

AUTISM IN NORTHEAST OHIO: AN EYE OPENING LOOK AT A DIFFICULT JOURNEY

INTRODUCTION

In 2015, the Autism Society of Greater Akron sought to shine a light on autism in our community by measuring the Autism Society's Quality of Life indicators for people living the autism journey in the Northeast Ohio area.

The staff and board of the Autism Society of Greater Akron wish to thank everyone who took the time to answer the questionnaires and to provide comments. The comments are some of the most powerful aspects of the survey and were, therefore, left in as part of the results.

By reaching out to parents/caregivers and to individuals with autism, the *Autism Wellness Survey* has revealed areas of significant need as well as areas where some progress is being made. Together, the findings provide an eye-opening look at a difficult journey.

BACKGROUND

Autism Spectrum Disorders

According to the Centers for Disease Control (CDC), Autism Spectrum Disorder (ASD) is a developmental disability that can cause significant *social*, *communication* and *behavioral* challenges. There is nothing about how people with ASD look that sets them apart from other people, but people with ASD may communicate, interact, behave, and learn in ways that are different from most other people. The learning, thinking, and problemsolving abilities of people with ASD can range from gifted to severely challenged. Some people with ASD need a lot of help in their daily lives; others need less.

A diagnosis of ASD now includes several conditions that used to be diagnosed separately: autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger syndrome. These conditions are now all called Autism Spectrum Disorder. Here are a few facts from the Autism Society:

- About 1 percent of the world population has Autism Spectrum Disorder. (CDC, 2014)
- Prevalence in the United States is estimated at 1 in 68 births. (CDC, 2014)
- More than 3.5 million Americans live with an Autism Spectrum Disorder. (Buescher et al., 2014)
- Prevalence of autism in U.S. children increased by 119.4 percent from 2000 (1 in 150) to 2010 (1 in 68). (CDC, 2014)
- Autism is the fastest-growing developmental disability. (CDC, 2008)
- Prevalence has increased by 6-15 percent each year from 2002 to 2010. (Based on biennial numbers from the CDC)
- Autism services cost U.S. citizens \$236-262 billion annually. (Buescher et al., 2014)
- A majority of costs in the U.S. are in adult services \$175-196 billion, compared to \$61-66 billion for children. (Buescher et al., 2014)

- Cost of lifelong care can be reduced by 2/3 with early diagnosis and intervention. (Autism. 2007 Sept. 11(5):453-63; The economic consequences of autistic spectrum disorder among children in a Swedish municipality. Järbrink K1.)
- The U.S. cost of autism over the lifespan is about \$2.4 million for a person with an intellectual disability, or \$1.4 million for a person without intellectual disability. (Buescher et al., 2014)
- 35 percent of young adults (ages 19-23) with autism have not had a job or received postgraduate education after leaving high school. (Shattuck et al., 2012)
- It costs more than \$8,600 extra per year to educate a student with autism. (Lavelle et al., 2014) (The average cost of educating a student is about \$12,000 NCES, 2014)
- In June 2014, only 19.3 percent of people with disabilities in the U.S. were participating in the labor force working or seeking work. Of those, 12.9 percent were unemployed, meaning only 16.8 percent of the population with disabilities was employed. (By contrast, 69.3 percent of people without disabilities were in the labor force, and 65 percent of the population without disabilities was employed.) (Bureau of Labor Statistics, 2014)

The Autism Society

The Autism Society, the nation's leading grassroots autism organization, exists to improve the lives of all affected by autism. We do this by increasing public awareness about the day-to-day issues faced by people on the spectrum, advocating for appropriate services for individuals across the lifespan, and providing the latest information regarding treatment, education, research and advocacy.

Founded in 1965 by parents of children with autism, the Autism Society is the leading source of trusted and reliable information about autism. Through its strong national network of affiliates, the Autism Society has spearheaded numerous pieces of state and local legislation, including the 2006 Combating Autism Act, the first federal autism-specific law.

The Autism Society of Greater Akron

The Autism Society of Greater Akron (ASGA) is one of more than 100 affiliates nationwide that are part of the Autism Society. ASGA was granted affiliate status by national in 1990, and was an all-volunteer organization until 2011 when it hired staff to provide more consistent and expanded programming. As a non-profit, ASGA has an independent volunteer board of directors that oversees its strategic priorities. ASGA's service territory is Summit, Stark, Medina, Portage and Wayne counties. All Autism Society affiliates have the same mission: to improve the lives of all affected by autism. All also have the same basic goals and programs:

- Increasing public awareness about the day-to-day issues faced by people on the autism spectrum;
- Advocating for appropriate services for individuals across the lifespan;
- Providing educational opportunities and support for families and individuals with ASD.
- Working together to create autism friendly communities.

Quality of Life Indicators

The Autism Society's vision is to increase the quality of life of everyone living with autism. When we say "quality of life," we're talking about basic human rights that allow people to interact with one another and the world on their own terms. Quality of life indicators such as the ability to communicate, the freedom to choose a career and opportunities for community involvement are essential aspects of the human experience, and we promote treatments, accommodations and acceptance with them in mind. The Autism Society is committed to supporting these ideals:

Respect and Dignity – People with autism should feel respected by those around them

Inclusion – People with autism should be welcomed to participate actively in their schools, workplaces and communities

Communication – People with autism should be able to express themselves and interact with others in a meaningful way

Health and Well-being – People with autism should feel and be well physically and have access to the services they need to stay healthy

Safety – People with autism should feel secure and be able to get help from their communities, law enforcement and others as needed

Academic Success – People with autism should have the opportunity to participate in school to their fullest capability and learn in an environment and manner that enables them to succeed

Social Connections – People with autism should have friends and supporters as well as ties to their communities

Independent Living – People with autism have the right to lead their own lives, and they should also have support if they need help caring for themselves

Meaningful Employment with Fair Wages – People with autism should have the opportunity to do work that contributes to their communities, and should receive compensation befitting their positions

Financial Stability – People with autism should be able to afford the things and services they need

Recreation and Leisure – People with autism should be able to pursue their interests and spend their free time in a meaningful way

Subjective Well-Being – People with autism should feel happy and enjoy life

Self-Identity and Acceptance – People with autism should understand and appreciate themselves, and feel understood and valued by others

Autonomy and Self-Sufficiency – People with autism have the right to make their own decisions

Pursuit of Dreams – People with autism should feel empowered to achieve their aspirations!

AUTISM WELLNESS SURVEY

Methodology

From July 15 through October 31, 2015 the Autism Society of Greater Akron conducted an *Autism Wellness Survey* to measure the "Quality of Life" of people living the autism journey in Northeast Ohio.

Two questionnaires were developed by a volunteer committee of the following professionals: a domestic relations attorney, pediatric nurse, community relations professional, two teachers of children with autism, and a social worker. All of the professionals have children with autism that range in ages and genders; one of the professionals has a sibling with autism.

One questionnaire was for Caregivers/Parents of Children with ASD. The other questionnaire was for individuals with ASD. Participants were asked to respond with AGREE, DISAGREE, or DOES NOT APPLY to a series of 22 statements based on the Autism Society's Quality of Life Indicators.

The names of the individuals who participated in the survey were taken only for purposes of prohibiting duplicative entries; all personal information will be kept strictly confidential and was understood to be confidential at the time individuals took the survey.

Survey Results

A total of 147 respondents answered the survey and six individuals with ASD from the following Ohio counties (in order of number of respondents): Summit, Stark, Medina, Portage, Lorrain, Wayne, Cuyahoga, Tuscarawas.

The results below rank the Autism Society's "Quality of Life" indicators in terms of how they were perceived by the survey respondents and the urgency of the responses.

- 1. The first grouping is for NI: Needs Improvement indicators that need a lot of work
- 2. The second group is for DP: Demonstrating Progress there has been progress on these indicator
- 3. The third and final group is for M: Mastered these indicators have been achieved

Of note is that caregivers commented that their answers often reflected where they were at this time and on the age of their children. In short, urgency is a relative term depending on one's individual journey and the challenge a family or person is tackling at that time.

Grade – Needs Improvement on these Quality of Life Indicators:

1. Meaningful Employment with Fair Wages

- Respect and Dignity
- o Financial Stability
- o Autonomy and Self-Sufficiency
- o Pursuit of Dreams

2. Safety

- o Health and Well-Being
- o Inclusion
- Social Connections

3. Financial Stability

- Respect and Dignity
- Autonomy and Self Sufficiency

4. Independent Living (to the extent possible)

- Respect and Dignity
- Autonomy
- Self Sufficiency

INDICATOR	SURVEY QUESTION	DISAGREE	AGREE
Employment	Employers are prepared to receive a person with ASD in	88%	12%
	their work environment.		
	There is sufficient transportation for people with ASD in our	71%	29%
	community, helping them to be as independent as possible.		
	Community-based job opportunities are available to us in my	66%	34%
	community (non-workshop or segregated environments).		
	The person with ASD has a bright future in my community.	66%	34%
Safety	For young children with ASD, there is appropriate child care	82%	18%
	available in my community.		
	There are reputable and affordable respite services available	68%	32%
	to us.		
	I believe a person with ASD is safe in his/her community	62%	38%
	without fear of harm or abuse.		
Financial Stability	The person with ASD will not lack financial stability during	81%	19%
	adulthood because resources are available for people with		
	ASD in my community.		
	Health insurance or other forms of financial support pays for	60%	40%
	needed therapies.		
Independent Living	We have access to reputable independent living facilities or	71%	29%
	feel that we will have access when the time is right.		
	The person with ASD will live independently or with some	53%	47%
	assistance in my community.		
CHILD'S AGE	CAREGIVER COMMENTS: Employment		
13 - 18	My child will get to adulthood in a year and the reality will sink	in pretty soon for	us. No
	amount of therapy or training seems enough to speed up her in	mprovement to be	e at the level
	that she can lead her own life. Having access to a BCBA at this	age would be tren	nendously
	helpful for my daughter to prepare for her transitional skills ge	ared toward the g	oal of being

	employable.
19 - 22	There is a great need for schools and community agencies and businesses to work together to provide meaningful vocational training and supported employment opportunities for the person with autism that has a "normal IQ," but would not be successful with totally independent employment. Transportation to and from employment would also be needed
19 - 22	(not the Metro bus!). It seems society drops the ball when reach magic 22 for some kids. NT (neuro-typical) or so can continue on in an educational environment for multiple years, yet the non NTs become warehoused in so many ways. The funding is spent but fails in way it is used. Structured learning environments should be continued. Is DD not developmentally delayed? Do they not learn differently?
19 - 22	My daughter is on a waiting list for waivers (state/federal funding) and because she does not receive waiver money, we do not have any services. Her Individualized Service Plan is a blank grid. Repeated meetings, even though I have brought supportive professional with me to speak on behalf of my daughter's situation, end without services for her. I feel her life is at a standstill because she received no transition services and there is no community for her to become a part of here.
23 - 30	I hope one day a person with ASD will have the same opportunity for full time employment with benefits as their typical counterpart.
CHILD'S AGE	CAREGIVER COMMENTS: SAFETY
6 - 12	Daycare options for young kids with Autism are not available in this area. Most daycare facilities are unable, or unwilling to take on a child with Autism.
6 - 12	Our community is lacking in needed resources for childcare, recreational activities, programming at non-peak hours, movies during morning times, and therapies in facilities that provide effective programming year round. Also, the summer programming available doesn't complement each other, but rather overlaps, so that camps and ESY are offered at the same time, and then the last weeks of summer, nothing is offered.
6 - 12	Child care is an issue especially for children who are more severe end of spectrum. We need more assistance from DD on providing parents who have to work full time with more options to find affordable care or training assists who can work in the child care centers. Especially for those who have meltdowns or need toilet assistance.
13 - 18	We have been unable to find any after school care programs for our 17 year old son with autism. Most day cares only take children through age 12. We were fortunate that our local day care took our son for an additional 5 years. Our son is not able to come home alone after school and be unsupervised while we are at work for several more hours.
2 - 5	For having a young one with ASD there are few places that are safe to take them out to play. Places that are fenced in are far away, and they are over run by typical children whom do not wish to take part with a ASD child. Even local parks are unsafe for walks. Many trails follow water ways without fencing of any kind that could stop a young ASD child from running into the water.
13 - 18	My child has PDD-NOS. We have public places that we frequent that we consider to be autism friendly and we spend our money there. We do not have Project Lifesaver in our community and many are unaware of the risks associated with wandering from a safe environment.
13 – 18	I spend a major portion of my day trying to find a way for my daughter to live safely, find trustworthy friends and a decent job. My daughter is going to outlive me and my concern is deep and painful. I would give anything to know she is going to be okay, that our community

	will help. But I can't even get basic needs met at her school. ASD is not her fault, but her	
	punishment for having it has been unending and severe.	
13 - 18	There is nowhere for kids to go when they age out of daycare.	
CHILD'S AGE	CAREGIVER COMMENTS: Financial Stability	
2-5	I am writing to you about my son who has just been diagnosed with AUTISM AS well as speech and Language difficulties at 3.5 years old. I hope that we as a community we can come together within our school systems to help our kids who have these difficulties in life to use every resource possible and in hopes that all the insurance companies help us too. Because it's such a huge financial burden on the family as well as our pocket books each day for therapy and I just want my son to be just a normal kid who always wears a smile on his face every day and just to enjoy life the way it was supposed to be.	
6 - 12	We struggle with finding the right resources and paying for them. We make too much money to receive public assistance and we have to pick and choose which therapies we can afford to pay	
6 - 12	My grandson is on Medicaid sponsored insurance and he is in need of ABA therapy. Insurance will NOT pay for this therapy and we have found no other way for him to get this much needed assistance.	
6 - 12	We pay a small fortune to supplement our grandson's education and therapy. Insurance does NOT cover everything and certainly does not cover extra help in school or socializing activities.	
13 - 18	No matter what the law mandates on coverage of medical bills with kids on ASD, insurance companies find the loopholes to deny you. Insurance and Medicaid will not pay for needed therapies. There is not enough energy left within us to have a constant fight with insurance companies on the top of taking care of our special needs kids. Our struggle goes on.	
31 - 40	My son will not have financial stability because resources are NOT available in my community.	
CHILD'S AGE	CAREGIVER COMMENTS: Independent Living	
23 - 30	My son fortunately is living in a private residence we, his parents have purchased near our home. This allows for daily assistance and medication monitoring. However, the question about adequate residence as a rule, in my opinion is minimal at best, unless you have financial means to enlist a reputable agency. Also, I think adult services needs to begin the transition in high school and attempt to steer our folk toward their interests instead of offering some choices after high school.	
23 - 30	Many parents tell me that providers don't check on their kids enough and they are often in need of groceries because providers don't come as needed. I am not sure that being independent gives them a quality of life. I wish it did, because I would love that for my son and for us someday. I also feel that there is not proper integration in our or any community.	

Grade – Demonstrating Progress on these Quality of Life Indicators:

- 5. Inclusion/Academic Success
 - Social Connections
 - o Self-Identify and Acceptance
 - Pursuit of Dreams
- 6. Recreation and Leisure
 - Inclusion
 - Social Connections
- 7. Self-Identify and Acceptance
 - o Subjective Well-Being
 - Social Connections
- 8. Health and Well-Being
 - Safety
- 9. Communication
 - o Impacts all of the goals/indicators

INDICATOR	SURVEY QUESTION	DISAGREE	AGREE
Inclusion/Academic Success	My community's schools for higher education, i.e., college, vocational or other, strive to provide meaningful education for people with autism.	67%	33%
	We have access to meaningful school programs that provide an inclusive learning environment with typical peers.	63%	37%
Recreation & Leisure	There are social and recreational programs designed for people with autism in my community.	63%	37%
	There are <i>community-based</i> social and recreational programs that welcome people with autism available in my community.	62%	38%
	Community (or school) based non-sports activities are available to us (i.e., Boy Scouts, after school clubs, etc)	52%	48%
	Community (or school) based sports activities are available to us.	51%	49%
Self-Identify & Acceptance	The person with ASD can speak for themselves and feels that their needs are being met as much as possible.	62%	38%
	The person with ASD has friends.	58%	42%
	My loved one with ASD is understood and accepted in my community.	37%	63%
	The person with ASD has a good quality of life.	28%	72%
Health & Well- Being	My community has medical professionals who understand autism.	55%	45%
Communication	We have access to appropriate communication therapies and devices.	35%	65%

CHILD'S AGE	CAREGIVER COMMENTS: Academic Success/Inclusion LIVING
6 - 12	School Districts need to provide better services for Autistic children. Teachers need to be better educated in Autism so they understand and have knowledge about how to deal with Autistic children in the classroom since they need the example of peers. There needs to be more recreational opportunities and summer camps available.
6 - 12	The school district our son attends has programming for higher functioning ASD students who can handle integration into the classroom fully, or self-contained units for students that are cognitively delayed. Our child falls in the middle somewhere and we are fighting to have them change his disability category so we can use the Autism Scholarship.
13 - 18	My child has PDD-NOS. My husband and I are seriously considering selling our home to move to a surrounding area that is more up to date and tolerant of those on the autism spectrum. As our school system has determined that the special education students are segregated to a school across town, it makes it difficult to explain to the neighborhood kids why he cannot go to his home school. This does not facilitate friendships.
13 - 18	My son is homeschooled and does not participate in school based activities, even though he should be allowed to do so; the school has not opened those to him. He is starting to visit places to learn about employment. I hope they will treat him as they treat everyone else. I feel that I had to be the driving force behind all of his therapies and activities. I do not think it is easy to navigate the therapy world or the world of services. People don't understand what they are eligible for. We need after school programs that would start to teach these teens skills for adult life.
CHILD'S AGE	CAREGIVER COMMENTS: Recreation and Leisure
6 - 12	Very hard to find programs that ASD diagnosed to be a part of. If they are not into sports they need socialization. We need to figure a way to improve and help them grow their wings. Society is not yet fully ready for these type of employees; the business's need training with assisting and helping these individuals become amazing adults!
6 - 12	There are limited programs in our County for ASD kids.
6 - 12	He seems happy but he has no real interests. Therefore he has no community participation. He goes to 4H provided by his school for ASD. He is not in a Public School anymore because they felt that he was a behavior problem and wanted him in a behavior school. However his behavior was because his sensory needs were not met in a Public School.
6 - 12	Few inclusive activities are available after school or on weekends. There is no clearinghouse of inclusive activities in the area. And there are almost no inclusive opportunities for children under 6. Aside from the public school developmental preschool program which is half day mth (and is terrific), there are no child care providers who have highly trained teachers/aides to properly accommodate a child on the spectrum. Ratios are way too high.
6 - 12	Many of the activities our son participates in are outside of our community. I would like to see more inclusive programs in the Akron area, especially those that include typical peers. Some of the things we are interested in are art classes, music/dance, and sports.
6 - 12	I have a 9 year old nonverbal child with classic autism. A lot of programs out there seem based on services for high functioning and verbal children with ASD. I would like to see more programs that include those on the more severe side of spectrum so they are not left out or programs that are more geared towards them. Social or music or sports specific to those who will need a little more one on one guidance taking turns with each kid.

CHILD'S AGE	CAREGIVER COMMENTS: Subjective Well-Being	
2 - 5	I would like to see a peer mentor to guide the families along with this huge overtaking journey that never ends with a lot of twists and turns. I really hope that our kids know that we are parents are the best advocates they have and they hopefully one day appreciate everything we as parents worked hard for to help them through the rough times.	
6 - 12	My son was diagnosed with ASD about 10 months ago, so we are still learning about the resources available. His quality of life is seriously complicated by anxiety which is not yet well controlled. We are still working through getting him the help he needs and figuring out to help him learn to manage both the ASD and the anxiety.	
6 - 12	Because Autism is so prevalent, I feel as a parent that every person who the child or adult comes in contact with should have some education or training on how to serve this particular demographic, such as retail personnel:)	
13 - 18	My son currently has a good quality of life because he's with me and I make sure that he's happy and well cared for, but I don't believe that will be the case when I'm no longer able to care for him. I've worked in the group homes that we put people with disabilities in and they are bleak and depressing. I'm scared about what will happen to my son when I'm no longer here.	
CHILD'S AGE	CAREGIVER COMMENTS : Health and Well-Being	
2 - 5	Our (more rural) county has some wonderful doctors and speech therapists, but overall the city is ignorant on the issue of disabilities in very young children.	
6 - 12	Our experiences at (local hospital) have been horrible. The neurologists there were not the least bit helpful and did not seem interested in getting to know our son or in recommending therapies for him. We have since sought out other doctors, even though they are outside of our insurance network.	
23 – 30	The most significant lack or need in our community is adult medical practitioners (primary care, neurologists, hospitals) who understand autism and are willing and able to provide an environment and service delivery model that is appropriate and effective in meeting the individual needs of a person with autism and his/her caregivers. As a person with autism ages and is no longer welcome in the pediatric world, there are very few if any acceptable options. I might add, that an exception to this is the pediatric dental practice which we go to that will treat people with developmental disabilities no matter the age.	

GRADE — **M**ASTERED THESE **Q**UALITY OF **L**IFE **I**NDICATORS:

None

SUMMARY

This *Autism Wellness Survey* should not be construed as statistically accurate or as the views of everyone impacted by autism in Northeast Ohio. The survey is intended to be a sampling of how individuals may feel about issues, services and programs available for people living with autism in our community.

By measuring Quality of Life indicators for people living the autism journey, the survey provides insights into areas of significant need as well as areas where some progress is being made. The findings provide an eye-opening look at a difficult journey and are and are intended to take the conversation about autism in Northeast Ohio to the next level.

Needs Improvement

The survey results are especially troubling in the areas related to employment, safety, financial stability, and independent living.

For example:

- 88% of the respondents believe that employers are not prepared to receive a person with autism in their work environment.
- 82% believe that appropriate childcare is not available for children with autism in our community.
- 81% believe that adults with autism will lack financial stability because resources for people with autism are not available in our community.
- 71% believe that adults with autism will not have access to reputable independent living facilities.

As one parent observed: "My daughter is going to outlive me and my concern is deep and painful. I would give anything to know she is going to be okay, that our community will help. ASD is not her fault, but her punishment for having it has been unending and severe.

Demonstrating Progress

The survey also revealed that some progress is being made in the areas of inclusion/academic success, recreation and leisure, self-identity and acceptance, and health and well-being.

For example:

- 37% of the respondents believe that they have access to meaningful school programs that provide an inclusive learning environment with typical peers.
- 48% believe that there are community- or school-based non-sports activities available to them, such as Boy Scouts, after-school clubs, etc. 49% believe that sports activities are available.
- 51% believe that our community has medical professionals who understand autism.
- 72% believe that a person with autism has a good quality of life.
- 65% of the respondents believe that they have access to appropriate communication therapies and devices in our community.

One parent observed: "My husband and I are seriously considering selling our home to move to a surrounding area that is more up to date and tolerant of those on the autism spectrum. As our school system has determined that the special education students are segregated to a school across town, it makes it difficult to explain to the neighborhood kids why he cannot go to his home school. This does not facilitate friendships."

Mastered

Finally, there are no goals that could be considered "Mastered" with these survey results.

CALL TO ACTION

The results and comments from the survey demonstrate that the autism journey in Northeast Ohio is a difficult one. We must focus on the critical areas identified in the "Needs Improvement" category, while at the same time pushing forward in the areas of "Demonstrating Progress." Unfortunately, we could not give even one "Mastered" grade, as all the indicators revealed we aren't there yet.

Over the next year, the Autism Society of Greater Akron will use the *Autism Wellness Survey* as an instrument for change. While we know change does not happen fast, many of the solutions to some of these problems have been around for a long time. It is time to take action. Our focus will not only be on sharing the results with lawmakers and leaders, but also on utilizing the results to help guide local programs and services that the society can adopt to add more supports in key areas.

But we cannot do it alone. We look forward to working collaboratively with other community organizations, businesses, and agencies – both those that work directly with individuals with autism and their families – and those that do not.

Being a part of the community is important to everyone. On behalf of individuals with autism and their families, we call on our community's businesses and employers, lawmakers, local leaders, teachers, coaches, neighbors and friends to help make the autism journey more positive, which in the end, will improve everyone's quality of life.

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