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Dear families touched by autism in our community:

Thank you so much for taking the time to talk with us or complete the online survey to share your perspective on the needs for our community! In the following report, you will find the following information:

- Research Objectives and Methodology
- Key Findings of:
 - Online survey
 - Service Providers
 - Parents of Children 14 years & under
 - Parents of Children 15 to 24 years
 - Parents (Caregivers) of Adults 25 years and older
 - Individuals on the spectrum

The information gathered in this assessment is being shared with Toledo Regional Autism Network members, community leaders, and stakeholders to guide and prioritize efforts and funding over the next several years.

Thank you so much for taking the time to provide your honest input into the services and needs in our community. Together, we can create a limitless future for all touched by autism!

If you have any questions/concerns, please do not hesitate to call or email me.

Sincerely,



Catina Harding
Executive Director, Great Lakes Collaborative for Autism

Key Findings for Caregivers

Research Objectives and Methodology

- Great Lakes Marketing conducted a Needs Assessment to help gain insight into the needs of families in the Northwest Ohio community affected by autism.
- As part of this project:
 - GLM moderated a focus group with representatives from organizations that provide services to persons with ASD.
 - GLM moderated focus groups to learn the general needs and priorities of area parents of children with an autism spectrum disorder and used this information to develop a comprehensive online survey that was promoted to families in the region.
 - 122 parents completed the online survey between November 2017 and January 2018.
 - GLM spoke with eight individuals diagnosed with autism spectrum disorder to learn about their likes, dislikes, and frustrations and challenges.
- A complete Statement of Methodology is appended.

Key Findings

Online Survey: Parents of Children with ASD

- Of the 122 parents who completed relevant sections of the online survey, 10% have multiple children diagnosed with ASD. About two-thirds of the families have additional children who have not been diagnosed with ASD.
- 62% of the responding families say they need some type of autism-related service but are not getting it. Needs were varied, but most were related to therapy, respite care, and social/life skills training. The greatest barriers to accessing services are the cost and availability. Awareness of service options is also a barrier.
- Over one-third of the families say that finding a community of people to be friends with their child is a major problem. Finding services and service providers is also a major problem.
- Families believe that expanding referral and support services to ensure families know local options, and providing support/advocacy to families to interact successfully with schools/educators should be the top priorities to make the community more autism friendly.
- More options are needed for family activities and parent support groups.
- A variety of behaviors (from delayed language development to sensory issues) created the motivation to seek a diagnosis. About half received the diagnosis from a developmental pediatrician. About one-in-three said the diagnosis process (from initial inquiry to formal diagnosis) took more than one year.
- Only one-third said that after the diagnosis they were provided with the information they needed for the *next step*.

Service Providers

- Focus group conversations with service providers indicated their recognition of the likelihood of families seeking services being placed on a waiting list. They recognize that access to transportation is a barrier for persons to access services.
- Service providers believe that the community is most in need of: short-term residential and respite care options, long-term residential options, and early intervention programs.
- Providers are concerned about the shortage of trained health care and educational professionals in the community and recognize the challenges with attracting and retaining such sought-after professionals.
- The rural areas are known to be underserved; however, the pervasive barrier is that funding is limited in all regions.

Parents of Children 14 years & Under

- Parents of young children have difficulty accessing educational services for children ages three to five. Although early intervention awareness has increased within the community, a continuum of preschool services is needed. Existing services are often not affordable or have limited space. Parents know that specialized therapy and educational services are crucial for children to successfully progress in school and are frustrated with their inability to afford or access beneficial services.
- Developmental pediatricians are needed to reduce the evaluation timeline and improve the accuracy of diagnoses.
- Skilled child care help is extremely difficult for parents to find and retain. For children of all ages, parents need access to reliable, skilled caregivers for before and after school, and during the summer. The lack of child care options makes it difficult for parents to work, aggravating financial concerns and increasing feelings of isolation.
- Autistic-friendly places in the community do not exist. Families need a safe place for their children to interact and socialize with other children of the same age.
- Parents learn the most valuable information from other parents. Families seek professionally facilitated emotional and educational support offerings that are sustainable and moderated by qualified individuals.
- Funding remains an issue for most families. Insurance does not cover the recommended number of therapy hours and scholarships typically do not cover the ideal educational offering.
- Parents who have children in an early intervention program are most frustrated by transportation options.

Parents of Children 15 to 24 Years

- Getting a correct and timely diagnosis is difficult. Within the medical community, doctors are more willing to diagnose for ADHD and other conditions before diagnosing for autism.
- Referrals between doctors are often generic because specialists who care for persons with ASD are not networking with each other.
- Public schools are disconnected from the autism community. Educators are neither trained to identify the behaviors of autism nor trained to speak to parents about the need for an evaluation.
- IEP meetings can be confrontational between parents and schools. Many parents would prefer to attend meetings accompanied by an advocate who is versed in the law and understands what students are entitled to receive.
- Limited social or job training opportunities exist for high school graduates. Social activities need to be facilitated by professionals so activities are appropriate, consistent, and sustainable. Volunteer efforts have filled the social gap to an extent, but schedules and content are dependent on the interest level of the volunteers and the events are often ineffective because professional assistance is needed to help attendees socialize.
- Respite care options are difficult to obtain or afford. Parents struggle to find trusted caretakers who are educated and trained to handle a child or young adult with autism.
- Parents of children in high school are most likely to be dissatisfied with social opportunities outside of school.
- Nearly all students have an IEP, but nearly half say they have to fight to get the services they need for their child.

Parents (Caregivers) of Adults 25 Years and Older

- Social activities for adults 25 years and older across the autism spectrum are needed. It is difficult to find a facilitator and volunteers to help organize, support, and fund social events. For those who are lower functioning, on-site professional staff is needed.
- Life coach services are needed to help high school graduates prepare for employment and possibly living on their own.
- Residential day programs are difficult to staff. Employee turnover is a major concern.
- Individual Options (IO) waivers are hard to get because of the long waiting list and requirement to wait until a child is 18 years or older.
- Transportation services available in Northwest Ohio lack quality. Some families have had bad experiences with TARPS (e.g., they are always late) and have found that CTS is a better option.
- Supervision or care between the hours of 2:30 pm-5:30 pm is hard to find and afford. Before 2:30 pm, the individual is usually in some type of day program.
- Educational training and lectures would help parents advocate for their children. Topics of interest include getting on waiver waiting lists for services, and when to

begin researching options for other services for the next developmental stage. Parents do find it difficult to attend meetings and need access to a website/blog where parents can view the training, communicate with parents in similar situations, and share resources with one another.

- Most young adults, age 25 or over, are living at home with family; however, the long-term goal is either to have their child living independently or independently in a support community.
- Few young adults drive, with most relying on family or mix of options.
- Less than one-in-five believe their child will seek post-secondary education.
- Most, about 70%, are very satisfied with the day program their young adult attends.

Individuals on the Spectrum

- The community needs a better understanding and awareness of autism. A few participants said they would like to sit on a panel and share their opinions with educators and other community groups.
- Alumni events should be organized at schools for those who have graduated but still wish to remain connected with friends. These alumni could also serve as mentors to current students.
- More services in college are needed for people with autism. Students need more financial aid, assistance with enrollment, and access to dedicated staff.
- Support getting a driver's license would help the families as well as the person seeking the license. Obtaining a license can be particularly challenging for autistic individuals.
- An independent living community for adults with autism (similar to a senior-adult community) is preferred to independent living options. A planned community could offer transportation assistance, security, and social opportunities. The complex should include both the general public and people with autism to reduce isolation and promote understanding.
- Social events need to be formalized. Well-meaning parents are filling the gap that should be filled by committed, knowledgeable professionals.