.

Within the New York State Department of Health (NYSDOH), the Division of Family Health (DFH) is responsible for supporting children and youth with special health care needs (CYSHCN).

One way that CYSHCN are supported is under the Title V Maternal and Child Health Services Block Grant (Title V) by providing funding to the state's local health departments (LHDs) to provide information and referral services to families with CYSHCN to help them navigate and access the complex and often overwhelming networks of medical, developmental and social-emotional care in NYS. Within the DFH, the Children and Youth with Special Health Care Needs (CYSHCN) program oversees the contracts with the LHDs and coordinates efforts to support CYSHCN across NYSDOH and other state agencies.

In addition, the DFH oversees the state's Early Intervention (EI) program, which is federally authorized under the Individuals with Disabilities Education Act (IDEA) established through the US Department of Education. The NYS EI program serves children under 3 years of age with a confirmed disability or established developmental delay in one or more of the following areas of development: physical, cognitive, communication, social-emotional, and/or adaptive. The EI program offers a variety of therapeutic and support services to eligible infants and toddlers with disabilities and their families. Ensuring positive family outcomes is central to the EI mission. The EI program is in the middle of a multi-year quality improvement project called Improving Family Centeredness Together (IFaCT), which consists of local teams of parents/caregivers, county EI officials, service coordinators and therapists implementing a quality improvement project that starts with an initial learning session with the goal of improving family-reported outcomes.

Furthermore, the DFH, with funding from the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA), oversees the state's Early Hearing Detection and Intervention (EHDI) program with the goals that every infant completes a hearing screening by one month of age, and infants who fail the initial hearing screening receive a follow-up diagnostic hearing test by three months of age, and infants who have confirmed permanent hearing loss are enrolled in early intervention services by six months of age. The EHDI program monitors the hearing screening and follow-up of infants born in NYS and engages hospitals, audiologists and other key stakeholders to ensure appropriate, timely screening and follow-up. The EHDI program has initiated regional quality improvement projects to address the state's low rate of follow-up after a failed hearing screening.

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The EHDI program, like the EI program, has engaged teams of parents/caregivers, county staff, birthing hospital staff, and audiologists that meet initially at an in-person learning session and then implement a local project with the goal of improving the follow-up infants and families receive.



### Care Mapping Process

The NYSDOH recognizes that the supports and care for CYSHCN can be improved. To better understand the gaps, barriers, and needs of families with CYSHCN, CYSHCN program staff implemented a process to collect feedback from parents and caregivers with CYSHCN and professionals who serve them. A formal mapping tool was used online or by paper to diagram roles, responsibilities, needs, and resources in providing care for CYSHCN and the changes most desired to help families meet their needs.

Care mapping recruitment was conducted between March 2017 and June 2018, and feedback from 138 caregivers and 40 providers was collected.

Caregivers and providers were engaged to provide feedback either through an online mapping tool or a paper tool. Parents from the EI Partners Training Project, LHD CYSHCN and EI staff, and Parent to Parent of New York State staff were provided guidance on using the online mapping tool and a link to independently create their own care map. Independent entry resulted in feedback from 29 caregivers and 21 providers. In addition, participants were recruited in collaboration with Families Together (13 caregivers) and the Leadership Education in Neurodevelopmental Disabilities (LEND) program at Westchester Institute for Human Development (4 caregivers) to participate in group mapping activities facilitated by NYSDOH via webinar with feedback entered into the online mapping tool.

While the online mapping tool allowed the NYSDOH to see common responsibilities, needs and resources identified by participants, its design did not provide the detail necessary to understand the specific challenges and barriers of caregivers and providers and what was needed to improve them. As a result, NYSDOH staff developed a paper tool to address these issues and continued to gather specific feedback at in-person facilitated care mapping sessions.

Participants, who used the paper tool at in-person sessions, were recruited by the New York City Department of Health and Mental Hygiene (NYC DOHMH) CYSHCN Health Education Forum (17 caregivers), Parent to Parent of New York State (48 caregivers and 2 providers), as well as the NYSDOH EI program (22 caregivers) and EHDI program (5 caregivers and 17 providers). Below is a summary of the care mapping themes based on feedback received from caregivers and providers. More in-depth summaries of the feedback collected from the regional care mapping sessions hosted by Parent to Parent of New York State (Appendix 1), the NYC DOHMH CYSHCN Health Education Forum (Appendix 2), sessions with the EI program (Appendix 3), sessions with the EHDI program (Appendix 4) and the online submissions (Appendix 5) are included with this report.

# Children and Youth with Special Health Care Needs in New York State – Statewide Family and Provider Care Mapping

## Summary of Care Mapping Themes

### Common challenges reported by caregivers of CYSHCN:

#### 1. Accessing and coordinating medical care and related services

- Obtaining a diagnosis and identifying appropriate care was challenging.
- Long distance travel was necessary to see specialists in most areas.
- Long wait lists were reported for appointments with certain specialists.
- Some parents said their pediatrician was helpful; many said they were left on their own to find resources after they received the diagnosis.
- A significant amount of time was spent looking for resources about their child's diagnosis and coordinating care.
- Parents with children who received services from the EI program did not receive enough instruction about how to provide therapy at home.



*“I found that finding a provider was the hardest. Every door I knocked on, I was turned away”.  
“[There should be] easier access to those resources so I do not have to  
be on a computer for 6 hours doing research”.*

#### 2. Identifying and coordinating child care

- Affordable care for CYSHCN, who have complex health or behavioral issues, was difficult to find.
- On-site nursing was difficult to find and expensive.
- Family members often reported needing to stop working, reduce hours, or change shifts to be able to care for their child.

*“If I didn’t have a flexible job I’d already be fired for missing  
too many days when my child is sick”.*  
*“It is difficult to get childcare in the summer, holidays and school vacations.  
I decided to work from home”.*

## Children and Youth with Special Health Care Needs in New York State – Statewide Family and Provider Care Mapping

### 3. Providing emotional and social supports for the child and family

- Social and recreational opportunities were lacking for CYSHCN to connect with other children.
- Summer camps, child care and other common socializing outlets were not readily available and were difficult to access.
- Emotional support services for both the child and family were lacking or difficult to access due to many demands caring for a child with special health care needs.

*“My son cries because he does not have any friends”.*  
*“[I wish I had] friends who would take my kid, the way I take theirs, to events”.*

### 4. Providing financial support, including health insurance

- The financial burden of caring for CYSHCN was reported to be significant.
- Common expenses included co-pays and deductibles for medical services and medications, therapy, adaptive equipment, vehicle and home modifications, travel for medical services, and child care.
- Health insurance was reported as a critical need.
- Medicaid was identified as the best option for coverage and out-of-pocket expenses but depending on the part of the state it was difficult to find providers that accepted Medicaid.
- Parents were frustrated with navigating their health insurance coverage.

*“As soon as you put a special needs label on something, the cost quadruples”.*  
*“I have to choose between paying mortgage and putting food on the table and the medical needs of my child”.*

### 5. Navigating and obtaining assistance from the school system

- Parents whose children did not receive services through the EI program struggled navigating the referral process through the school.
- Some parents felt their concerns were minimized by the school systems, which led to delays in services.
- Many parents felt that although the process of getting an appropriate Individualized Educational Plan (IEP) or 504 Plan was overwhelming or cumbersome, but it led to helpful interventions.
- Lack of communication between medical providers and the school was a concern.

*“At CPSE [Committee on Preschool Special Education] meetings, they just push papers in front of you to sign. Someone needs to advocate for the parent”.*  
*“Need someone to make these different groups of professionals talk to one another”.*

# Children and Youth with Special Health Care Needs in New York State – Statewide Family and Provider Care Mapping

## 6. Integrating the child and their family into the community

- Accessibility in their communities was an issue.
- Barriers to simple tasks like taking their child to the store or providing support to older CYSHCN activities of daily living was frustrating. Most shopping carts do not accommodate older CYSHCN and family-friendly restrooms for older children, who still require diaper changes, are lacking.

*“I have a hard time going out because my son is in diapers but is too big for the changing tables. I have to bring my own supplies to change him and put my child on the floor. It’s gross”.*

*“A child with special needs does not live in a vacuum. They are part of a family and have to address their needs and other family needs”.*

## 7. Transitioning to adult services

- Transitioning from youth to adult services was reported as being a stressful process for both parents and the transitioning youth with developmental disabilities.
- Concern about the shortage of day habilitation services for adults, leaving a gap of services for high-need individuals.
- Need for their children to develop skills to promote independence as well as effective communication and time management.

*“This is the worst time of my life”.*

*“It is a disaster that children with Autism have nowhere specifically to go as an adult”.*

## 8. Providing and coordinating transportation

- Transportation was a barrier to accessing care for their CYSHCN.
- Medical specialists were often in urban areas which required long distance travel to access specialized care for those living in rural and suburban areas.
- Financial burden of travel costs included mileage, food and lodging.
- There was a shortage of public transportation in rural areas.
- Coordinating medical transportation was time consuming and unreliable due to the transportation company’s shared-ride services, which require riders to reserve a wide time slot for pick-up in advance, so multiple riders can be accommodated.
- Adapting personal vehicles with specialized equipment was expensive and costly to maintain.

*“In my community, moms don’t drive”.*

# Children and Youth with Special Health Care Needs in New York State – Statewide Family and Provider Care Mapping

## Common challenges reported by providers of services for CYSHCN:

### 1. Connecting with families of CYSHCN

- Disseminating information on resources and promotional activities was important.
- Successful outreach was dependent on establishing a connection between the families and the community partners.
- While providers said providing printed educational materials is important, they did not think the materials effectively reached all families.
- Developing websites, blogs, creating a social media presence, and community coalitions were also considered effective outreach strategies.

### 2. Knowledge of available resources

- Providers in resource-rich areas of the state felt it was overwhelming to identify and keep up with all the different resources and opportunities.
- Providers in more rural areas felt discouraged at a lack of local resources to offer families.
- Finding information was a time-consuming process.
- Finding the time to research and to keep up to date on current information was a significant challenge.

### 3. Continuity of care

- Due to Health Insurance Portability and Accountability Act (HIPAA) concerns, communication among multiple providers was difficult at times and a barrier to integrated, coordinated care over time.
- Patient navigators and case managers were helpful but not always available to all patients.
- There were not enough Medicaid Health Homes available to those who needed them and those who did not qualify fell through the cracks.
- Lack of transportation and affordable medical care were barriers for effective continuity of care.





# Children and Youth with Special Health Care Needs in New York State – Statewide Family and Provider Care Mapping

## Suggestions for change discussed by caregivers included:

### 1. Information readily available

- Caregivers wanted information on specialists and community organizations provided at the time of diagnosis.
- Caregivers wanted a single place, such as an information hub, where they could find information on State programs throughout the child's development.
- Caregivers wanted materials and resources readily available and easy to find.

### 2. Regulatory or policy changes

- Caregivers wanted fewer regulations and policies in place regarding access to services to decrease the delays experienced in receiving services. Suggestions included improving training requirements and certification processes for providers that offer services under the Office of People with Developmental Disabilities (OPWDD) Self-Direction grant program, and fewer restrictions on the type of therapies covered by OPWDD, and simplifying the guardianship process.
- Caregivers wanted an increase in staffing levels at agencies to increase the number of providers available to care for children approved to receive services.
- Caregivers wanted increased reimbursement rates for providers who work with the OPWDD, EI and associated agencies, to increase provider availability and improve access to care.
- Caregivers wanted a reduction in the amount of paperwork required to apply for services and for the application process to be streamlined and/or consolidated across agencies.
- Caregivers wanted to be compensated for staying home to care for their special needs child under the age of 21, as is currently allowed when providing care for an adult under the Consumer-Directed Personal Assistance Program (CDPAP).

### 3. Improved health insurance coverage and financial assistance

- Caregivers wanted a reduction in out-of-pocket expenses for medical and other health related costs.
- Caregivers wanted better coverage under their private health insurance plans (including dental and vision coverage).
- Caregivers wanted more financial assistance to help pay for the costs not covered by insurance.

### 4. More opportunities for connections amongst caregivers and CYSHCN

- Parents wanted support groups to share information and experiences.
- Caregivers desired more group activities in the community for the children.

# Children and Youth with Special Health Care Needs in New York State – Statewide Family and Provider Care Mapping

## Suggestions for change discussed by providers included:

### 1. Guidance and technical assistance for public health workforce

- Providers from LHDs who serve CYSHCN identified the need for defined policies, requirements, and guidance. LHD staff said they wanted uniform guidance from NYSDOH, such as a CYSHCN policies and procedure manual, which outlines eligibility and program activities. Since the definition of CYSHCN includes a broad range of health issues ranging from mild to severe, physical, developmental, behavioral or emotional, and from birth to age 21, it is challenging to have a single set process for assisting CYSHCN and their families.
- Providers from LHDs identified the need for more individualized technical assistance to assist them to reach families and serve them.

### 2. More funding

- Providers felt that more funding is needed to support programs and services for CYSHCN.
- LHDs are unable to provide the type of care coordination that many families need with the limited funding they receive. With additional funding, additional promotion and outreach activities and more staff time could be devoted to the program.
- Providers wanted additional funds to support families' high out-of-pocket medical expenses.

### 3. Improved access to quality health care

- Providers wanted to increase specialized provider capacity to meet the demands of a growing CYSHCN population.
- The care that is provided must be more family-centered and coordinated.

## Next Steps

The findings from the care mapping sessions are being integrated into NYSDOH's plans for the next five-year procurement cycle for funding of CYSHCN programs at LHDs and is being used to inform the statewide work of the CYSHCN, EI and EHDI programs to support the health and developmental needs of young children and their families. Grant recipients will use this information to inform their work. NYSDOH plans to continue to gather feedback from families and aims to build capacity at LHDs to better serve CYSHCN and their families through resource development, training opportunities for providers and families, and emphasis on identifying social and emotional supports. NYSDOH is committed to sharing this feedback with stakeholders and partners, i.e., Parent to Parent of New York State, the NYS Association of County Health Officials (NYSACHO), the Office of Mental Health (OMH), the Office for People with Developmental Disabilities (OPWDD), and the Office for Child and Family Services (OCFS).

## Appendices

- Appendix 1 Feedback from Caregivers by Region Participating in Regional Listening Sessions Hosted by Parent to Parent of New York State
- Appendix 2 Feedback from Caregivers Participating in the New York City Department of Health and Mental Hygiene CYSHCN Health Education Forum
- Appendix 3 Feedback from Caregivers with Children Served by the Early Intervention Program
- Appendix 4 Feedback from Caregivers and Providers Participating in the Early Hearing Detection and Intervention (EHDI) Program Learning Collaborative
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# Appendix 1

## Feedback from Caregivers by Region Participating in Regional Listening Sessions Hosted by Parent to Parent of New York State

To engage parents across the state, the NYSDOH entered into a contract with Parent to Parent of New York State to host care mapping sessions with parents and caregivers of CYSHCN. In total, 47 caregivers from 17 counties provided feedback at six regional care mapping sessions. Specific feedback documenting the caregivers' experiences, opinions, and perceptions from each regional session hosted by Parent to Parent is summarized below.

**Albany County:** *Ten caregivers attended a group session in Colonie on February 5, 2018.*

### 1. Accessing and coordinating medical care and related services

- A lack of knowledge among medical providers to successfully make referrals to services and evaluations was reported.
- Caregivers did their own research or learned by word of mouth about available resources, even though it takes a lot of time.
- Lack of communication between medical providers and between medical providers and schools was an issue.
- A lack of qualified providers available for therapy through state programs, such as the Office for People with Developmental Disabilities (OPWDD) and the NYSDOH Early Intervention (EI) program was experienced. It was believed the lack of providers was due to poor reimbursement rates.
- There were long wait lists for in-home medical assistance from state programs such as OPWDD Self-Direction and Care at Home programs.
- There was a shortage of mental health services available locally.
- Parents often administered medication to their child/children at home. Medication charts were helpful to keep track of multiple prescriptions for multiple children.
- Agency requirements were burdensome and created delays in receiving services. For example, when a provider is approved to provide services for one state agency they should not have to go through another approval process to provide the same services for a sister agency.
- Independent therapists and home care providers were more accessible than those provided by state programs, however also more expensive.
- Independent Living Centers (ILCs), such as Southern Adirondack Independent Living (SAIL), were helpful in providing referrals and durable medical equipment.

### 2. Navigating and obtaining assistance from the school system

- Caregivers identified the importance of receiving therapy in school. Individualized Education Plans (IEPs) were important and helpful in assuring necessary services are received in a school setting, but the availability of different therapies varied greatly by school.
- Having a parent representative at Committee on Special Education (CSE) meetings was very helpful.
- Other parents of school children with special needs were seen as trusted allies.

## Appendix 1

### 3. Transitioning to adult services

- Caregivers of CYSHCN approaching transition to adult services expressed that it was an extremely stressful time.
- Shortages of, and long wait lists for, day habilitation programs were common. Several caregivers stated wait lists were over a year long.
- Since adult services don't begin until 21 years of age, caregivers reported a gap in services if a CYSHCN completed school or left school before reaching the age of 21.
- Medicaid Service Coordinators were helpful in providing support during the transition period.
- Caregivers were concerned about the number of CYSHCN diagnosed with autism and where they will live once they reach adulthood.
- Caregivers shared the need to obtain guardianship of their CYSHCN once he/she became a legal adult, so they can assist them in important decision-making.

### 4. Providing financial support, including health insurance

- Not all caregivers in this group were aware of the availability of Medicaid waivers and that they may qualify for services based on diagnosis despite being over the income guidelines for regular Medicaid.
- High out-of-pocket costs for co-pays, deductibles and medical supplies were reported.
- Lack of locally available specialists sometimes necessitated going out of state for services, which may not be covered by Medicaid and result in out-of-pocket costs.
- Caregivers reported lost wages due to the volume of medical appointments and long-distance travel for specialists as well as missing work to care for a child when they are sick, during school vacation, and over the summer.
- Caregivers identified the need to set up Special Needs Trusts and Achieving a Better Life Experience (ABLE) accounts to save for the child's future without making them ineligible for State and Federal benefits.

### Suggestions for change

1. Caregivers wanted administrative processes, such as applying for program benefits, to be simplified. The amount of paperwork required to apply for services at multiple agencies needs to be reduced by consolidating and/or streamlining the application process.
2. Caregivers wanted better collaboration and sharing of information between state programs to reduce the redundancy in providing the same information to each program.
3. Caregivers wanted better communication between state agencies and community-based organizations to increase the availability of resources and decrease compartmentalizing of services.
4. Caregivers wanted a "Single Point of Access" for information on all services.
5. Caregivers wanted regulatory changes to allow them to be paid as parent caregivers for their children with special needs, which is currently only allowed for caregivers of adults with special needs in NYS.

# Appendix 1

**New York County: *Eight Spanish-speaking caregivers attended a group session in Manhattan on February 9, 2018.***

## **1. Accessing and coordinating medical care and related services**

- Caregivers struggled to find qualified providers and specialists who had knowledge on their child's specific conditions and who could assist with referrals.
- The process of getting an accurate diagnosis was complicated, especially not knowing how/where to begin the process.
- Some parents felt minimized by the provider when discussing their child's diagnosis. Parents felt discredited that their provider dismissed their concerns at times because of their language or education level.
- A limited number of caregivers reported that they received a referral for the Early Intervention (EI) program. Few caregivers knew about the state's EI program when their child was under the age of three. Two caregivers reported that their children were denied EI services, but their children later received a diagnosis (at age 8 and age 13).

## **2. Providing financial support, including health insurance**

- Caregivers found that having Medicaid was helpful and that many providers accepted Medicaid, so access was not an issue.
- Those with private insurance reported that limitations in coverage led to reaching a cap early in the year. Some parents had to quit their jobs to get Medicaid because of the high out-of-pocket costs with private insurance.
- Obtaining Social Security Income (SSI) was described as helpful because the child is automatically enrolled in Medicaid. Some parents had to decide between housing and SSI for their child; if they accepted SSI it put them over the income threshold for subsidized housing. With the cost of housing in NYC, the decision was difficult. Some parents received SSI without fully understanding the benefit package.
- Caregivers reported that not speaking English or being bilingual was an ongoing barrier to accessing services. Caregivers said understanding insurance benefits is challenging, and even more so when speaking a language other than English. Some parents stated that Medicaid Service Coordinators were helpful explaining financial and health insurance topics. However, parents with limited English proficiency perceived that the interpreter did not always provide the full explanation of the benefits.

## **3. Navigating and obtaining assistance from the school system**

- Parents found that jargon and acronyms used by the school were difficult to understand.
- Caregivers said the process of developing an Individualized Education Plan (IEP) was overwhelming, especially with input from multiple individuals at the Special Education committee meetings.
- Parent representatives were important and helpful for Committee on Special Education (CSE)/Committee on Preschool Special Education (CPSE) meetings, but not all school districts accommodated having one available. One parent, who volunteered as a parent representative, said the school avoided having her present at committee meetings.

## Appendix 1

- Parents reported that it was best to approach the school as an advocate, rather than a parent, to be taken seriously.
- Several parents reported that teachers and other professionals at their schools were not well trained to support children with special needs, especially those with developmental delays and behavioral issues (i.e., issues that cannot be identified from physical appearance). Parents felt that both they and their children were treated unfairly by the school due to the children's special needs.

#### 4. Providing and coordinating transportation

- Caregivers reported they struggled to travel for medical appointments because most relied on public transportation, which is difficult with some CYSHCN. One parent explained that moms in her neighborhood don't drive, so relying on friends or others for appointments is necessary.
- Caregivers were concerned about their child being bullied and their safety on public school buses.

#### Suggestions for change

1. Caregivers wanted information on referrals and services at the time of diagnosis.
2. Caregivers wanted greater availability of financial assistance and waivers for high medical costs. This would supplement insurance for those that do not have sufficient coverage.
3. Caregivers wanted more inclusion and social opportunities for children with special needs.

**Suffolk County:** *Eleven caregivers attended a group session in Hauppauge on February 16, 2018.*

#### 1. Identifying and coordinating child care

- Parents of children with complex medical needs discussed the need to stay home when their child is unable to attend school due to sickness because most daycares cannot provide the medical supervision needed.
- Caregivers reported that some states have medical daycares but they were not aware of such programs in New York.
- Caregivers expressed their desire for a program that would allow a caregiver to be paid to provide care for their children at home. Consumer-Directed Personal Assistance Program (CDPAP) allows only caregivers of adults to be paid.
- CDPAP will provide nursing type services at home for children, but parents expressed their opinion that there were provider shortages, due in part to low reimbursement rates.
- Caregivers stressed the importance of a flexible or understanding work environment because many days are missed to care for the child.
- Paid Family Leave (PFL) could be great if the employer offered it, but some public employers opted out.
- The Care at Home (CAH) Program was helpful for those who qualified.

# Appendix 1

## 2. Providing and coordinating transportation

- Lack of public transportation on Long Island caused serious concerns because most specialized services are in New York City or farther.
- Caregivers reported that a mechanism to reimburse caregivers for mileage, tolls, and parking for medical appointments was not available.
- Travel costs for community habilitation or respite services were reimbursable through OPWDD Self-Direction grants. For example, if a grandparent was approved to provide respite, the parent's travel to the grandparent's home for respite would be reimbursable.
- Cost and stress associated with overnight stays for appointments with medical specialists were of concern, especially when a child needed to be in a hospital for an extended period. Hospitals may allow one parent to stay with the child, but other family members needed to get separate accommodations.
- Suffolk County Accessible Transportation (SCAT) was identified as a medical transport option open to the public. Appointments had to be made days in advance and scheduled pickup and return times are given in a one-hour window. If caregivers had a pre-arranged return time for SCAT and the appointment ran late, they had to cancel the appointment or risk being stranded.
- Some families needed adaptive equipment added to their personal automobile. One caregiver applied for a modification grant from OPWDD to adapt a van for wheelchair accessibility. When the modification was approved, seven years had passed since the initial request, and a new van was needed. Modification grants only covered adapting the vehicle and not equipment repairs.
- Some non-profit agencies offered adaptive equipment (Share the Voice, Suffolk Independent Living Organization).
- Caregivers reported a need for specialized car seats and strollers as children outgrow standard models, and those items were costly and not covered by insurance.

## 3. Providing financial support, including health insurance

- Caregivers reported that understanding health insurance benefits was challenging. For example, if a medical provider changed a prescribed medication it was up to the parent to know whether it was covered by insurance or they needed to cover out of pocket.
- Caregivers were not aware of the availability of waiver programs unless they heard about them from another parent.
- Community organizations like Parent to Parent of New York State and other similar groups were good sources of information.
- One caregiver shared the resource GoodRX.com, which is a website to get drug prices at different pharmacies and coupons to help parents save out-of-pocket costs for prescription copays.
- Many therapy services had to be paid out of pocket when insurance, waivers, and grants did not cover costs.



## Appendix 1

### 4. Integrating the child and their family into their community

- Caregivers discussed issues with accessibility in relation to restrooms. Changing tables did not support older children, resulting in the need to bring personal equipment and supplies to aid in changing older children. Caregivers said it was easier to change the child in the car, which may interrupt a shopping trip.
- Family and gender-neutral restrooms were helpful when the child is older.

### 5. Providing emotional and social supports for the child and family

- Parents reported the desire for more camps, sports, and other social activities for CYSHCN, including more inclusive camps so CYSHCN could attend with typical kids.
- Additional staff such as a personal aid or caregiver with medical or special education background may be needed, which meant paying for both the activity and the extra staff.
- Religious organizations were sometimes helpful in providing social opportunities for children.
- Caregivers reported a need for a break from the stresses of providing and coordinating care for their CYSHCN, and there were not enough support groups or respite opportunities for parents.
- Family and friends did not always understand the needs and challenges of CYSHCN, so they were not a reliable source for respite.

### Suggestions for change

1. Parents wanted a resource guide of services available across the lifespan that describes what to expect and what will be provided from available services.
2. Caregivers wanted medical providers to inform them of services and needs at the time of diagnosis.
3. Caregivers wanted regulatory changes allowing them to be compensated for choosing to stay home with a CYSHCN under age 21.
4. Caregivers desired more parent respite organizations.
5. Parents wanted paid Family and Medical Leave Act (FMLA) required for employers of families with a special needs child.

**Broome County:** *Eight caregivers attended a group session in Binghamton on February 23, 2018.*

### 1. Accessing and coordinating medical care and related services

- Five caregivers said their pediatrician was helpful in giving referrals to specialists. It was easier to obtain information on available resources when their pediatrician provided a referral to a specialist.
- Emergency Departments were not knowledgeable about special needs or rare disorders.
- Travel to larger cities was required to reach certain specialists, specifically pediatric psychiatrists, developmental specialists and pediatric dentists.
- Once a specialist was identified, wait lists could be one to two years long.
- Patient Navigators located at the hospital were helpful in handling logistics. For example, if the pediatrician made a referral, the Patient Navigator arranged for reduced rates at nearby hotels and restaurants.
- Service coordinators through Medicaid and other programs were also helpful at providing information on available resources, but hard to get.

# Appendix 1

## 2. Providing and coordinating transportation

- Caregivers reported that the frequency and distance required to travel for appointments could be a financial burden, especially if frequent appointments were needed.
- One parent reported that their personal travel for medical appointments (mileage, food, hotel) was reimbursed by Medicaid with prior approval. Other parents were unaware of this benefit or the eligibility criteria.
- Adapting their personal vehicle with specialized equipment was a big expense for families.
- Caregivers living in rural areas had few options for public transportation. Rural Health Network is a volunteer organization that covered transportation to medical services for people who lived in rural areas, but the need for services exceeded capacity.

## 3. Navigating and obtaining assistance from the school system

- Caregivers stressed that knowing where to start to get their child special education services at school was a challenge. School service coordinators or social workers were considered a helpful resource for five parents.
- Schools did not require a parent member to be at the Committee on Special Education (CSE) meetings, but when they were it was helpful to parents who were new to the process. One caregiver volunteered as a CSE parent member but felt the school minimized her role as a parent advocate on the committee.
- Overall, caregivers felt school staff needed more training on addressing special needs in children.
- Southern Tier Independence Center (STIC) Parent Technical Assistance Program was cited as a helpful program that provided information regarding the special education process including referrals, evaluations, and transitions to enhance families' skills and ability to effectively advocate for their child's needs and to work collaboratively with the education system. The program served families of children with special needs ages 3-21 and professionals and staff within the education setting.
- Educational plans (i.e., IEP, 504) were identified as essential to the child's success at school, however a great deal of variation in services provided by the school districts was reported.
- Although school evaluations were provided free of charge, caregivers did not feel the results were always accurate. Therefore, some caregivers requested an outside evaluation, which they perceived to be more accurate than school evaluations, but the evaluations were also expensive.
- Caregivers reported poor communication between the medical providers and the school. The caregiver had to follow up with both parties to ensure the information shared was accurate.

## 4. Identifying and coordinating child care

- Caregivers reported that paying for child care, therapies and programs outside of school is expensive.
- For those who qualified, Department of Social Services (DSS) provided financial assistance for daycare and a list of participating providers to choose from.
- Other child care coordinating agencies were also helpful. Bridges to Health (B2H) is a waiver program designed to provide children in foster care who have significant mental health, developmental disabilities, or health care needs with services to help them live in a home or community-based setting. B2H provided their covered families eligibility determinations and referrals to child care agencies.
- Caregivers reported that respite services were difficult to find, especially for young children. Self-Direction was considered helpful in providing respite services, but a shortage of providers was cited.
- Several caregivers decided to not work, to change jobs, or change job shift to better care for their children.

# Appendix 1

## 5. Transitioning to adult services

- Caregivers wanted to ensure their children had skills for independence when transitioning to adult care.
- Some parents reported having a positive experience using the Adult Career and Continuing Education Services-Vocational Rehabilitation (ACCES-VR), a program for employment readiness for young adults with disabilities. ACCES-VR paid for equipment, supplies, and tuition as well as assisted clients with finding employment.
- The STIC was reported to offer grants for technology to increase independence and promote self-reliance.

## 6. Integrating the child and their family into their community

- Parents wanted to take their child into the community for everyday activities.
- Special shopping carts available at Target and Wegmans accommodated their children's needs, but these were not available at other stores.
- Caregivers reported that family bathrooms were helpful.
- One caregiver stressed that she wanted her children to feel that they can do all the things that typical children do, but she had to bathe her children in bed, because she did not have an accessible bath for them in her home.
- Caregivers stated that handicapped parking permits were helpful for CYSHCN with both physical and developmental disabilities. Parking close to an entrance allowed parents to feel safer.

## 7. Providing emotional and social supports for the child and family

- Caregivers reported that their children had difficulty making friends.
- Support groups and activities specifically for children with special needs, such as the Magic Paintbrush Program, a Broome Tioga Board of Cooperative Educational Services (BOCES) program that provided activities and materials to creatively engage individuals of all ages with physical or developmental disabilities, were identified as helpful.
- One caregiver reported that she volunteered to lead girl or boy scouts, which provided both her and her children a social outlet.
- Volunteer-based afterschool activities were not helpful due to unreliable staffing.
- Integration with typical kids was not desired by all parents; some parents thought their child did best interacting with children who had similar challenges. One concern raised was that as children age and recognize their differences they may be bullied by typical kids.

## Suggestions for change

1. Caregivers wanted more training or continuing education for school psychologists and teachers on how to properly treat and communicate with CYSHCN and their families. They also wanted more consistency in the services provided to children with special needs across school districts and the state.
2. Caregivers requested a single point of receiving information for the child's needs.
3. Caregivers wanted more programs to identify children's strengths and to help them excel. They felt the focus should be on the abilities children have instead of their disabilities, because their children have talents to offer. Caregivers viewed this as important for fostering independence and preparing for transition.

# Appendix 1

**Monroe County: Eight caregivers attended a group session in Rochester on February 28, 2018.**

## **1. Accessing and coordinating medical care and related services**

- Caregivers stressed the importance of getting a correct and current diagnosis. Medical needs and diagnoses may change, and many children have co-existing conditions. Pediatric specialists, such as developmental pediatricians and pediatric psychiatrists, should be able to see children with dual or multiple diagnoses, but they often give only one diagnosis and do not explore further. Caregivers expressed frustration that they received conflicting diagnoses from different specialists.
- Care coordination was lacking between medical care and services which left the caregiver to coordinate multiple services and specialists.
- Caregivers wanted information on other services available for their child. Caregivers said they needed strong advocacy skills to be successful in getting the information needed to care for their child.
- Caregivers felt the emergency room (ER) should be avoided because ER professionals did not have training or awareness to deal with CYSHCN. When the ER was used for medical care, there was no subsequent referral for follow-up.
- A lack of pediatric psychiatrists was reported, leading to long waiting lists for appointments.
- There was concern that there was no partial hospitalization coverage or other models of care for children with mental health issues.
- Caregivers reported having difficulty understanding their health insurance coverage. Caregivers had to educate themselves on insurance coverage and advocate for their child. Understanding prescription drug coverage was challenging; for example, if a medication was changed within a certain time frame, their insurance did not always reimburse the caregiver for the expense.
- Caregivers reported tracking the changes in their child's symptoms (improvements and side effects) when starting a new medication was challenging. Caregivers reported that keeping track of medications and refills was difficult when caring for multiple children with multiple medications.
- Caregivers reported that the EI Program was very helpful for eligible children.
- Schools, including the Committee on Preschool Special Education (CPSE) and the Committee on Special Education (CSE), were somewhat helpful, although the level of support varied by school district.
- Private therapists were helpful, but most required out-of-pocket costs.
- Services from OPWDD and OMH were both seen as helpful, but children were only able to receive services from one or the other. Caregivers of children with a dual diagnosis of a developmental and mental health issue felt frustrated in having to choose which agency would best serve their child.

## **2. Identifying and coordinating child care**

- Caregivers reported that specialized daycare facilities were helpful but there are not enough available. Most caregivers agreed that typical daycare settings for CYSHCN were not helpful since their children required more individualized supervision and support.
- One-on-one support services were necessary for some children, but the expense of extra staff to provide this individualized care within the daycare setting had to be covered by the caregiver.

# Appendix 1

- OPWDD Self-Direction respite providers were helpful, but finding a provider on short notice for unplanned events, for example when the child was home due to sickness or on a snow day, was difficult.
- Family and friends could be helpful for child care, but only if they were trained to provide appropriate care.

### 3. Providing emotional and social supports for the child and family

- Parents in this group expressed that support groups with child care provided were the best option for caregivers because families learned about other resources and child care was offered for their CYSHCN. These groups were especially helpful if child care was provided to siblings as well as CYSHCN while parents attended the group. This child care setting provided a social opportunity for children with special needs and their siblings who were typically developing.
- Adult respite organizations were available, but were difficult to take advantage of because the caregiver would have to arrange child care to attend.
- On a short-term basis, while parents were grocery shopping, some stores provided child care. Some parents used it to spend time together.
- OPWDD Self-Direction community habilitation programs help older children learn about living in the community. Also, while children participated in the community program, it allowed parents a respite from caregiving.
- Peer groups and support groups available through social media were helpful for older children.
- Recreational programs like Challenger Sports, an organization designed to provide sports programs to individuals with learning and physical disabilities, provided social opportunities for youth.
- Mentor programs like Big Brothers/Big Sisters and youth advocacy programs were also effective social outlets.

### 4. Transitioning to adult services

- Parents identified many legal issues, such as securing a healthcare proxy, as CYSHCN transition to adult services. A healthcare proxy is critical to ensure continued access to medical records to coordinate insurance coverage.
- Caregivers also stated that they needed to obtain continued legal guardianship to continue to make decisions once their child turned 21 years old.
- Caregivers discussed the important life skills their adolescents with special needs must learn, including how to arrange transportation for appointments.

### 5. Transportation

- Medicaid transportation was available, but there were often travel delays and multiple stops (i.e., pooled transport) which could make travel time-consuming.
- Acclimation programs were available and were helpful. Acclimation programs guide the participant through a “test run” or simulated transportation experience, such as practicing riding the public city bus with the help of a volunteer. Some caregivers had used a program called ‘ROC Your Flight’ that guided people with disabilities through the airport security and boarding process to prepare them for future flights.

# Appendix 1

## 6. Safety for the child and family

- Caregivers discussed ways to keep their family safe, especially when their child has a mental health issue.
- Caregivers reported negative experiences with crisis response programs. For example, one caregiver called “Mobile Crisis” (sponsored by OMH) and found they could not respond to a mental health emergency for over 24 hours. NY Systemic, Therapeutic, Assessment, Resources & Treatment (NY START) is a similar crisis prevention and response program for children receiving OPWDD services.
- Safety equipment was available through state agencies (OPWDD/OMH), but due to a lengthy application process many caregivers chose not to apply.
- Caregivers suggested meeting with professionals/first responders prior to an emergency so they could be familiar with the child’s needs.
- The “Yellow Dot” program alerts police and Emergency Medical Services (EMS) to a child’s condition by placing a yellow dot sticker on the car window or home window. This way the first responder is aware of the child’s condition and can respond appropriately.
- Caregivers felt that supports were more helpful in urban areas versus rural areas. The group agreed there were many more support services available in Rochester and Monroe County than in surrounding counties.
- Caregivers stated it was important to understand that a caregiver’s mental health issues could impact care for the child.
- Residing in a safe neighborhood with neighbors who understand their child’s health condition was helpful, but not all had that environment.
- Parents shared that community-based organizations that provide training were helpful, but most are in urban areas; the city of Rochester had these programs, the surrounding counties did not. AutismUp, which is a community-based organization in the Rochester area, provided training on autism to local police and other services and supports for families with children with autism. Rochester Regional Center for Autism Spectrum Disorder (RRCASD) provided mindfulness training with parents and at schools. National Council on Alcoholism and Drug Dependence – Rochester Area (NCADD-RA) trained teachers and school staff on fetal alcohol spectrum disorders. Availability of training in these areas helped to ensure that providers in the community were educated on handling a CYSHCN before an issue arises.

## Suggestions for change

1. Caregivers wanted more timely access to services for their child. Caregivers wanted shorter wait lists for specialists and providers through state programs like OPWDD.
2. Caregivers wanted the training and certification requirements for respite providers through the OPWDD Self-Direction Program to be changed to increase access to services. Caregivers would like an alternative to the full-day respite training, because respite providers sometimes had other fulltime jobs and may not be able to take a day off for training.
3. Caregivers desired care coordination that better coordinated services and communication between educational, medical, and insurance providers.
4. Caregivers wanted supported community services, such as nutrition services, transportation, and comprehensive case management, which are provided to the aging population.

# Appendix 1

**Nassau County:** *Two caregivers attended a group session in Freeport on June 18, 2018. This session was hosted in partnership with Advantage Care Health Center FQHC and Nassau County Health Department.*

## 1. Accessing and coordinating medical care and related services

- Caregivers discussed various insurance coverages and their benefits. They felt that Medicaid and Marketplace insurance were more helpful than private insurance, especially when it included dental coverage.
- Finding dental providers who accepted Medicaid was difficult.
- These caregivers reported having little difficulty finding medical specialists and received appropriate referrals from their primary care providers. Waiting lists of one or two months for specialists such as an Ear, Nose and Throat (ENT) specialist were reported.
- Caregivers felt that being proactive in asking questions and researching online was successful in navigating their child's health care.

## 2. Identifying and coordinating child care

- Finding affordable child care was challenging. Cost can be a barrier for private child care services, although some town-offered or church-sponsored programs were identified as affordable.
- The child care assistance benefit through DSS helped those who qualified with child care while they worked. That child care benefit was immediately terminated if the caregiver lost her/his job; there was no extension while the parent looked for a new job. Losing child care made it difficult to look for new employment while also caring for their child.
- Families who did not qualify for financial assistance through social services, struggled to afford daycare.
- Head Start was identified as a helpful resource for those who qualified and was available for those who were unemployed.
- Afterschool programs served as a way of keeping older children safe and out of trouble. Extracurricular activities, such as sports, were cited as a good option for older children.

## 3. Navigating and obtaining assistance from the school system

- One caregiver was not comfortable with large, urban public schools. She felt that private schools were better because of a smaller class size and more individual attention without requiring a special education plan. However, the cost of tuition was a barrier.
- Caregivers of children with a 504 Plan, a written education plan for students with disabilities who require reasonable accommodation while attending school who do not have an Individualized Education Plan (IEP), reported it was helpful in providing necessary assistance in school, but sometimes the child needed additional help which was not provided by the school district.
- Caregivers reported paying for tutors to help their child. This additional professional help was costly but was more affordable when parents identified a college student who tutored.

## Appendix 1

### 4. Parenting and discipline

- Parents discussed the challenges of disciplining and providing emotional and financial support for their children. Behavioral issues led children to get into trouble. Caregivers had difficulty deciding on a discipline plan for their children. Caregivers felt that teaching respect and having open communication was more effective than taking away privileges. Caregivers looked for positive role models or mentors for their children.
- At times, professional counseling was necessary and helpful.
- Two-parent homes were felt to be more supportive financially than single-parent homes. Caregivers also felt a child's opportunities were largely dependent on the family's finances.

### Suggestions for change:

1. Caregivers wanted financial assistance for child care while they looked for employment.
2. Caregivers wanted child care options to be more affordable for those that do not qualify for social service financial assistance.
3. Caregivers wanted additional cost-free resources and programs for special needs children, such as tutoring, afterschool programs, and social activities.
4. Caregivers wanted more availability of Medicaid dental providers and more affordable private dental coverage.





## Appendix 2

### Feedback from Caregivers Participating in the New York City Department of Health and Mental Hygiene CYSHCN Health Education Forum

NYSDOH facilitated an in-person group discussion following the New York City Department of Health and Mental Hygiene (NYC DOHMH) Quarterly Health Education Forum held in Queens, New York on September 14, 2017. Feedback was provided by 17 caregivers, many of whom were also professionals that work at agencies or organizations that service CYSHCN. Specific feedback documenting the caregivers' experiences, opinions, and perceptions from this discussion is summarized below.

#### 1. Accessing and coordinating medical care and related services

- Caregivers reported long wait lists, up to six to seven months, for developmental or neurological evaluations.
- Caregivers said there are not enough speech therapy and occupational therapy providers. There was a reported wait of over four months for speech therapy services. And once services were available, the frequency was not enough.
- There were long waiting lists for Medicaid Service Coordinators. Parents said they had to wait up to a year to get a coordinator and services started, even after completing all the evaluations needed.
- Caregivers had trouble finding primary care physicians and specialists that participated with their health plan or that provided adequate coverage.
- Doctors did not share information with other doctors or schools. One caregiver mentioned that exchange of information between medical providers was improved with Regional Health Information Organizations (RHIOs), which allows sharing medical records between physicians.
- Doctors often did not give referrals or information along with the child's diagnosis.
- Finding information about services and resources was difficult. One parent said she happened to stumble upon the information for the Quarterly Health Forum. Another parent only learned about EI from another parent in the neonatal intensive care unit (NICU), not from the medical staff.
- There was a gap reported for insurance coverage of services such as applied behavioral analysis. Some caregivers said it was provided for children with autism, but would be beneficial to children with other diagnoses such as attention deficit hyperactivity disorder (ADHD).
- Several caregivers expressed the need for medical equipment and supplies. Obtaining insurance coverage of these items was a challenge. For example, children outgrow wheelchairs quickly and Medicaid only covered replacement within prescribed time frames. They also reported long wait lists to get approved equipment such as wheelchairs and Hoyer lifts.

## Appendix 2

### 2. Navigating and obtaining assistance from the school system

- Caregivers mentioned several times that it is important to have an advocate for the Committee on Preschool Special Education (CPSE) and parent members at meetings. Without the help of a parent member/advocate, parents felt they were expected to sign the Individualized Educational Plan (IEP) without fully understanding the process.
- Caregivers desired more updates from the school on how their child is doing, so adjustments could be made when needed.
- Caregivers said finding the right school that meets the child's needs was the key to success. Not all schools were able to provide necessary services.

### 3. Providing emotional and social supports for the child and family

- Caregivers said there was a need for more recreational programs and extracurricular activities for social development of CYSHCN. Social skills were identified as very important for transition to adulthood.
- Parents also wanted social opportunities and support groups for themselves.
- There was a lack of aides and programs that can cover transporting the child for recreational activities. Finding transportation for programs and events was a challenge that limited the activities available to children.

### 4. Safety for the child and family

- Parents were concerned for their child's safety at home, during medical care, and at school. They reported that bullying is an issue.
- Caregivers said safety equipment and devices such as fire extinguishers, alarm systems and tracking devices were needed.
- Parents said safety training, developing safety plans, and conducting safety drills were necessary for preparing both parents and providers, such as teachers.

#### Suggestions for change:

1. Caregivers wanted mentors to guide and train providers and professionals who work with CYSHCN. Medical providers were specifically mentioned
2. Caregivers would like online or telephonic live chat support available to assist families in finding resources to help their CYSHCN.
3. Caregivers wanted access to current, up-to-date resource guides.

## Appendix 3

### Feedback from Caregivers with Children Served by the Early Intervention Program

Caregivers participated in care mapping activities at IFaCT learning sessions in the Bronx on January 18, 2018, in Kingston on January 22, 2018, and in Fayetteville on February 2, 2018. At these sessions, each caregiver was grouped with a table of providers. NYSDOH introduced the care mapping activity and each caregiver completed their own independent paper mapping tool. In total, feedback was received from 22 caregivers from 18 different counties. A summary of their feedback is below.

#### 1. Accessing and coordinating medical care and related services

- There were long wait times for appointments with specialists and therapists, such as occupational therapists or speech therapists.
- Families spent a great deal of their free time researching medical providers and therapists.
- A lack of communication between service providers and caregivers meant the responsibility of coordinating medical appointments was left to the caregiver.
- Caregivers felt they assumed responsibility for decision-making as to which services or evaluations their child would need, without the appropriate information to make these decisions.
- Caregivers found it helpful when their child's care was coordinated through either their insurance or through a service coordinator, which are provided by the EI Program, Office for People with Developmental Disabilities (OPWDD), or other systems of care.

#### 2. Parental support

- Caregivers stated they wanted to connect with other families in similar situations. Often, caregivers relied on family and friends for support.
- Some caregivers reported that there were not enough support groups available outside the Monday-Friday workday for working families.
- Establishing friendships with similar families provided not only a source of support, but also allowed for the exchange of valuable information and experiences.
- Some parent advocates were sought out as a resource for learning and to help train caregivers to become advocates for their own children.
- Social media and online parent groups were successful means of reaching other families for some caregivers.

#### 3. Social activities and community integration for child

- Caregivers recognized the need for socialization as an important part of their child's development. Some caregivers desired social opportunities with children with similar needs, while others wanted their child integrated with typical peers.
- Most common outlets for socialization for children under the age of three were playgroups, playgrounds, pre-schools (including Head Start) and family.
- Finding social opportunities that are available outside of work hours, are free, or are available locally in rural areas has been difficult for some families.

## Appendix 3

### 4. Knowledge and skills to provide therapy at home

- Caregivers looked for strategies to continue therapy for their child at home. They wanted therapists to provide training and technical assistance to allow them to continue the child’s therapy at home.
- Carry-over therapy is important for children in preparation for the transition out of Early Intervention when the child turns three.
- Caregivers stressed the difficulty in balancing the need to provide therapy at home and connecting their child in the community.

### Suggestions for change:

1. More information on the resources and services should be available for their child. Five caregivers specifically expressed the desire for a local resource center or “information hub.”
2. More parental support groups and opportunities for connections with other caregivers. Caregivers wanted emotional and social support from other families with similar challenges, as well as a better way to share information and experiences that could help families.
3. More group activities available for children, specifically toddlers. Caregivers wanted their children involved in group activities for play, therapy and school as well as in their community in general.



## Appendix 4

### Feedback from Caregivers and Providers Participating in the Early Hearing Detection and Intervention (EHDI) Program Learning Collaborative

Caregivers and providers, in separate groups, provided feedback on two specific topics related to EHDI: 1) receiving a diagnosis of hearing loss and 2) referral to Early Intervention services. Feedback was received from 5 caregivers and 17 providers. Caregiver feedback reflects their experiences at the time of hearing screening and diagnosis. Feedback received from caregivers and providers at the EHDI sessions is summarized below.

#### 1. Inconsistent messaging and the need for emotional support when receiving a failed newborn hearing screening result

- Some caregivers reported being told in the hospital that fluid in the ear was a possible reason that their infant did not pass their initial hearing screening, without providing any further information about next steps or the importance of follow-up after a failed hearing screening.
- Birthing hospital staff stated that the hospital's policy is to not tell a parent fluid in the ear is the reason for the failed hearing screening. Staff reported their policy is to give parents the result of the screening.
- Staff recognized the importance of educating the family about the test result and the need for follow-up testing. Their goal is to not overly alarm the family but to ensure the results are taken seriously.
- It was acknowledged by both caregivers and providers that inconsistent messaging can lead to delays in diagnosis and a lack of trust in the provider community.

#### 2. Finding and accessing a provider who can perform the appropriate diagnostic testing

- A limited number of audiologists perform an auditory brainstem response (ABR) test, which is the test to diagnose hearing loss in an infant.
- Some caregivers expressed frustration at being referred to a provider who could not perform the necessary ABR test, that test results were not properly documented to qualify for EI services, or that they were referred to a provider who did not participate with their health insurance plan. These issues lead to delay in diagnosis and intervention services.
- Hospital staff reported that if the infant is not added to the family's health insurance plan soon after birth, it can cause a delay in scheduling appropriate diagnostic testing.
- Hospital staff reported that not knowing the infant's health insurance plan can cause problems when they try to schedule a follow-up appointment with an audiologist.
- As required by New York State Public Health Law, most birthing hospitals provided parents with a list of audiologists who are approved to perform diagnostic testing, however one hospital's procedure was to refer families back to its own audiology practice only.
- Transportation and excessive driving distances caused issues for caregivers traveling from rural locations. However, birthing hospital staff did not recognize this barrier or challenge when scheduling follow-up diagnostic testing.

## Appendix 4

### 3. Lack of communication between providers

- Caregivers and providers both reported a lack of communication between the birthing hospital and the pediatrician.
- Audiologists reported that if an infant does not pass the follow-up diagnostic hearing test, they make a referral to the EI Program, as required by New York State Public Health Law, but not all caregivers reported receiving a referral for EI from the audiologist.
- Caregivers reported that their pediatricians were not always aware of the failed hearing screening results. Pediatricians should be made aware of hearing screening results to ensure follow-up appointments are kept. The pediatrician's role in reminding the caregivers about follow up testing was viewed as important since the infant is seen several times between birth and three years for well child visits.
- Most families were not aware that they could contact the EI Program directly, without a referral from the audiologist or pediatrician.

### 4. Lack of designated Early Intervention service coordinators for hearing loss

- Caregivers reported that the process of choosing an EI service coordinator is overwhelming. The EI Program serves children with many types of disabilities and diagnoses and must ensure a multidisciplinary evaluation, so evaluators may not be able to diagnose hearing loss or assess the needs of children with hearing loss.
- EI providers stated that many areas of the state do not typically have an audiologist as part of the multidisciplinary evaluation team, and children must have a supplemental evaluation scheduled if the child does not get referred with diagnosed hearing loss.

### Suggestions for change

1. Both caregivers and providers said they wanted a designated Early Intervention evaluator and coordinator that specializes in hearing loss.
2. Caregivers wanted a follow-up home visit or telephone call from a Public Health Nurse for all parents/caregivers of infants who did not pass the hearing screening. The nurse would serve as a single point of contact for referrals and supports available locally as well as state programs.
3. Public Health Law mandates education for caregivers of infants who do not pass hearing screening, however compliance with this mandate is difficult to enforce. Caregivers expressed their desire for more emphasis at the birthing hospital on what the screening means and what steps are needed for follow-up both verbally or via video and via print distribution.
4. Caregivers felt they were provided with an overwhelming amount of information when they left the hospital; staff should ensure that all caregivers of infants who did not pass the hearing screening are provided with specific information on hearing loss such as the "Can your baby hear you?" brochure with an emphasis on important next steps.

## Appendix 5

### Feedback from Caregivers and Providers Obtained via the Online Mapping Tool or a Group Webinar

NYSDOH virtually engaged caregivers and providers through multiple partners and organizations. The Early Intervention (EI) Partners Training Project, local Title V staff from both the CYSHCN and EI programs, and Parent to Parent of New York State staff were provided instruction and an online mapping tool to complete a map of their own from the role of either caregiver or provider. Independent entry resulted in feedback from 29 caregivers and 21 providers. Participants recruited through the Westchester Institute for Human Development's Leadership Education in Neurodevelopmental Disabilities (LEND) fellowship program and Families Together in New York State's Family Advocacy group completed group mapping activities via webinar which resulted in feedback from 17 caregivers.

The most commonly identified challenges and suggestions for change from caregivers and providers who used the online mapping tool are summarized below.

#### Feedback from Caregivers

##### 1. Providing financial support, including health insurance

- Providing financial support for my family was a common responsibility identified by caregivers.
- Obtaining financial support for services was identified as a common need.
- Having health insurance was important to cover necessary health services.

##### 2. Integrating the child and their family into their community

- Many caregivers said they needed opportunities for community involvement or social opportunities for their child.
- Few caregivers identified resources for social supports, which indicated these were not available or not accessible for CYSHCN.

##### 3. Social and Emotional Support

- Caregivers said they needed support for their needs and their families' needs.
- Caregivers said their key responsibility was to ensure their child had social opportunities and emotional support.
- Caregivers said they needed understanding from their community and friends.
- Parents identified their network of family and friends as a helpful resource.

##### 4. Information and Knowledge

- Most caregivers said they needed information, knowledge, or the skills to find the information.
- Caregivers needed information on their child's diagnosis given in terms they could understand.
- Two parents mentioned the need for an up-to-date resource guide.
- Parents identified resources that were needed, including coordination of services or case managers, family advocacy groups, training and educational opportunities, and education from health care providers.

## Appendix 5

### Suggestions for change reported by caregivers included:

1. Caregivers wanted more financial support available for families of CYSHCN.
2. Caregivers wanted more help with care coordination activities.
3. Caregivers wanted more opportunities and equipment so their child can be active and involved in their community.
4. Caregivers wanted more family and peer support in caring for their CYSHCN.

### Feedback from providers

#### 1. Knowledge of resources, programs and providers

- Most providers said they needed to know about local resources in their community, availability of providers and specialists, and how state programs serve CYSHCN.
- Some providers noted that there were not enough qualified providers available locally or that capacity was an issue.
- Finding time to become familiar with all the resources is a challenge for LHD staff who have other responsibilities.



#### 2. Networking and outreach opportunities

- Providers recognized that networking and outreach activities are needed to reach families in need.
- Common methods of outreach included attending health fairs and community events, developing social media, and networking with schools and local agencies to provide information about the CYSHCN program.
- Some providers stated they wanted more contact with families and to receive more referrals from the Early Intervention Program.
- Several providers identified the need for a current resource guide.



## Appendix 5

### Suggestions for change reported by providers included:

#### 1. More funding

- Providers felt that more funding is needed to support programs and services for CYSHCN.
- Providers said they needed more staff and time to meet the needs of families.

#### 2. Guidance and training

- Providers would like a clearer understanding of policies and procedures for the CYSHCN program and detailed guidance on grant activities.
- Providers would like guidance and training from state agencies, including NYSDOH and OPWDD, and from their local health department.



