Oklahoma Autism Needs Assessment Survey
Parents, Caregivers and Individuals Living with Autism Spectrum Disorders

A report by:
The Oklahoma Family and Interagency Autism Council
May 31, 2013

Oklahoma Autism Network
Tolbert Center for Developmental Disabilities
College of Allied Health
University of Oklahoma Health Sciences Center
1200 North Stonewall Avenue
Oklahoma City, Oklahoma 73117
Phone: 405.271.7476
Toll Free: 1.877.228.8476 or 1.877.2AUTISM
Fax: 405.271.2630
Email: okautism@ouhsc.edu
Web: www.okautism.org
Address correspondence concerning this report to the Julie Smith and Jennifer Moyano, Oklahoma Autism Network, College of Allied Health, University of Oklahoma Health Sciences Center, 1200 North Stonewall Avenue, Oklahoma City, OK 73117; email: julie-smith@ouhsc.edu and jennifer-moyano@ouhsc.edu
Executive Summary

The Individuals with Autism and Their Families, Oklahoma Plan
In April 2001, Howard Hendrick, the director of the Oklahoma Department of Human Services, brought together stakeholders “to discuss the development of a comprehensive plan that would move the state to the cutting edge of research, service delivery and supports for people with autism of all ages in the state of Oklahoma.” The Autism Working Group was convened by the Developmental Disabilities Services Division (DDSD) of the Oklahoma Department of Human Services and the Lee Mitchener Tolbert Center for Developmental Disabilities (Department of Rehabilitation Science, College of Allied Health, University of Oklahoma Health Sciences Center). Participants included representatives of the primary agencies and providers serving people with autism in Oklahoma, representatives of higher education, and parents of people with autism. The Autism Working Group created The Individuals with Autism and Their Families, Oklahoma Plan detailing their vision and recommendations. The Oklahoma Autism Network at the University of Oklahoma Health Sciences Center was established in October 2003 as a statewide administrative unit to facilitate the planning, financing and administration of the various recommendations of the Oklahoma Plan.

The Oklahoma Family and Interagency Autism Council
In 2009, the Oklahoma Autism Network convened the Oklahoma Family and Interagency Autism Council with membership from state agencies, parents, higher education, and community providers. As outlined in the Oklahoma Plan, this Council serves to:

- Facilitate the efficient and effective exchange of information on Autism Spectrum Disorder (ASD) activities among state agencies, professionals, and families;
- Coordinate ASD-related activities within the state for individuals across the ASD spectrum and across the lifespan;
- Increase public understanding of the member agencies’ activities, programs, policies, and research related to ASD;
- Provide input to updates of the Individuals with Autism and Their Families, Oklahoma Plan; and
- Provide an opportunity for those invested in Oklahomans with autism and their families to network and build relationships that foster collaboration between agencies, organizations, and family members.

Needs Assessment
The Oklahoma Plan outlines the primary functions of the autism networks including developing and implementing a system for ongoing monitoring of the needs of people with autism over time, and alerting agencies to the changing needs of specific individuals or groups. Two national surveys exist including the National Survey of Children’s Health (NSCH) (2007) and the National Survey of Children with Special Health Care Needs (NS-CSHCN) (2009/2010). On the NSCH, the number of Oklahoma parents reporting their child has an autism spectrum disorder is unknown because only national level data is reported for this question. On the NS-CSHCN, the number of parents was too small to analyze statistically, 49 have the condition, 16 had the condition at some point but not currently, and 674 do not have the condition. Additionally, the two surveys do not include data about adults with or without special health care needs.
The Oklahoma Family and Interagency Autism Council recommended the Oklahoma Autism Network to design and implement a needs survey for parents or caregivers of individuals with autism spectrum disorders and individuals with autism spectrum disorders within the state of Oklahoma. The survey assisted in the collection of information about demographics, service experiences and needs (screening and diagnosis, early intervention and school services, therapeutic interventions, etc.), barriers and/or limitations to accessing services, employment, waiver services, adult services, crisis intervention, and financial resources.

This report outlines the methodology and findings of the Oklahoma Autism Needs Assessment Survey of parents and caregivers of individuals with ASD and individuals with ASD 18 years of age or older who live in Oklahoma. The results are reported in sections listed below. Recommendations are included within each section and all are provided in a recommendations section as well.

**Key Findings of the Oklahoma Autism Needs Assessment Survey**

**Getting a Diagnosis**

- The ratio of males to females is 4:1. The Centers for Disease Control and Prevention (CDC) report that among the Autism and Developmental Disabilities Monitoring Network (ADDM) sites the ratio of males to females is 5:1.
- Combined responses from caregivers and individuals self-reporting indicate 13.4% (24/179) are Native American. The ADDM does not report data specific to Native American populations.
- The median age of diagnosis is 3.4 years compared to the ADDM mean age of 4.0 years.
- Among individuals self-reporting, 90% (9/10) have depression and 40% (4/10) have a learning disability.
- Caregivers report 37% of children also have ADHD and nearly 25% also have a learning disability.
- Caregivers report 15% of children also have an intellectual disability.

**Impact of Accessed Services**

- Less than 25% of parents report their student receives assistive technology, behavior management with a behavior support plan, extended school year, intensive behavioral therapy, sensory integration therapy, or social skills training as part of their individualized education program (IEP).
- Over 40% of parents report that their student does not currently receive but needs behavior management and/or sensory integration therapy as part of their IEP.
- Approximately 15% of parents report their student does not currently receive but needs assistive technology services as part of their IEP.
- Over 40% of parents and three of seven adults report they do not receive but need social skills training.
Five of the six families report more time for themselves, work, and other chores as a result of their child receiving DDSD waivered services.

Four of the six families report they have a better understanding of their child as a result of SoonerStart early intervention services.

**Barriers and Limitations to Accessing Services**

- Over half of caregivers report a lack or shortage of providers.
- The hardest to find are psychologists, psychiatrists and practitioners to address behavior.
- Nearly 60% of caregivers have purchased private services during the last 3 years. The average monthly cost for services per child is $825, and 18% of caregivers pay $1,000 or more a month for services. The average monthly cost of in-home behavioral therapy is $1,307.
- 58% of caregivers with children under the age of 9 years have purchased private services during the last 3 years. The average monthly cost for services per child is $1,339, and 33% of caregivers pay $1,000 or more a month for services. The average monthly cost of in-home behavioral therapy is $2,381.
- One-third of caregivers report lack of insurance or costs of services as a challenge to accessing primary health care, and regardless of type of provider, caregivers have difficulty paying for services. In comparison, 42% of caregivers with children under the age of 9 years report lack of insurance or costs of services as a challenge to access. In-home behavioral therapy, occupational therapy, social skills training and speech language therapy are services most frequently identified as not covered by insurance.
- Over two-thirds of caregivers are not aware of the DDSD Medicaid Waiver programs.
- Twenty four caregivers have applied for the Medicaid Waiver program and have not yet received the services. Their reported wait time ranges from 12 months to 8 years or an average of 3 years, 7 months.

**Crisis Intervention**

- 46% of families who responded to this question report that they have experienced a crisis in which they were concerned for the safety of their child or of themselves.
- 40% of families contacted their physician for help during a crisis. 21% accessed ER, Police, or 911.

**Employment of Individuals with ASD**

- Over 80% of caregivers indicate that their children need one-on-one job coaching to find and keep a job. Social skills training (70%) and vocational training (63%) are also greatly needed.
- Eight of the 10 individuals living with autism who responded are not employed.

**Impact of ASD on the Family**

- Nearly 55% of caregivers have not developed long term care plans for when they are no longer able to care for their children.
Nearly 40% of caregivers report they or their partner stopped working outside the home. For caregivers who stopped working and their partners continue to work, 17% of their partners decreased their work hours; whereas, 22% of their partners increased their work hours.

The internet was reported by more caregivers than any other source as their primary source of information.

Over one-third of the caregivers access autism support groups.

**Adults Living with ASD**

- Only 2 out of the 10 individuals with ASD have completed a college degree.
- 80% of individuals with ASD who were self-reporting, state that they either do not have or would like more friendships. 40% state that they either do not have or would like to have more romantic relationships.
- 50% state that they either do not have or would like to have more mentors.
The Oklahoma Family and Interagency Autism Council

Rene' Daman, PT, MS, Chair
Director, Oklahoma Autism Network, College of Allied Health, University of Oklahoma Health Sciences Center

Department of Education
Jenny Giles, Coordinator, Special Education Services
Tracey Lindroth, Coordinator, Special Education Services
Cynthia Valenzuela, Executive Director, Special Education Services

Department of Health
John Corpolongo, MS, Chief
Edd D. Rhoades, Jr., MD, MPH

Department of Human Services, Developmental Disabilities Services Division
Michaela Bishop, Training Director, Developmental Disabilities Services Division
James Nicholson (Former Division Director)

Department of Rehabilitation Services
Marla Baker, External Relations Coordinator

Higher Education
University of Central Oklahoma
Mary Sweet-Darter, Faculty, College of Education and Professional Studies

University of Oklahoma
James Martin, PhD, Zarrow Family Professor of Learning Enrichment, Zarrow Center, Jeannine Rainbolt College of Education

University of Oklahoma Health Sciences Center
Wanda Felty, Community Leadership and Advocacy Coordinator, Oklahoma LEND Core Faculty, Center for Learning and Leadership, College of Medicine

Martha Ferretti, PT, MPH, FAPTA Professor Chairman, Department of Rehabilitation Sciences, College of Allied Health
Bonnie McBride, PhD, BCBA, Assistant Professor Pediatrics, Department of Pediatrics
Jennifer Moyano, OTR/L, Training and Outreach Coordinator, Oklahoma Autism Network, College of Allied Health
Judy Pluess, Family Services Coordinator, Oklahoma Autism Network, College of Allied Health
Julie D. Smith, MS, OTR/L, Assistant Director, Oklahoma Autism Network, College of Allied Health

Oklahoma Developmental Disabilities Council
Jenifer Randle, Advocacy and Training Coordinator

Parents
Joni Bruce, Executive Director, Oklahoma Family Network
Melinda Lauffenburger, Executive Director, AutismOklahoma.org
Jennifer Miller, Co-Founder, Resource Director, Autism Center of Tulsa
Shawna Muns, Parent
Michelle Wilkerson, Co-Founder, Program Director, Autism Center of Tulsa

Private Providers
Sherilyn Walton, Family Support Coordinator, TARC
Larry Wood, Rose Rock Academy

Youth and Family Services
Dee Blose, Executive Director
# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Executive Summary</td>
<td>1</td>
</tr>
<tr>
<td>The Oklahoma Family and Interagency Autism Council</td>
<td>5</td>
</tr>
<tr>
<td>Autism Spectrum Disorders (ASDs)</td>
<td>9</td>
</tr>
<tr>
<td>Recommendations</td>
<td>11</td>
</tr>
<tr>
<td>Methodology</td>
<td>15</td>
</tr>
<tr>
<td>Results</td>
<td></td>
</tr>
<tr>
<td>Demographic Characteristics</td>
<td>17</td>
</tr>
<tr>
<td>Getting a Diagnosis</td>
<td>21</td>
</tr>
<tr>
<td>Impact of Accessed Services</td>
<td>25</td>
</tr>
<tr>
<td>Barriers and Limitations to Accessing Services</td>
<td>35</td>
</tr>
<tr>
<td>Crisis Intervention</td>
<td>39</td>
</tr>
<tr>
<td>Employment of Individuals with ASD</td>
<td>41</td>
</tr>
<tr>
<td>Impact of ASD on the Family</td>
<td>45</td>
</tr>
<tr>
<td>Adults Living with ASD</td>
<td>49</td>
</tr>
<tr>
<td>References</td>
<td>53</td>
</tr>
</tbody>
</table>
Autism Spectrum Disorders (ASDs)

What is Autism

Autism Spectrum Disorders (ASDs) are a group of related brain based disorders that usually appear before the age of three. While individuals with ASDs can exhibit a wide range of functional abilities, they share three areas of difficulty; social interaction, communication, and behavior. The current version of the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (DSM-IVTR) describes five distinct Pervasive Developmental Disorders including Autism, Asperger’s Syndrome and Pervasive Developmental Disorder-Not Otherwise Specified. The *DSM-V*, due out in 2013, unites these disorders and outlines diagnostic criteria for Autism Spectrum Disorder.

The causes of Autism Spectrum Disorders are not known currently. Research is exploring genetic and environmental factors that may impact the developing fetal brain. There is no cure for Autism Spectrum Disorders, but with effective intervention, individuals with ASD make progress and develop new skills.

Prevalence

The Centers for Disease Control and Prevention (CDC) estimates that an average of 1 in 88 children in the U.S. has an ASD. The CDC is working to find out how many children have ASDs, discover the risk factors, and raise awareness of the signs (CDC, 2012, [http://www.cdc.gov/ncbddd/autism/index.html](http://www.cdc.gov/ncbddd/autism/index.html)).

Currently, we do not know how many Oklahomans have an ASD. Our best guess is based on information the Oklahoma State Department of Education gathers about children receiving special education services through their annual Child Count. Through the annual Child Count, children are identified in one of 13 categories, including Autism. In 2011, 3,586 children aged 3-21 were identified under the Autism category. This number does not include children with ASDs who are served under another category, children with ASDs who are not receiving special education services, or those under age 3 or over age 21.

<table>
<thead>
<tr>
<th>Children served under Autism Category in Oklahoma</th>
<th>Child Count by Age Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>98-99</td>
<td>02-03</td>
</tr>
<tr>
<td>Age 3-5</td>
<td>*</td>
</tr>
<tr>
<td>Age 6-11</td>
<td>305</td>
</tr>
<tr>
<td>Age 12-17</td>
<td>135</td>
</tr>
<tr>
<td>Age 18-21</td>
<td>14</td>
</tr>
<tr>
<td>TOTAL (Age 3-21)</td>
<td>454</td>
</tr>
</tbody>
</table>

* not reported

Prevalence data provides information on the estimates of individuals with ASD who require education and health intervention, allows agencies and programs to plan for funding and resources (ADDM, 2009), shows the magnitude of the problem, and describes the characteristics, such as race, ethnicity, and gender (ADDM, 2007). The Oklahoma Family and
Interagency Autism Council recommended the Oklahoma Autism Network develop a mechanism for determining the prevalence rate in Oklahoma. Such information is vital for determining the needs and developing programs that support individuals with ASD and their families.
Recommendations

Results are discussed in each section of this report. The following is a summary of the recommendations for each of section.

Demographic Characteristics

- Identify strategies to increase the response rate across the state for caregivers and individuals living with ASD. Although responses were received from caregivers in 37 counties, the majority of responses were from caregivers in Cleveland, Oklahoma and Tulsa counties. Specific strategies should be identified to reach caregivers in all counties, especially rural areas. Other considerations include reaching a diverse population in terms of race/ethnicity, language, age, diagnosis, and service systems (SoonerStart Early Intervention, public school programs, Department of Human Services-Developmental Disabilities Services Division, Department of Rehabilitation Services, etc.).

- Consider alignment of questions to national (National Survey of Children’s Health and National Survey of Children with Special Health Care Needs) and state surveys.

Getting a Diagnosis

- Explore the needs of the Native American population, and encourage partnerships with tribal organizations to increase early identification.

- Early identification efforts (routine screening in primary care, universal screening in SoonerStart Early Intervention) should continue and expand.

- High rates of depression in adults surveyed suggest that the mental health community will encounter individuals with ASD. More information is needed about the unique mental health needs of this population so that mental health providers are able to respond to those needs.

- The ADDM Network (2012) found that only 38% of individuals with ASD also had an intellectual disability. In Oklahoma only 15% of survey respondents reported their child also had an intellectual disability. Currently, to qualify for DDSD Programs, individuals with ASD are required to also have an intellectual disability.

Impact of Accessed Services

- Identify ways to increase the availability and quality of behavior support services for students in public schools. Consider ways to partner with other organizations, such as the Oklahoma School Psychology Association and similar organizations, to enhance behavioral assessment and intervention in the public schools.

- Identify barriers and ways to increase the availability of assistive technology services in public schools. Consult with the Oklahoma Assistive Technology Center and Able Tech regarding both issues since they are two of the primary service providers for assistive technology services in Oklahoma.

- Social skills are identified as a core deficit in ASD yet services to specifically address this core deficit area are reported to be available to less than 25% of students in public schools. Identify barriers and ways to increase the availability of social skills training for students in public schools.

- Identify ways to increase the number of responses from individuals receiving Developmental Disabilities Services Division (DDSD) waivered services.
Identify ways to increase the number of responses from individuals receiving SoonerStart early intervention services.

Identify ways to increase supports available to adults with ASD, particularly adults who are not eligible for DDSD waivered services.

Barriers and Limitations to Accessing Services

Increase the number of providers. Over half of caregivers report a lack or shortage of providers. Improvements may require a multi-pronged approach to training, recruitment and retention of service providers. Training should occur across disciplines and levels of education (pre-service training, professional development, and graduate programs). One focus of training should include improving providers’ understanding of the characteristics of ASD and how to address challenging behaviors.

Improve access to providers. This recommendation is two-fold. On one hand, as of March 19, 2013, 7,109 individuals were on the DDSD Waiver Request Waiting List (Oklahoma Department of Human Services, 2013). A great need exists to decrease the number of individuals on the waiting list. On the other hand, over two-thirds of caregivers are not aware of the DDSD Medicaid Waiver programs. Increased public awareness activities of the program and other existing programs and services (i.e., SoonerStart Early Intervention, public school services) are needed.

Improve access to insurance coverage. One third of the caregivers and individuals living with ASD report the cost of services or lack of insurance coverage as a barrier to accessing services. Nearly 60% of caregivers (86 of 147) have purchased private services during the last 3 years. The services caregivers have the most difficulty paying for are recommended to treat the core characteristics of autism. To date, 32 states have passed autism insurance legislation. Approaches to insurance coverage for other states should be reviewed and recommendations made to the Oklahoma Family and Interagency Autism Council.

Crisis Intervention

Families of children with ASD need to establish crisis intervention plans. 46% of families who responded to this question report that they have experienced a crisis in which they were concerned for the safety of the child or of themselves. Families may access a template to create a crisis intervention plan at http://okautism.org/families/SafetyandEmergencyReadiness.asp.

“In Oklahoma all people with autism are safe and none are denied services. A seamless continuum of effective, integrated options for assistance, including crisis intervention, is available for every person across his or her life span” (Oklahoma Plan, 2002). Increase awareness of existing services and how to access them. Identify existing options, identify gaps, and enhance and/or develop additional programs.

Prepare physicians to assist families to develop and access crisis intervention services. 40% of families who responded to this question contacted their physician for help during a crisis.

Emergency room personnel, Police and 911 need to be prepared to assist families of individuals with ASD who contact them for assistance during a crisis. 21% of families who responded to this question accessed ER, Police, or 911 during a crisis. Identify mechanisms for training first responders about the needs of individuals with ASD.
Employment of Individuals with ASD

- Collaborate with the Oklahoma Transition Council to improve school based transition education programs and post-secondary education systems throughout the state. The council’s mission is to improve transition education, planning, and services that lead to successful post school outcomes for students with disabilities. It consists of representatives of state agencies (Departments of Education, Rehabilitative Services, Human Services, etc.), public schools, parent organizations, university programs, and others. Recommended activities include:
  - Increase awareness and training of tools for transition to adulthood.
  - Enhance and / or develop programs to assist individuals with ASD to understand their strengths and needs relevant to their disability.
  - Enhance and / or develop programs to assist individuals with ASD to develop and use self-determination skills.
  - Develop employment services that address the specific challenges faced by adults with autism in the workplace.
  - Support individuals with autism in the workplace so they can be successful and maintain employment.

Impact of ASD on the Family

- Increase awareness of estate and future planning resources and training. Over half of caregivers have not developed long term care plans for when they are no longer able to care for their children. Estate and future planning involves legal and financial decisions, as well as living arrangements. Planning early affords caregivers more options and the ability to change the plans as their children grow and develop.
- Improve access to insurance. See recommendation under Barriers and Limitation to Supports and Access to Services.
- Improve systems of support that connect caregivers to programs and services. Over half of the caregivers and individuals living with autism report they have difficulty finding and / or paying for services. Explore and recommend how existing systems of support can help caregivers find, evaluate (eligibility, cost, effectiveness and benefit), and access available services.
- Increase awareness about how to evaluate the evidence of information found on the internet. While valid and reliable information can be found on the internet, the opposite is also true. Caregivers should have access to sources that will help them evaluate the information found on the internet. Evaluation is important to making decisions about financial, time, and family commitments. Explore and recommend how systems of supports can help caregivers evaluate information about autism spectrum disorders including signs and symptoms, screening and diagnostic procedures, core challenge areas for skill development, intervention methodologies, and assessment, implementation and evaluation of information.
Adults Living with ASD

- Explore the needs of individuals with ASD who attend or plan to attend college. Two out of the ten individuals with ASD who completed this survey have completed a college degree.

- Explore the social needs and opportunities for social engagement of adults with ASD. 80% of individuals with ASD who were self-reporting, state that they either do not have or would like more friendships. 40% state that they either do not have or would like to have more romantic relationships.

- Explore opportunities for mentorship. 50% of individuals with ASD who were self-reporting, state that they either do not have or would like to have more mentors.

Dissemination

- Share results of this survey with the legislature and state agencies to alert them to needs of families and individuals.

- Share results of this survey with the Governor’s Blue Ribbon Panel for Developmental Disabilities. The panel will develop a comprehensive plan to support individuals with developmental disabilities and their families, to address the state’s growing waiting list for thousands of individuals requesting DDSD community services, and to research and analyze best practices for the comprehensive delivery of high quality services to Oklahomans with all issues related to providing community services for individuals with developmental disabilities. An annual report will be submitted to the Governor regarding its findings on March 5, 2015.

- Share results of this survey with the public by posting on the Oklahoma Autism Network website at: http://okautism.org/
Overview and Sampling
The study was a nonexperimental design, research survey to examine the needs of individuals with ASD as described by them or their parents or caregivers. Quantitative data was collected through an online survey. Purposive sampling was used. Targeted state and private programs and parent organizations disseminated the announcement of the survey. Those eligible to participate in the survey were parents and caregivers of individuals with ASD and individuals with ASD 18 years of age or older who live in Oklahoma.

Development of Survey Questions
To create the on-line survey, existing statewide autism needs surveys were reviewed for applicability or adaptability including the Statewide Autism Needs Assessment (Alabama Autism Collaborative Group, 2008), Indiana Parent/Family Needs Assessment Survey (Indiana Resource Center for Autism at Indiana University, 2009), New Mexico Adults with Autism State Plan, Needs Assessment and Best Practices Review (New Mexico Developmental Disabilities Planning Council, 2010), Autism Survey (North Dakota Department of Human Services, Division of Mental Health and Substance Abuse, 2010), Pennsylvania Autism Needs Assessment: A Survey of Individuals and Families Living with Autism (Pennsylvania Department of Public Welfare, Bureau of Autism Services, 2011), and the Survey Regarding Autism Spectrum Disorders (Vermont Inter-Agency Autism Spectrum Disorders Planning Advisory Committee, 2007). Questions were adapted from surveys of the Indiana Resource Center for Autism and the Pennsylvania Department of Public Welfare Bureau of Autism Services. Questions for parents and caregivers of individuals with ASD resulted in nine categories including demographics, early intervention, education services, employment, waiver services, purchased services, crisis intervention, autism information, and financial resources. Questions for individuals with ASD resulted in eight categories including demographics, education, employment, living situation, relationships, social, health/education services, and crisis intervention. The questions were reviewed by colleagues and members of the Oklahoma Family and Interagency Autism Council for content, wording and changes.

Electronic Survey Description
The survey was available for three months in an online format using SurveyMonkey. The software allowed for skip logic so that participants were presented with questions based on prior responses (see Figure 1. for the survey algorithm). For instance, a parent who indicated that he/she had a child birth to 36 months moved forward to the early intervention category and skipped the education services category. The survey format also allowed participants to skip questions they did not wish to answer. They could also save their responses and complete the survey at a later time. SurveyMonkey provided Secure Sockets Layer (SSL) technology that allowed for the collection of anonymous responses through a secure, encrypted connection.

The survey for parents and caregivers consisted of 111 questions. However, the number of questions answered depended on the age of the individual with ASD. Participants never completed all 111 questions. Skip logic, described above, allowed the participant to answer questions relevant to the particular age population. The survey for individuals with ASD consisted of 37 questions. The survey questions were designed to help participants answer questions as quickly
as possible. Questions formats included drop-down box, select from a list, and open-ended. Open-ended questions were minimized.

To reach as many potential participants as possible, recruitment flyers were disseminated through personal contacts and emails by state and local programs serving individuals with ASD including the Oklahoma Autism Network, parent support organizations, local private practitioners, and state agencies such as the Oklahoma State Departments of Education, Health, Human Services and Mental Health and Substance Abuse, as well as through media. Potential participants were directed to the OUHSC Oklahoma Autism Network website (http://okautism.org/) where consent was described and a link to the on-line survey was provided. Participants could quit the survey at any point and the majority completed the survey in less than 30 minutes.

Survey Participants
204 participants selected “I am a parent or caregiver of an individual with an autism spectrum disorder.” Of the 204 surveys submitted, 169 were included in the analysis because 35 surveys contained no data. 11 participants selected “I am an individual with autism spectrum disorder and 18 years of age or older.” One survey contained no data leaving 10 surveys for analysis.

Data Analysis
Descriptive statistics were used to summarize participants’ responses to the survey questions. Response data were presented in means, medians, ranges, and frequencies, and relationships between responses were examined and reported.

Figure 1. Survey Algorithm
Demographic Characteristics

Number of Parents / Caregivers and Home Counties

Responses of 169 parents or caregivers are included in the survey results. The survey consisted of 111 questions in nine categories including demographics, early intervention, education services, employment, waiver services, purchased services, crisis management, autism information, and financial resources.

- Parents represent the largest number of responses.
- Caregivers from 37 counties participated in the survey. While it appears caregivers from northwest Oklahoma did not participate in the survey, they were not required to identify where they live.

**Total number of responses**

<table>
<thead>
<tr>
<th>Parents or Caregivers</th>
<th>169</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individuals with an Autism Spectrum Disorder</td>
<td>10</td>
</tr>
</tbody>
</table>

**Relationship to Child**<br>

<table>
<thead>
<tr>
<th>Relationship to Child</th>
<th>n=169</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent</td>
<td>159</td>
</tr>
<tr>
<td>Grandparent</td>
<td>6</td>
</tr>
<tr>
<td>Foster Parent</td>
<td>0</td>
</tr>
<tr>
<td>Guardian</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
</tr>
</tbody>
</table>

**Child**<br>

<table>
<thead>
<tr>
<th>Age (in years)</th>
<th>n=169</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-2 yrs</td>
<td>5</td>
</tr>
<tr>
<td>3-5 yrs</td>
<td>31</td>
</tr>
<tr>
<td>6-8 yrs</td>
<td>35</td>
</tr>
<tr>
<td>9-11 yrs</td>
<td>37</td>
</tr>
<tr>
<td>12-14 yrs</td>
<td>20</td>
</tr>
<tr>
<td>15-17 yrs</td>
<td>16</td>
</tr>
<tr>
<td>18-30 yrs</td>
<td>25</td>
</tr>
</tbody>
</table>

- Of the 169 caregivers that responded to the child’s race or ethnicity, 30% of the children were identified with a race or ethnicity other than Caucasian including 13.6% as Native American.

Child Information Reported by Parents / Caregivers

- Nearly 64% of caregivers report their children with ASD are aged 11 years or younger.
- 4 of 5 caregivers report the individual they completed the survey about is male.
- 17 caregivers adopted their children with ASD.
- The average number of children per household is 2.4, and the average number of children with ASD per household is 1.1.
- Twenty caregivers report having more than one child with ASD in the home.
- 164 of 169 caregivers report the child lives in the parent’s home and almost 90% are satisfied or very satisfied with current living situation.

**Diagnosis - Caregivers Reporting**

- Autism: 26.8%
- Aspergers Syndrome: 1.2%
- Pervasive Developmental Disorder: 49.4%
- Other: 22.6%
### Parent / Caregiver Information

- Of 169 caregivers, approximately 76% of mothers are married, 15% are divorced and 9% are single.

- The majority of caregivers have a high school degree, and 55% of the mothers have a college degree or above, with approximately 15% reporting that they have a professional degree. Approximately 36% of fathers have a college degree or above.

- Nearly one-third of the respondent's annual household income is less than $40,000, and over half is less than $60,000 annually. The median household income for Oklahoma is $44,287. The largest numbers of responses were from caregivers living in Oklahoma, Cleveland and Tulsa Counties where the median household income is $44,413, $53,759, and $47,005 respectively.
Individuals Living with ASD Information

Responses from 10 individuals with ASD aged 18 years and older are included in the survey results. The survey consisted of 37 questions in eight categories including demographics, education, employment, living situation, relationships, social, health / education services, and crisis.

- Individuals with ASD from 6 counties participated in the survey.
- 60% are male.
- 60% are aged 29 years or younger and range in age from 19 to 53 years.
- 50% have a high school diploma, 30% have some college, and 20% have a college degree.

<table>
<thead>
<tr>
<th>Age</th>
<th>n=10</th>
</tr>
</thead>
</table>
| 18-29 | 60.0%| 6  
| 30-39 | 10.0%| 1  
| 40-49 | 0.0% | 0  
| 50-59 | 30.0%| 3  

<table>
<thead>
<tr>
<th>Marital status</th>
<th>n=10</th>
</tr>
</thead>
</table>
| Married        | 10.0%| 1  
| Never married  | 80.0%| 8  
| Divorced/Separated | 10.0%| 1  
| Widowed        | 0.0% | 0  

<table>
<thead>
<tr>
<th>Have Children</th>
<th>n=10</th>
</tr>
</thead>
</table>
| Yes            | 20.0%| 2  
| No, but planning on having children | 30.0%| 3  
| No, undecided | 10.0%| 1  
| No, I do not want children | 40.0%| 4  

- 60% are currently unemployed, 20% are unemployed but currently looking for a job, and 20% work full-time.
- 7 of the 10 individuals have a household income less than $20,000.
- 5 of the 10 individuals live alone and 2 live with parents or other relatives. Ninety percent are satisfied or very satisfied with their current living situation.
Getting a Diagnosis

Introduction

Nationwide there have been efforts to enhance screening and early identification of ASD's. Here in Oklahoma, those efforts have included general awareness activities, increased training for physician and other providers on screening tools and methods, and targeted programs that provide screening opportunities throughout the state. In this section we looked at demographic and diagnostic information reported by caregivers as well as individuals with ASD. In some sections we were able to compare the information from this data set with statistics reported by the CDC from the ADDM Network. However, we cannot conclude that this data set is a representative sample for the State of Oklahoma. Therefore, the national data is presented for information and is not intended as a comparison.

Gender

- Among all respondents, caregiver reported and individuals with ASD, 79% were male and 21% females. This represents a male to female ratio of 4:1. The CDC reports that among the ADDM reporting sites the ratio of male to female is 5:1.

Race / Ethnicity

- 13% of the combined caregiver and individual respondents are Native American. There has been very little reported about the needs of this population as a group.
Among caregiver respondents, 49% have a diagnosis of Autism. The 1% who report “other” indicate that they suspect their child has ASD but no formal testing has been completed.

Among individuals reporting, 70% have a diagnosis of Asperger’s Syndrome.

Among all respondents combined, 48% have a diagnosis of Autism.

9 out of the 10 individuals with ASD report having an additional diagnosis of depression. Although the sample size is small, it is an indicator that depression may be a factor for adults with ASD.

4 out of the 10 individuals also report having an additional diagnosis of a learning disability.

37% of caregivers report that their child has an additional diagnosis of ADHD.

Nearly 25% report their child also has a learning disability.

Over 20% of caregivers report their child has an anxiety disorder.

15% of caregivers report their child also has an intellectual disability.
Caregivers were asked what type of professional diagnosed their child. 49% indicate their child was diagnosed by a psychologist.

**Type of Professional Diagnosing**

<table>
<thead>
<tr>
<th>Type of Professional</th>
<th>n=162</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychologist</td>
<td></td>
</tr>
<tr>
<td>School Psychologist</td>
<td></td>
</tr>
<tr>
<td>Psychiatrist</td>
<td></td>
</tr>
<tr>
<td>Pediatrician</td>
<td></td>
</tr>
<tr>
<td>Developmental Team</td>
<td></td>
</tr>
<tr>
<td>Neurologist</td>
<td></td>
</tr>
<tr>
<td>Center-based Team</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
</tbody>
</table>

**Average Age at Diagnosis**

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>n=157</th>
<th>Average</th>
<th>Median</th>
<th>Range</th>
<th>ADDM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism</td>
<td>(75)</td>
<td>3.5</td>
<td>3</td>
<td>1 - 12</td>
<td>4.0</td>
</tr>
<tr>
<td>Aspergers</td>
<td>(38)</td>
<td>6.7</td>
<td>6</td>
<td>1 - 17</td>
<td>6.3</td>
</tr>
<tr>
<td>PDD-NOS</td>
<td>(44)</td>
<td>4.8</td>
<td>4</td>
<td>1 - 13</td>
<td>4.5</td>
</tr>
</tbody>
</table>

ADDM: Autism and Developmental Disabilities Monitoring Network

**Recommendations**

- Explore the needs of the Native American population, and encourage partnerships with tribal organizations to increase early identification.

- Early identification efforts (routine screening in primary care, universal screening in SoonerStart Early Intervention) should continue and expand.

- High rates of depression in adults surveyed suggest that the mental health community will encounter individuals with ASD. More information is needed about the unique mental health needs of this population so that mental health providers are able to respond to those needs.

- The ADDM Network (2012) found that only 38% of individuals with ASD also had an intellectual disability. In Oklahoma only 15% of survey respondents reported their child also had an intellectual disability. Currently, to qualify for DDSD Programs, individuals with ASD are required to also have an intellectual disability.
Impact of Accessed Services

Introduction
Included in the survey are multiple questions for caregivers and individuals with ASD related to the impact of services provided through the various service systems in Oklahoma. The majority of the survey respondents have a school age child with up to 120 caregivers rating the impact of services provided through their local public school. Six caregivers have a child in SoonerStart Early Intervention and an additional six caregivers have a child receiving waivered services through Developmental Disabilities Services Division, Department of Human Services.

SoonerStart Early Intervention, Oklahoma State Department of Education
SoonerStart is Oklahoma’s early intervention program (Part C) under the Individuals with Disabilities Education Act (IDEA), Amendments of 2004. It is designed to enhance the development of infants and toddlers and to enhance the capacity of families to meet the needs of their infants and toddlers with disabilities and developmental delays. SoonerStart is a joint effort of the Oklahoma Departments of Education, Health, Human Services, Mental Health Services, the Commission on Children and Youth, and the Oklahoma Health Care Authority. The program serves eligible families of infants and toddlers aged birth to 3 years, and there is no direct cost to families for the services.

- Six of the families who responded to the survey have a child currently receiving SoonerStart services.
- All six families report receiving family training, counseling, and home visits through SoonerStart.
- Five families report receiving speech-language pathology and audiology services.
- 5 of the 6 families are satisfied or very satisfied with SoonerStart services.

![Services Received as Part of IFSP](image)
As a direct result of early intervention services, my child:

\[ n = 6 \]

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is doing better at home</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Has improved his/her behavior</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Is doing better in social situations</td>
<td>1</td>
<td>0</td>
<td>5</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Is better able to communicate his/her needs</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Is better able to deal with problems</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>0</td>
</tr>
</tbody>
</table>

- The majority of families are either neutral or agree they have seen improvements in their child as a direct result of early intervention services.

As a direct result of early intervention, our family:

\[ n = 6 \]

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has more time for ourselves</td>
<td>1</td>
<td>1</td>
<td>3</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Has more time for recreational activities</td>
<td>2</td>
<td>0</td>
<td>3</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Has more time for friends and other relatives</td>
<td>1</td>
<td>1</td>
<td>3</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Has been better able to take vacations and trips</td>
<td>0</td>
<td>0</td>
<td>5</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Has more time to spend on own work and chores</td>
<td>0</td>
<td>0</td>
<td>5</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Has experienced less overall family stress</td>
<td>1</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Has experienced less overall stress</td>
<td>1</td>
<td>0</td>
<td>3</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Has experienced less financial worry</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Has a better understanding of our child and his/her developmental needs</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

- In general, families are more neutral with regards to the changes in their family as a direct result of early intervention services.
- 4 of the 6 families report they have a better understanding of their child and his/her developmental needs as a result of early intervention services.
Educational Services, Local Education Agencies

Local education agencies must provide special education and related services (Part B) as mandated by IDEA to eligible children with disabilities, aged three through 21. The purposes of IDEA are “(a) to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living; (b) to ensure that the rights of children with disabilities and their parents are protected; (c) to assist States, localities, educational service agencies, and Federal agencies to provide for the education of all children with disabilities; and (d) to assess and ensure the effectiveness of efforts to educate children with disabilities” (IDEA, 2004, §300.1).

- Over 50% of parents report their student receives occupational therapy and / or speech language therapy as part of their Individualized Education Program (IEP).
- Less than 25% of parents report their student receives assistive technology, behavior management with a behavior support plan, extended school year, intensive early behavioral therapy, sensory integration therapy, or social skills training as part of their IEP.
- Over 40% of parents report their student does not currently receive but needs behavior management, sensory integration therapy and / or social skills training to be successful in school.

![Additional Services Needed to be Successful at School](chart.png)
The majority of caregivers report the quality of the following services provided by the schools is good or very good: 1) extended school year, 2) occupational therapy, 3) one-on-one paraprofessional, and 4) speech therapy services.

The majority of caregivers report the quality of the following services provided by the schools is poor or very poor: 1) functional behavioral assessment, 2) behavior intervention plans, 3) counseling, 4) applied behavior analysis, 5) parent counseling and training, 6) rehabilitation counseling, 7) sensory integration, and 8) social work services.

70 of the 122 respondents report being satisfied or very satisfied with the services provided by their school.

30 of the 122 respondents report being dissatisfied or very dissatisfied with the services provided by their school.
As a direct result of the services at school, my son/daughter is:

\[ n = 120 \]

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is doing better at home</td>
<td>21</td>
<td>30</td>
<td>38</td>
<td>23</td>
<td>7</td>
</tr>
<tr>
<td>Is doing better at school</td>
<td>30</td>
<td>45</td>
<td>24</td>
<td>11</td>
<td>9</td>
</tr>
<tr>
<td>Has improved his/her behavior</td>
<td>14</td>
<td>37</td>
<td>35</td>
<td>24</td>
<td>7</td>
</tr>
<tr>
<td>Is doing better in social situations</td>
<td>18</td>
<td>40</td>
<td>21</td>
<td>29</td>
<td>10</td>
</tr>
<tr>
<td>Is better able to deal with problems</td>
<td>13</td>
<td>22</td>
<td>44</td>
<td>26</td>
<td>12</td>
</tr>
</tbody>
</table>

The majority of families report their child is doing better as a direct result of services at school, with the exception of doing better in the ability to deal with problems.

As a direct result of the services at school, our family:

\[ n = 118 \]

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has more time for ourselves</td>
<td>4</td>
<td>21</td>
<td>42</td>
<td>31</td>
<td>18</td>
</tr>
<tr>
<td>Has more time for recreational activities</td>
<td>5</td>
<td>20</td>
<td>41</td>
<td>33</td>
<td>18</td>
</tr>
<tr>
<td>Has more time for friends and other relatives</td>
<td>4</td>
<td>12</td>
<td>47</td>
<td>38</td>
<td>15</td>
</tr>
<tr>
<td>Has been better able to take vacations and trips</td>
<td>3</td>
<td>13</td>
<td>47</td>
<td>33</td>
<td>20</td>
</tr>
<tr>
<td>Has more time to spend on own work and chores</td>
<td>2</td>
<td>28</td>
<td>38</td>
<td>31</td>
<td>18</td>
</tr>
<tr>
<td>Has experienced less overall family stress</td>
<td>8</td>
<td>24</td>
<td>33</td>
<td>33</td>
<td>19</td>
</tr>
<tr>
<td>Has experienced less overall stress</td>
<td>11</td>
<td>18</td>
<td>30</td>
<td>37</td>
<td>21</td>
</tr>
<tr>
<td>Has experienced less financial worry</td>
<td>5</td>
<td>8</td>
<td>44</td>
<td>35</td>
<td>25</td>
</tr>
</tbody>
</table>

The majority of families disagree that their family is doing better as a direct result of services provided through the schools.
Developmental Disabilities Services Division, Department of Human Services

The Developmental Disabilities Services Division (DDSD) serves individuals aged 3 and older who have an intellectual disability (IQ of 70 or below). In addition, they may have other developmental disabilities such as autism, cerebral palsy, Down Syndrome, etc. Services range from in-home supports, such as therapy and habilitation services to community living and support services. The Medicaid Home and Community Based Services (HCBS) Waivers and State funds are used for the services.

- Twenty four caregivers have applied for the Medicaid Waiver program and have not yet received the services. Their reported wait time ranges from 12 months to 8 years.
- Six families who completed the survey are currently receiving DDSD services.
- Of those receiving services, three are on the In-Home Support Waivers for Adults, one is on the In-Home Support Waiver for Children, and two are on the Community Waiver.

![Diagram: Types of Services Received in the Past Three Years as a Result of Waiver Money](chart)

*Types of Services Received in the Past Three Years as a Result of Waiver Money*

*n=6*
As a direct result of the Medicaid Waiver, my son/daughter:

\[ n = 6 \]

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is doing better at home</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Is doing better at school</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Has improved his/her behavior</td>
<td>0</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Is doing better in social situation</td>
<td>0</td>
<td>3</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Is better able to deal with problems</td>
<td>0</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

- 4 of the 6 families report their son or daughter is doing better at home as a direct result of the Medicaid Waiver.

As a direct result of the Medicaid Waiver, our family:

\[ n = 6 \]

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has more time for ourselves</td>
<td>0</td>
<td>5</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Has more time for recreational activities</td>
<td>0</td>
<td>4</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Has more time for friends and other relatives</td>
<td>0</td>
<td>4</td>
<td>0</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Has been better able to take vacations and trips</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Has more time to spend on own work and chores</td>
<td>0</td>
<td>5</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Has experienced less overall family stress</td>
<td>0</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Has experienced less overall stress</td>
<td>0</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Has experienced less financial worry</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

- The majority of families report they have more time for themselves, more time for recreational activities and friends, and more time for work and chores as a direct result of the Medicaid Waiver.
- The majority of families report they are better able to take vacations and trips as a direct result of the Medicaid Waiver.
Quality of Health Care Services

Parents / caregivers were asked to rate the quality of health care services for their child with ASD. They indicate the most difficulty with general doctors, pediatricians, and medical tests.

![Bar chart showing problems with quality of health care services]

Individuals Living with ASD

<table>
<thead>
<tr>
<th>Specialty Health and Education Service Needs</th>
<th>n=9</th>
</tr>
</thead>
<tbody>
<tr>
<td>Services</td>
<td>Receiving</td>
</tr>
<tr>
<td>----------------------------------------</td>
<td>------------</td>
</tr>
<tr>
<td>Behavioral Support (e.g. TSS)</td>
<td>1</td>
</tr>
<tr>
<td>Career Counseling</td>
<td>1</td>
</tr>
<tr>
<td>Case Management</td>
<td>1</td>
</tr>
<tr>
<td>Drug and Alcohol Counseling</td>
<td>0</td>
</tr>
<tr>
<td>Mental Health Counseling</td>
<td>2</td>
</tr>
<tr>
<td>Occupational/Speech Therapy</td>
<td>0</td>
</tr>
<tr>
<td>Physical Therapy</td>
<td>0</td>
</tr>
<tr>
<td>Relationship Counseling</td>
<td>0</td>
</tr>
<tr>
<td>Social Skills Training</td>
<td>0</td>
</tr>
<tr>
<td>Speech/Language Therapy</td>
<td>0</td>
</tr>
<tr>
<td>Supported Employment</td>
<td>0</td>
</tr>
<tr>
<td>Transitional Planning</td>
<td>1</td>
</tr>
<tr>
<td>Vocational Training</td>
<td>1</td>
</tr>
</tbody>
</table>
3 of the 8 individuals with ASD who responded report that they do not receive but need case management and transitional planning.

3 of the 7 individuals who responded report that they do not receive but need relationship counseling and social skills training.

3 of the 7 who responded report that they receive but need more supported employment services.

**Recommendations**

- Identify ways to increase the availability and quality of behavior support services for students in public schools. Consider ways to partner with other organizations, such as the Oklahoma School Psychology Association and similar organizations, to enhance behavioral assessment and intervention in the public schools.

- Identify barriers and ways to increase the availability of assistive technology services in public schools. Consult with the Oklahoma Assistive Technology Center and Able Tech regarding both issues since they are two of the primary service providers for assistive technology services in Oklahoma.

- Social skills are identified as a core deficit in ASD yet services to specifically address this core deficit area are reported to be available to less than 25% of students in public schools. Identify barriers and ways to increase the availability of social skills training for students in public schools.

- Identify ways to increase the number of responses from individuals receiving Developmental Disabilities Services Division (DDSD) waivered services.

- Identify ways to increase the number of responses from individuals receiving SoonerStart early intervention services.

- Identify ways to increase supports available to adults with ASD, particularly adults who are not eligible for DDSD waivered services.
Barriers and Limitations to Supports and Access to Services

Introduction
Included in the survey are several questions intended to assess the barriers and limitations to supports and access to services. The questions focused on the availability and access to providers, costs and payment of services, insurance coverage, problem behavior and transportation.

No Providers or Shortage of Providers for Primary Health or Dental Care

- 1 in 5 caregivers have difficulty accessing primary health care and 1 in 3 have difficulty accessing dental care due to their child’s behavior problems.
- Caregivers from 28 counties report barriers to accessing primary health and dental care due to shortages of providers.
- Over half of caregivers report they have difficulty accessing primary health care services due to a lack or shortage of providers, and where providers exist nearly 1 in 10 report providers in their area will not serve individuals with ASD. Shortages are noted in 26 counties.
- 1 in 4 caregivers report challenges accessing dental care because of a lack of provider availability and services to individuals with ASD. Shortages are noted in 17 counties.
- Regardless of the type of provider, caregivers have difficulty finding providers. The hardest to find are psychologists and psychiatrists followed by practitioners to address behavior.

Problem Behaviors
- 1 in 5 caregivers have difficulty accessing primary health care and 1 in 3 have difficulty accessing dental care due to their child’s behavior problems.

Availability of Service Providers
- Caregivers from 28 counties report barriers to accessing primary health and dental care due to shortages of providers.
- Over half of caregivers report they have difficulty accessing primary health care services due to a lack or shortage of providers, and where providers exist nearly 1 in 10 report providers in their area will not serve individuals with ASD. Shortages are noted in 26 counties.
- 1 in 4 caregivers report challenges accessing dental care because of a lack of provider availability and services to individuals with ASD. Shortages are noted in 17 counties.
- Regardless of the type of provider, caregivers have difficulty finding providers. The hardest to find are psychologists and psychiatrists followed by practitioners to address behavior.
All individuals living with ASD report a shortage of service providers. The six counties include Cleveland, Comanche, Oklahoma, Pontotoc, Tulsa, and Washington.

**Awareness of Programs**
- Over two-thirds of caregivers are not aware of the DDSD Medicaid Waiver programs.
- Twenty four caregivers have applied for the Medicaid Waiver program and have not yet received the services. Their reported wait time ranges from 12 months to 8 years.
- Three individuals living with autism report they are in school, and they all attend college. They are all aware of the assistance and/or resources for individuals with disabilities, and they all access assistance and/or resources.

**Lack of Insurance Coverage / Cost of Services**
- 1 in 3 caregivers report lack of insurance or cost of services as a challenge to accessing primary health care.
- Of 142 caregivers reporting about insurance coverage, 30 report they had been denied coverage. The most common reasons include no coverage for an autism spectrum diagnosis and no coverage for specific services (e.g., behavioral, biomedical, medical tests, occupational therapy, social skills groups, and speech-language pathology). Other reasons include services were deemed educational and not medical, and denial of life insurance.
- Nearly 60% of caregivers have purchased private services during the last 3 years. The average monthly cost for services per child is $825, and 18% of caregivers pay $1,000 or more a month for services.
Regardless of the type of provider, caregivers have difficulty paying for services. The average monthly cost by service purchased ranges from $187 for psychiatric therapy / medications to $1,307 for in-home behavioral therapy.

58% of caregivers with children under the age of 9 years have purchased private services during the last 3 years. The average monthly cost for services per child is $1,339, and 33% of caregivers pay $1,000 or more a month for services. The average monthly cost of in-home behavioral therapy is $2,381.

Over one-fourth of caregivers report no insurance coverage for occupational therapy and in-home behavioral therapy.

Approximately one-third of caregivers report no insurance provider coverage for social skills training and speech language therapy.

Seven of the individuals living with ASD indicate that their services are paid through Developmental Disabilities Services (1), Medicaid (1), out-of-pocket (1), private health insurance (3) and tribal health insurance (1). Two are unsure of how services are paid.
Of 70 caregivers, 58.5% estimate the monthly cost for services or resources needed to successfully support their child at home is less than $1,500.

**Recommendations**

- **Increase the number of providers.** Over half of caregivers report a lack or shortage of providers. Improvements may require a multi-pronged approach to training, recruitment and retention of service providers. Training should occur across disciplines and levels of education (pre-service training, professional development, and graduate programs). One focus of training should include improving providers’ understanding the characteristics of ASD and how to address challenging behaviors.

- **Improve access to providers.** This recommendation is two-fold. On one hand, as of March 19, 2013, 7,109 individuals were on the DDSD Waiver Request Waiting List (Oklahoma Department of Human Services, 2013). A great need exists to decrease the number of individuals on the waiting list. On the other hand, over two-thirds of caregivers are not aware of the DDSD Medicaid Waiver programs. Increased public awareness activities of the program and other existing programs and services (i.e., SoonerStart Early Intervention, public school services) are needed.

- **Improve access to insurance coverage.** One third of the caregivers and individuals living with ASD report the cost of services or lack of insurance coverage as a barrier to accessing services. Nearly 60% of caregivers (86 of 147) have purchased private services during the last 3 years. The services caregivers have the most difficulty paying for are recommended to treat the core characteristics of autism. To date, 32 states have passed autism insurance legislation. Approaches to insurance coverage for other states should be reviewed and recommendations made to the Oklahoma Family and Interagency Autism Council.
Crisis Intervention

Introduction

The *Oklahoma Plan* outlines a vision that “in Oklahoma all people with autism are safe and not denied services,” and “that a seamless continuum of effective, integrated options for assistance, including crisis intervention, is available for every person across his or her lifespan”. This survey included 12 questions for caregivers and 5 questions for adult individuals with ASD regarding the need for crisis intervention.

**Need for Crisis Intervention**

- 46.2% of families who responded to this question report that they have experienced a crisis in which they were concerned for the safety of their child or of themselves.

**Supports During Crisis**

- 40% of families contacted their physician.
- 15% stated that they had handled it themselves or contacted a family member.
- 21% accessed ER, Police, or 911.
Hospital Admissions

- Only 6 families report that their child required an inpatient hospitalization.
- 50% of those 6 families report that their child was admitted for self-injurious behavior.
- None of the adult individuals with ASD report an inpatient hospitalization.

Police Interactions

- 28% of caregivers and adult individuals with ASD combined report that they have had an interaction with police.
- 1 caregiver reports that their child has been charged with a crime.
- None report that their child was incarcerated.
- No adult individuals with ASD report being arrested or charged with a crime.

Recommendations

- Families of children with ASD need to establish crisis intervention plans. 46% of families who responded to this question report that they have experienced a crisis in which they were concerned for the safety of the child or of themselves. Families may access a template to create a crisis intervention plan at http://okautism.org/families/SafetyandEmergencyReadiness.asp.
- “In Oklahoma all people with autism are safe and none are denied services. A seamless continuum of effective, integrated options for assistance, including crisis intervention, is available for every person across his or her life span” (Oklahoma Plan, 2002). Increase awareness of existing services and how to access them. Identify existing options, identify gaps, and enhance and/or develop additional programs.
- Prepare physicians to assist families to develop and access crisis intervention services. 40% of families who responded to this question contacted their physician for help during a crisis.
- Emergency room personnel, Police and 911 need to be prepared to assist families of individuals with ASD who contact them for assistance during a crisis. 21% of families who responded to this question accessed ER, Police, or 911 during a crisis. Identify mechanisms for training first responders about the needs of individuals with ASD.
Employment of Individuals with ASD

Introduction

Findings of a national survey (Cooper, Sterzing, Wagner, and Taylor, 2012) of 500 parents, guardians and young adults with an ASD indicate that youth with an ASD have significantly lower rates of employment than youth with speech impairments, learning disabilities and intellectual disabilities. The results also indicate that during six years following high school, a third of youth with ASD participate in post secondary education and just over half are employed. However, during the two years following high school, over half are not employed or participate in post secondary education. The Oklahoma Autism Needs Assessment Survey included questions about employment status, types of employment, needs and challenges.

Reported by Parents and Caregivers

Thirty-six families responded to questions regarding individuals aged 15 and older.

- Of the 36 caregivers who responded, 6 report their child is employed in a community job.
- One indicates their child, a high school student, is employed in a sheltered workshop.

Caregivers were able to answer a free response question about their child’s type of employment.

- Of the 10 who responded, 4 report their child works between 30 to 40 hours per week. Two work 15 to 20 hours and four work less than 10 hours per week, respectively.
- The average annual income ranges from $2,500 to $25,000.
The most frequently reported supports and services needed in finding and keeping a job are one-on-one job coach (83%), social skills training (70%) and vocational training (63%).

Reported by Individuals Living with Autism

Ten individuals living with autism responded to questions related to employment.

- 80% of the individuals with ASD who responded are not employed.
- Three report they use the internet, job fairs, newspaper, and word of mouth to search for employment.
- Three also rate finding employment opportunities, creating a resume, interviewing, and following up after an interview as very difficult for them in the job search process. They rate filling out applications as difficult.
Compared to their peers, those employed full-time report a variety of discriminations in their work environment. They have not shared their diagnosis with co-workers with the exception of supervisors.

3 of the 4 rate their comfort level with peers and authority figures as uncomfortable or very uncomfortable.

**Recommendations**

- Collaborate with the Oklahoma Transition Council to improve school based transition education programs and post-secondary education systems throughout the state. The council’s mission is to improve transition education, planning, and services that lead to successful post school outcomes for students with disabilities. It consists of representatives of state agencies (Departments of Education, Rehabilitative Services, Human Services, etc.), public schools, parent organizations, university programs, and others. Recommended activities include:
  - Increase awareness and training of tools for transition to adulthood.
  - Enhance and / or develop programs to assist individuals with ASD to understand their strengths and needs relevant to their disability.
  - Enhance and / or develop programs to assist individuals with ASD to develop and use self-determination skills.
- Develop employment services that address the specific challenges faced by adults with autism in the workplace.
- Support individuals with autism in the workplace so they can be successful and maintain employment.
Impact of ASD on the Family

Introduction
In addition to the need for specialized services and the costs associated with autism (see Barriers and Limitations to Supports and Access to Services), the impact on the family also includes the need to develop long-term plans when they are no longer able to care for their child, on their workforce participation, and their need for evidence based information and support.

Long Term Plans
- 164 of 169 caregivers report the child lives in the parent’s home and about 90% are satisfied or very satisfied with the current living situation.
- Over 50% of the caregivers have not developed long-term plans for when they are no longer able to care for their children; however, the majority of the children are 11 years of age or younger. 10% of caregivers have children between 18 and 24 years of age.

Costs of Services and Supports
- 1 in 3 caregivers report lack of insurance or cost of services as a challenge to accessing primary health care.
- Nearly 60% of caregivers have purchased private services during the last 3 years.
- The average monthly cost for services per child is $762, and 16% of caregivers pay $1,000 or more a month for services.
Workforce Participation

- Of the 76 caregivers who stopped working outside the home, 11 of their partners have also decreased their work hours; whereas, 14 partners increased their work hours.

Information about ASD

- Caregivers report the internet as their primary source of information.

- While caregivers also frequently report state and national organizations as their primary source of information, school personnel, private therapists, and pediatricians were less frequently reported.

- 54 of 146 caregivers access autism support groups where families help one another.
Recommendations

- Increase awareness of estate and future planning resources and training. Over half of caregivers have not developed long term care plans for when they are no longer able to care for their children. Estate and future planning involves legal and financial decisions, as well as living arrangements. Planning early affords caregivers more options and the ability to change the plans as their children grow and develop.

- Improve access to insurance. See recommendation under Barriers and Limitation to Supports and Access to Services.

- Improve systems of support that connect caregivers to programs and services. Over half of the caregivers and individuals living with autism report they have difficulty finding and / or paying for services. Explore and recommend how existing systems of support can help caregivers find, evaluate (eligibility, cost, effectiveness and benefit), and access available services.

- Increase awareness about how to evaluate the evidence of information found on the internet. While valid and reliable information can be found on the internet, the opposite is also true. Caregivers should have access to sources that will help them evaluate the information found on the internet. Evaluation is important to making decisions about financial, time, and family commitments. Explore and recommend how systems of supports can help caregivers evaluate information about autism spectrum disorders including signs and symptoms, screening and diagnostic procedures, core challenge areas for skill development, intervention methodologies, and assessment, implementation and evaluation of information.
Introduction
This section reports on aspects of everyday life for adults with Autism Spectrum Disorder (ASD). Responses of 10 individuals with ASD aged 18 years and older are included in the survey results. Responses of 16 caregivers who indicated that their child was 18 years of age or older and no longer receiving Special Education services are also included in this report where possible.

<table>
<thead>
<tr>
<th>Age</th>
<th>n=26</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>18-29</td>
<td>80.8%</td>
<td>21</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30-39</td>
<td>7.7%</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>40-49</td>
<td>0.0%</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>50-59</td>
<td>11.5%</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Marital Status
- 80% of the individuals with ASD self-reporting have never been married.

Parenting
- 2 of the 10 individuals with ASD who self-reported have children of their own.
- 3 others plan on having children.
Education

- Of the 10 individuals with ASD who self-reported, 2 have completed a college degree and 5 have completed high school or have their GED.

Travel to Work & Activities

- 75% of the individuals with ASD who were self-reporting indicate that they drive themselves or use public transportation.

Employment

- 75% of caregivers report their adult child is unemployed.
- 80% of the adults with ASD who self-reported are unemployed.
- Of those individuals self-reporting, 70% have a diagnosis of Asperger’s syndrome.
Living Situation

- All 16 of the caregivers reporting about their adult children state that their children live at home with them.
- 75% of the caregivers report they are satisfied or very satisfied with their living arrangement. 6% report they are very dissatisfied.
- 9 of the 10 individuals with ASD report they are satisfied or very satisfied with their living arrangement.

Leisure

- 80% of individuals with ASD who were self-reporting state that they spend time in spiritual activities and exercise.
- 70% state that they spend time doing household chores and in social activities.
80% of individuals with ASD who were self-reporting, state that they either do not have or would like more friendships.

50% state that they either do not have or would like to have more mentors.

40% state that they either do not have or would like to have more romantic relationships.

**Recommendations**

- Explore the needs of individuals with ASD who attend or plan to attend college. Two out of the ten individuals with ASD who completed this survey have completed a college degree.

- Explore the social needs and opportunities for social engagement of adults with ASD. 80% of individuals with ASD who were self-reporting, state that they either do not have or would like more friendships. 40% state that they either do not have or would like to have more romantic relationships.

- Explore opportunities for mentorship. 50% of individuals with ASD who were self-reporting, state that they either do not have or would like to have more mentors.


