INDIANA INSTITUTE ON DISABILITY AND COMMUNITY
INDIANA RESOURCE CENTER FOR AUTISM

Indiana Autism Spectrum Disorder Needs Assessment: An Examination of Hoosiers Navigating Autism Services and Supports

The Indiana Resource Center for Autism (IRCA) is located at Indiana University's Indiana Institute on Disability and Community. The IRCA is legislatively mandated to do a Needs Assessment Survey every three years (IC-12-11-8-3). The purpose of the survey is to identify: (A) the status of services provided to individuals with autism and their families; and (B) the need for additional or alternative services for individuals with autism and their families.

Autism spectrum disorder (ASD) is a pervasive neurodevelopmental disability. While each individual with ASD is different, all have some form of language or communication difficulties and experience challenges in social communication and social interaction. These social communication challenges include but are not limited to social-emotional reciprocity, nonverbal communication behaviors, or adjusting behavior to suit various social contexts. In addition, individuals on the autism spectrum also engage in restricted, repetitive patterns of behavior, interests, or activities. The severity level of these characteristics can differ significantly.

According to the Centers for Disease Control prevalence has gone from 1 in 150 to 1 in 54 in a matter of 16 years (Data & Statistics on Autism Spectrum Disorder | CDC). According to the U.S. Department of Education, as of Fall 2018 approximately 10.5% of school-aged children (6-21) with ASD received special education services under the Individuals with Disabilities Education Act (IDEA, 2004). This means that more than 650,000 students have a formal diagnosis of ASD. Only three disability categories are more prevalent than ASD: specific learning disability, speech or language impairment, and other health impairment.

Since no database currently exists in Indiana with the actual number of people on the autism spectrum, either statewide or by county, the only accurate figures come from the December 1 child count data collected by the Indiana Department of Education, Department of Special Education. These data are collected from all public-school districts across Indiana. Last year's identification rate was 1 in 62. Using this year's school enrollment data and the child count data from December 2020, this year's identification rate is 1 in 66. The child count data does not include children who are not on special education service plans, are homeschooled, or are in non-public schools/programs. All who have either an IEP or special education service plan are counted. Until this year, prevalence numbers have continued to trend in the direction of more students being identified. This year the trend shifted in response to COVID. ASD continues to be the fourth most prevalent disability category among Hoosier youth.

Given the prevalence of ASD across the Hoosier State, it is incumbent upon the IRCA to access the current state of the State to be more systematic and intentional in improving care and quality of life for Hoosiers with ASD and their families. In an effort to reach Hoosiers impacted by ASD, the IRCA partnered with the Arc of Indiana, the Autism Society of Indiana, Ball State University, Purdue University, Riley Child Development Center, Ascension St. Francis-Evansville, Easterseals Crossroads, In*Source, and Indiana University School of Social Work in developing and disseminating the Indiana ASD Needs

Assessment Survey. The current Needs Assessment Statewide Report was conducted from March 2021 to July 2021.

The Indiana ASD Needs Assessment Survey was collaboratively designed to collect data surrounding multiple domains (e.g., education, employment, funding sources. behavior, mental health, living arrangements) and address the lifespan, including toddlers, school-aged children, and adults. The Indiana ASD Needs Assessment is designed to be accessed by a range of autism stakeholders. These stakeholders include family members, educational leaders, service providers, community organizations, and policymakers. The primary purpose of data and information collected is to address the needs and gaps in services of individuals affected by ASD in Indiana. Information will be shared with an Indiana policy group focused on autism issues that IRCA leads.

Statewide Demographic Summary

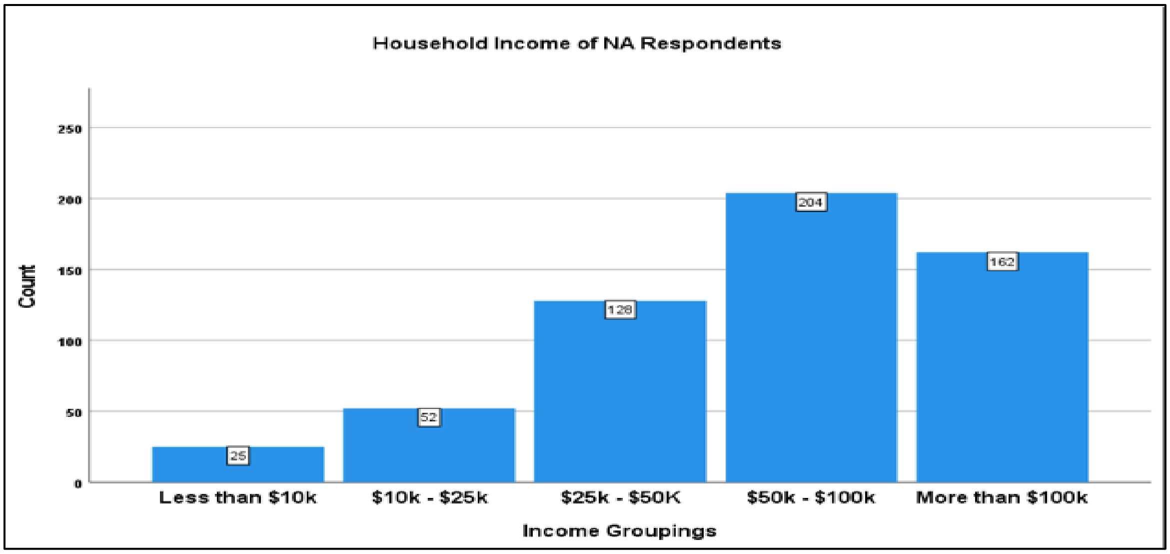
608 caregivers of individuals with ASD completed the IN ASD Needs Assessment. The majority of respondents (84%) were categorized as a biological/adoptive parent. Nearly 10% of respondents indicate their role was grandparent, foster parent, or legal guardian. Additional respondents included siblings, aunts or uncles, spouses, behavioral/clinical case managers, teachers, or individuals with ASD. The ages of the individuals represented are summarized in the table below. Of those who have a family member with ASD who is older than 18 years of age, 45.2% indicated they are their legal guardian. 18% of the 606 respondents indicated they had more than one family member with ASD.

Type of Respondent	Number of Respondents	Percentage of Respondents
Biological/Adoptive Parent	513	84.0
Grandparent	18	3.0
Foster Parent	2	0.5
Legal Guardian	19	3.0
Other	56	9.5
Total	608	100

Age of individual with ASD	Number of Individuals	Percentage of Individuals
0 – 2 years	10	1.0
3 – 4 years	41	7.0
5 – 13 years	273	45.0
14 – 17 years	103	17.0
18 – 21 years	90	15.0
22 years and older	89	15.0
Total	606	100

Of those who were represented in the survey, 76.0% were male, 22.3% were female, and 1.7% identified as non-binary or preferred not to answer. The ratio of males to females reflects the national trend of 4 to 1 of males to females.

As demonstrated in the table below, the majority of family members who responded (n=366) indicated a household income of $50,000 or more, with only 25 respondents reporting an income of less than $10,000 a year.



Almost all respondents (99%) had at least a high school degree or GED, with more than half (56%) indicating they had at least a bachelor's degree.

77.4% of respondents identified the family member with ASD as White/Caucasian, followed by Black/African American (7.9%), Hispanic/Latinx (4.3%), Asian (1.9%), American Indian (0.5%) and 3% preferred not to answer this item on the Needs Assessment Survey.

Race/Ethnicity	IN ASD Needs Assessment Percentage
Asian/Pacific Islander	1.9
Black/African American	7.9
Hispanic/Latinx	4.3
White	77.4
American Indian/Alaskan Native	0.5
Other	5.0
Prefer not to Answer	3.0
Total	100

51% of all family members reported living in a suburban locale, 31% reported living in rural communities, followed by 18% from an urban community.

78.2% of respondents report that their family member with ASD has at least one co-occurring disability along with ASD. The most commonly reported co-occurring disability was ADHD followed by anxiety and intellectual/developmental disability. Other co-occurring disabilities include bipolar, seizure disorder, obsessive compulsive disorder, sensory processing disorder, specific language disorder, and excessive behaviors**.**

The average age of diagnosis was 5.5 years, with the most common age being 3.0 years. Age of diagnosis ranged from 2 to 58 years.

The average age of beginning services was 5.1 years, with the most common age being 3.0 years. The age of when services began ranged from 0.5 to 41 years.

544 respondents (family members) provided a response for the living situation of their family member with ASD. For those who have a family member with ASD younger than 18 years of age, 98% reported the individual with ASD lives at home with a parent/guardian or other family member/caregiver. For those who have a family member with ASD older than 18 years of age, 82% reported the individual with

ASD lives at home with parent/guardian or other family member/caregiver. Of the 18% who reported other living situations, 15% live in an independent living situation with (n=10) or without (n=13) live-in support.

School-Based Services

Of those who responded, 458 reported the type of educational program their family member with ASD is currently enrolled in. Almost half (n=222; 48.5%) indicated their loved one with ASD is in a public-school educational program, followed by an ABA Center/Program (n=99; 21.6%), no current educational program (n=32; 7.0%), and homeschooling (n=24; 5.2%).

The most reported education placements for individuals with ASD were full-time general education classroom (n=104; 26.9%), and a combined general education and special education classroom (n=104; 26.9%). Approximately 13% (n=52) of respondents indicated their family member with ASD is supported full time in a self-contained special education classroom.

Respondents (360) identified the types of Individualized Education Program (IEP) services their family member with ASD receives at their educational program and placement. The table below presents the top four IEP services students reported by family members who responded to the 2021 IN ASD Needs Assessment.

IEP Service Received	Frequency	Percentage
Speech Therapy	228	63.3
Occupational Therapy	198	55.0
Social Skills Training	105	29.2
Behavior Management	96	26.6
Counseling/Mental Health Therapy	50	13.9
Total	360	100

Respondents (342) identified the types of Individualized Education Program (IEP) services their family member with ASD *needs* to receive at their educational program and placement. The table below presents the top five IEP services students *need* to receive.

IEP Service Needed	Frequency	Percentage
Social Skills Training	188	55.0
Behavior Management	123	26.0
Sensory Integration Training	98	28.7
Occupational Therapy	93	27.2
Counseling/Mental Health Therapy	83	24.3
Total	342	100

Using a 1-5 Likert scale with 1=strongly disagree, 2=disagree, 3=neutral, 4=agree, and 5=strongly agree, respondents reported their perceptions of the impact services received at school were having on their family member with ASD.

Survey Item	Number of Responses	Likert Score out of 5
Doing Better at Home	471	3.55
Behaviors Have Improved	464	3.44
Communication Has Improved	466	3.63
Is Doing Better in Social Situations	460	3.38
Is Better Able to Deal or Cope with Stress	468	3.14

Only 64% of the respondents who have a family member with ASD between the ages of 14 and 17 (n=143) reported their school developed and/or discussed a transition plan with them.

When asked questions related to behavior, it was found that 11.5% of youth with ASD (out of 410 responses) have been suspended or expelled from school in the last three years. Most reported being suspended or expelled due to behavioral challenges (e.g., aggression, disruption to school routines, etc.). Another 28.4% of youth with ASD have been restrained or placed in seclusion (e.g., timeout or quiet room) in the last three years. The reasons for being restrained or placed in seclusion range from self-injurious to refusing to listen.

Respondents answered that 17.1% of youth with ASD (out of 409 responses) have been placed on reduced day in their respective school programming. Of the 17.1% of youth with ASD who have been placed on a reduced day, over half (61.4%) were placed on a reduced day as a response to challenging or interfering behavior.

For those youth with ASD who were suspended/expelled, restrained/placed in seclusion, or placed on reduced day in the last three years, 44% did not receive a functional behavior assessment (FBA) and a subsequent behavior intervention plan (BIP) was neither developed nor implemented. Only 36% had an FBA conducted and a BIP developed. The remaining 20% respondents indicated they were not aware if an FBA was conducted or if a BIP was developed.

Mental Health & Justice System Interaction

Recognizing the co-occurrence of ASD and mental health, a series of questions were asked about available services and the impact of mental health struggles. Of the 485 who responded to this question, 37 (7.6%) of individuals with ASD have received short-term crisis management intervention at a hospital in the past three years. The average length of stay for individuals with ASD who received short-term crisis management intervention at a hospital was 7.5 days. Most lengths of stay were only one day, with a range from one to 30 days. Reasons for receiving short-term crisis management intervention at a hospital include:

- Aggression toward parents
- Hearing voices, suicidal thoughts, self-cutting, depression, and anxiety
- Psychiatric evaluation needed
- Seizure control
- Judge ordered
- Medication adjustment
- Stress management

Of the 484 family members who responded, 9.1% (n=44) individuals with ASD have attempted or threatened suicide. 1.4% reported they prefer not to answer this question.

1 in 5 family members have contacted their Community Mental Health Center (CMHC) to help address the mental health needs of their family member with ASD. Of those who contacted their CMHC to address mental health needs, 38% were unable to access any type of mental health services.

A series of questions were asked to determine the incidence of those on the autism spectrum interacting with the criminal justice systems. Of the 482 who responded to this questions, 1% (n=4) have been arrested or charged with a crime in the past three years. Those who had been arrested or charged with a crime were charged with battery or bringing a weapon to school. All cases were dropped. Only one of the four individuals was offered a diversion program. Only one was incarcerated for any duration of time.

Employment

Of the 309 respondents who have a family member with ASD who is eligible for employment, 15% (n=47) report that their family member with ASD is currently employed. For those who are employed, community employment was the most reported type of employment setting (56.1%). 30% (n=12) reported no day programming.

Family members of individuals with ASD who were of age but did not have employment at the time of the Needs Assessment Survey were asked to select applicable barriers to employment. The top barrier was a lack of options (n=92; 46%). A personal lack of interest (n=61; 30.5%) was the second most prevalent barrier, followed by lack of transportation (n=29; 14.5%) and fear of losing benefits (n=18; 9.0%).

Family members of those with ASD were asked to report the type of services or supports those with ASD need to be successful in finding and keeping a job. The top service/support was social skills training (n=184) followed by a job coach (n=149) and appropriate accommodations in the workplace (n=149).

Those who reported about a family member who is currently employed (n=47), reported that the individual with ASD works an average of 25 hours per week and has a yearly income of $16,231. The range of hours worked, and yearly income was 4 to 40 and $2,200 to $65,000 respectively.

Medicaid Waiver/Insurance Services and Needs

When asked about the Medicaid Waiver, 53.4% of respondents reported that their family member with ASD receives funding through the Waiver. Another 8.2% reported that they did not know what the Medicaid Waiver was; and 38.4% indicated their family member does not receive funding through the Medicaid Waiver.

The majority of respondents (92.6%) receive funding through the Family Support Waiver (FSW), with the remaining 7.4% of individuals with ASD receiving funding through the Community Integration and Habilitation (CIH) waiver.

After applying for the waiver, the average wait time to receive services through the Medicaid Waiver was 23.3 months. The median wait time was 11 months, with most family members reporting a wait time of 12 months. Wait time ranged from 0 months to 216 months (18 years).

When reporting the types of services the individual with ASD receives because of waiver money, most families reported case management (n=150), behavioral support services (n=102), respite care (n=82), and music therapy (n=65).

For those family members who have a loved one with ASD who receive waiver services, 58.7% are satisfied with the availability of waiver services; 41.3% are unsatisfied with the availability of services. For those who were not satisfied, the primary complaint was a lack of qualified or enough staffing to receive reliable and consistent waiver services such as respite, speech or occupational therapy, and applied behavior analysis therapy.

For those family members who have a loved one with ASD who receives waiver services, 76.0% are satisfied with the quality of waiver services; 24.0% are not satisfied with the quality of waiver services. For those who were not satisfied with the quality of waiver services, the main concern was a lack of quality training to direct support professionals (DSP) and a lack of services for individuals with intensive needs and supports.

For those family members who have a loved one with ASD who receive waiver services, 47.2% of family members indicated there were not sufficient funds available through waiver programs to purchase needed services for the individual with ASD. Many family members indicated they had to choose between necessary services due to a lack of funds to purchase all needed services. For example, family members reported wanting both behavioral supports and respite. They had to use their budget to pay for behavior support and so did not receive adequate respite services as a result.

For those family members who have a loved one with ASD who receives waiver services, more than half (55.7%) reported an insufficient number of qualified waiver service providers available in their area. Family members (88.4%) who have a loved one with ASD who receive waiver services reported being satisfied with case management services. For those who were not satisfied with case management services, family members believe this type of service can be improved by case managers better aligning services with needs and ensuring the services are developmentally appropriate.

On a 1-5 Likert-type scale (1=strongly disagree, 2=disagree, 3=neutral, 4=agree, 5=strongly agree) respondents reported their perceptions of the impact of Medicaid Waiver services on ***the family member with ASD***:

Survey Item	**Number of Responses**	**Likert Score out of 5**
Doing Better at Home	218	3.67
Doing Better at School	196	3.36
Behaviors Have Improved	213	3.54
Communication Has Improved	212	3.53
Is Doing Better in Social Situations	214	3.44
Is Better Able to Deal/Cope with Stress	215	3.35

Using a 1-5 Likert scale with 1=strongly disagree, 2=disagree, 3=neutral, 4=agree, and 5=strongly agree, respondents reported their perceptions of the impact of Medicaid Waiver services on ***their whole family***:

Survey Item	**Number of Responses**	**Likert Score out of 5**
Has More Time for Themselves	220	3.05
Has More Time for Recreational Activities/Hobbies	217	3.02
Has More Time for Friends and Other Relatives	216	2.94
Has Been Better Able to Take Vacations and Trips	216	2.77
Has More Time to Spend on Own Work and Chores	216	3.07
Has Experienced Less Overall Family Stress	217	3.11
Has Experienced Less Overall Stress	213	3.13
Has Experienced Less Financial Worry	214	3.37

9% (n=38) of family members who responded to this Needs Assessment Survey (n=425) have been denied health insurance coverage for their family member with ASD in the last three years. These families were denied health insurance coverage due to a range of factors, including being out of network, insufficient diagnosis, unrelated medical reasons, high familial incomes, “not medically necessary” services, and company did not cover an autism spectrum disorder diagnosis. Of those denied health insurance coverage, 64% were denied health insurance through an employer, 30% were denied Medicaid insurance, and the remaining 6% were denied an Affordable Care Act insurance plan.

65.2% of family members with ASD were unable to access a life insurance plan.

To receive necessary services, 42% (n=204) of family members report paying for private services for their family member with ASD (n=481).

While 62% of family members were able to access the services they wanted and needed for their family member with ASD, it is important to note that more than a third (38%) were unable to access the services they wanted and needed for their family member with ASD.

We asked family members what additional types of services or resources they need to successfully support their family member with ASD and improve their family's quality of life. The top service or support was dental care (n=145), followed by respite care (n=144), mental health support (n=138), and counseling (n=110).

Many family members have faced barriers when caring for their loved one with ASD. The top barriers faced are a lack of access to childcare (n=144) and a lack of paid time off (n=96). Respondents (82) indicated other barriers to caring for their loved one with ASD. These other barriers include having to work multiple jobs, lack of services near home, lack of understanding and awareness of ASD in the community, and financial challenges and burdens.

For those family members who support a loved one with ASD, 55% reported having to reduce or stop employment to care for the family member with ASD. For those who have had to reduce or stop employment to care for their family member, 48% report having lost employment or career opportunities due to caregiver demands.

Pratt, C. (2021). *Indiana autism spectrum disorder needs assessment: An examination of Hoosiers navigating autism services and supports.* Retrieved from https://www.iidc.indiana.edu/irca/what-we-do/research/indiana-autism-spectrum-disorder-needs-assessment.html.