# Oklahoma Plan

### **Individuals with Autism and Their Families**

Progress Report March 30, 2012

### A report by:

# The Oklahoma Family and Interagency Autism Council

#### **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



# **Executive Summary**

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 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 Individuals with Autism and Their Families, Oklahoma Plan.

In May of 2009 the first progress report was made available, providing an update on the activities that took place since the publication of the original *Oklahoma Plan*. 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. This Council was identified as the statewide interagency and family coordination team in the original *Oklahoma Plan* and 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.

The Council reviewed the original state plan and progress report and recommended the organization of three committees to address activities outlined in the plan. The committees include crisis intervention, regional supports and access to services, and secondary transition and adult life. A fourth committee was already convened to address early childhood issues. The committees meet in person, and through teleconferencing and videoconferencing. Each committee drafted a logic model describing the situation / problem; desired changes in organizations, communities and / or systems; long-term and short-term outcomes; activities; and needed resources. These logic models continue to evolve and be updated as needed to reflect progress and as new goals are identified. Each logic model is described fully in the appendix, and the long term goals are outlined below:

- 1. Individuals with ASD will be educated and supported in the Least Restrictive Environment.
- 2. Children with ASD and challenging behavior will be safely included in typical childcare environments.
- 3. First responders will appropriately address the needs of individuals with ASD in crisis.
- 4. Health systems will recognize and address the needs of individuals with ASD in crisis.
- 5. Service providers (private occupational therapist, speech language pathologist, physical therapist, licensed professional counselors, psychologist) will provide support to individuals/families in crisis.
- 6. Families will access community based services that will support the family unit staying together.
- 7. A continuum of options for crisis intervention will be available.

#### **Early Childhood Committee**

- 1. Develop a broad based network of individuals that are qualified to provide evidence-based services.
- 2. Develop a broad based network of individuals that can provide training and technical assistance.
- 3. Decreased interval between screening and treatment or services
- 4. Systematic valid and reliable statewide screening process
- 5. Increased access to quality diagnostic services
- 6. Key stakeholders know one another and collaborate to develop and maintain coordinated service infrastructure. Continuous efforts toward public education and awareness of ASD.
- 7. Increased support and funding for programs
- 8. Assure public policies support our goals and objectives.
- 9. Centralized information infrastructure

#### **Regional Supports and Access to Services Committee**

- A statewide infrastructure is in place to provide a seamless continuum of effective, integrated options
  for timely and easily accessed assistance available for every person across his or her life span, and for
  their families and caregivers.
- 2. Professionals working with people with autism provide contemporary and effective services.
- 3. Individuals with ASD, families, and caregivers are provided effective support, training and technical assistance.
- 4. Students with autism receive an appropriate, individualized education based on current best practices (e.g., NRC, 2001; Dunlap et al., 2003).
- 5. Safe and time-effective substitute (e.g., child care, respite, day services) care is available for all ages.
- 6. Oklahoma's system of support for people with autism and their families is monitored with oversight and grievance procedures that ensure accountability and effectiveness that will be regularly measured and reported. Family members are involved in this process.
- 7. Families access parent-led organizations, natural supports, and training opportunities within their community.

#### **Secondary Transition and Adult Life Committee**

- 1. Key legislators become champions for post-secondary transition outcomes and the autism spectrum disorder community.
- 2. Quality school based transition education programs throughout the state
- 3. Quality transition education programs in Oklahoma's post-secondary education system
- 4. Individuals with autism spectrum disorder employed in jobs that match their interests and skills
- 5. Individuals with autism spectrum disorder living and having fun doing what they want and wish in the community of their choice with those who care about them.
- 6. Individuals with autism spectrum disorder understand their strengths and needs.
- 7. Individual with autism spectrum disorder have increased self-determination skills.

This report also includes an update on progress that has been made in autism related supports and services since 2009 and documentation of the need for additional services, expanded research, and a system for gathering information about the number of individuals with ASD in Oklahoma.

# 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**

Cynthia Bernardi-Valenzuela, Associate Director, Special Education Services Jenny Giles, Coordinator, Special Education Services

#### **Department of Health**

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

# Department of Human Services, Developmental Disabilities Services Division

James Nicholson, Division Director

#### Department of Mental Health and Substance Abuse

Traci Brownlow, former Communication and Events Specialist, Children, Youth and Family Services

#### **Department of Rehabilitation Services**

Marla Baker, External Relations Coordinator

#### **Higher Education**

University of Central Oklahoma

Mary Sweet-Darter, PhD, Associate Professor,
Department of Psychology, 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 Beth DeGrace, PhD, OTR/L, Department of Rehabilitation Sciences, College of Allied Health 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 Irene McEwen, PT, PhD, FAPTA, Department of Rehabilitation Sciences, College of Allied Health 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

#### Oklahoma Developmental Disabilities Council

Jenifer Randle, Advocacy and Training Coordinator

#### Oklahoma Health Care Authority

Jennifer King, Behavioral Health Lynn Mitchell, Medicaid Director Jolene Ring, Behavioral Health, retired

#### **Parents**

Health

Joni Bruce, Executive Director, Oklahoma Family
Network
Deborah Decker, AutismOKC.org
Melinda Lauffenburger, Executive Director,
AutismOklahoma.org
Jennifer Miller, Co-Founder, Resource Director,
Autism Center of Tulsa
Christina Newendorp

Michelle Wilkerson, Co-Founder, Program Director, Autism Center of Tulsa

#### **Private Providers**

Lori Jordan, MBA, former Executive Director, Camelot of Oklahoma

#### **Youth and Family Services**

Dee Blose, Executive Director

# Everything changed!!



Taylor and BJ Lowell with their 4-year old son Remy

They have been participating in the Early Foundations:
Autism Model and Outreach Project since January 2010.

We were hoping first and foremost, to be a social family. Our son had a lot of self injurious behavior which made going out very difficult. We also wanted to address his behavior and how we could help him cope with his emotions in a different way. We had felt very helpless as parents, we felt like we did know how to help our son and really we just wanted the tools to help him and us all deal with his issues in a way that would be best for him.

It has made us better parents, we now know how to help our son...He is more social, his behavior is so much better controlled. He is the kid we always knew was there, they have given us our family back.

We feel more secure as parents of a child with autism...They have given us so many tools that we can be successful with our son's future. Our son is just an amazing kid and we really do owe so much to Early Foundations for that. He has changed in every aspect of his life, his future looks very good.

# **Table of Contents**

Executive Summary	1
The Oklahoma Family and Interagency Autism Council	4
Update of Autism Spectrum Disorders in Oklahoma	9
Need	
What is Autism	12
Prevalence	12
Costs	13
Early Identification and Intervention	15
Access to Services	15
Secondary Transition and Adult Life	15
Crisis Intervention	16
Research	17
Needs Assessment	18
References	19
Appendices	
Appendix A - Committee Members	21
Appendix B - Committee Logic Models	24
Appendix C – Oklahoma Services and Supports	43
Appendix D – Oklahoma Parent-Led Organizations	51

# He understands the power of communication

Eli Kimbrell, 5-year old son to Sara Kimbrell

Sara and Eli participated in ConnectedKids:
Training Parents to Use
Developmental and
Behavioral Strategies
with their Child with
Autism Spectrum
Disorder during 2010.



The ConnectedKids program was recommended to us by a therapist at JD McCarty Center. We were looking to increase Eli's communication skills because he didn't have any communication other than eye contact and taking me to an item he wanted or bringing an item to me. We are so happy that now he is pointing and using sign and is capable of using a communication device. We have learned so much as a family.

The biggest change I can see is the new confidence I have. I feel I am a much better advocate for him now. Another goal I had for myself was to start a support group to help other parents in all areas. Our first meeting was in February...Before this program I would have never felt I could start such a big task.

The biggest change I can see in him is the eagerness to communicate his wants and needs. He really understands the power of communication. We have met some goals that we had set as a family, and it feels amazing. We have gone out to eat and to church as a family. This used to be a challenge that we wouldn't brave.

Our hopes and plans for the future are still the same; to give Eli the best possible life and make him as independent as we can. We are very honored we were one of the families selected to participate in this program.

# **Update on Autism in Oklahoma**

#### Senate Bill 135

In May 2009 the Oklahoma legislature passed Senate Bill 135 with the intent of expanding services available to individuals with autism and their families. Several significant changes have occurred in the state through implementation of the bill.

Developmental Disabilities Services Division (DDSD), Department of Human Services created the Oklahoma Licensed Behavior Analyst Board. This Board serves to provide licensing of Board Certified Behavior Analysts (BCBA) and certification of Board Certified Assistant Behavior Analysts (BCaBA) practicing in the state of Oklahoma. The statute became effective November 1, 2009. Currently, 25 Board Certified Behavior Analysts and two Board Certified Assistant Behavior Analysts are licensed to practice in Oklahoma. The intent of this section of the Bill is to provide an avenue for behavior analysts to become recognized providers through the state's Medicaid system. The Oklahoma Health Care Authority (OHCA) is working to implement a code to allow schools to bill for behavior support services. The required training that will allow paraprofessionals to be trained to bill this code is in the final stages of development. The OHCA continues to work towards implementation of a billing code for behavior analysts (BCBAs) and assistant behavior analysts (BCaBAs).

The Oklahoma State Department of Education received funds through SB 135 to provide specialized training in autism for Oklahoma's SoonerStart early intervention program direct service providers. Training has been provided to early intervention providers in the use of behavioral strategies for young children suspected of or who have a diagnosis of an ASD.

SoonerSUCCESS, a program through the Child Study Center at the University of Oklahoma Health Sciences Center received funds to provide primary care evaluation training for physicians to evaluate children with ASD. Thus far 30 physicians in the Oklahoma City and Tulsa metro areas have received initial training in the STAT-MD, a training designed to teach enhanced diagnostic consultation and screening procedures to pediatric medical providers serving young children. To date approximately 15 of these physicians have completed the reliability process for this training. An on-line collaborative (Autism Collaborative) has been developed for ongoing training and support for physicians in the diagnosis and care of children with ASD.

Senate Bill 135 also outlined the need for an applied behavior analysis treatment project to Developmental Disabilities Services Division, Department of Human Services Division to establish an applied behavior analysis treatment project. This project, ConnectedKids, is being designed and implemented by the Oklahoma Autism Network at the University of Oklahoma Health Sciences Center. ConnectedKids is currently completing the pilot phase and will begin the full study in March of 2012. The research project involves parent training in the use of applied behavior analysis with 4-5 hours of intervention provided each week in the home for the parent and child.

This law also established a program modeled after Early Foundations, an outreach program that provides early intensive behavioral intervention for children with autism. Early Foundations now has 4 sites, including Oklahoma County, Tulsa County, Canadian County, and Cleveland County, covering 50% of the child population in the state. The program serves 23 children across the 4 sites. The program received a federally funded grant through the Institute of Educational Services to study the efficacy of the Early Foundations model. This is a multisite (University of Washington partner University) research project using randomization with standard care as the control group.

#### **Other Progress**

Since 2009 there have been other expansions of services for individuals with ASD across the lifespan, including expanded screening services for young children, expanded professional development, and several pilot programs, including a work study program

Early screening for autism is more widely available in the state for young children. SoonerStart, Oklahoma's early intervention program continues to provide screening for all children who are enrolled in their program. Free screening is also available through several community programs, including Oklahoma Early Access Autism Project and the LINK Project. While several more providers in Oklahoma are providing diagnostic evaluations, there continues to be a minimum wait of four to six months for many families seeking a medical diagnosis of ASD.

Training for pre-service professionals and for professional development has expanded, resulting in a greater number of practitioners with knowledge about supporting individuals with ASD. Several University programs now provide coursework specific to autism, such as programs at the University of Central Oklahoma and University of Oklahoma Health Sciences Center. A wider range of professionals are also seeking additional training in autism, including childcare providers, local church programs, mental health providers, and vocational rehabilitation professionals Professional development opportunities have expanded through the Oklahoma Statewide Autism Conference and other trainings. The Oklahoma Statewide Autism Conference is a two-day conference that has included over 35 speakers each year for the past three years presenting evidence-based information related to autism.

Supports for students transitioning out of high school are also slowly expanding. The Department of Rehabilitation Services (DRS) provides several programs that individuals with ASD can access. Project SEARCH is a transition program designed for students seeking transition from high school to an innovative workforce. The program is now available in five communities in Oklahoma. Another DRS program is an autism work study pilot program through collaboration between Goodwill Industries, Inc. and Tulsa Public Schools. The Zarrow Center

for Learning Enrichment at the University of Oklahoma also provides resources to support successful transition that can be used by educators, vocational rehabilitation professionals, individuals, and families. One example is the Me! Lessons for teaching Self-Awareness and Self-Advocacy that is available for use from the Zarrow Center website. The University of Central Oklahoma is in the process of developing a supported program for individuals with ASD who attend their University.

Parent-led organizations have continued to provide support to families in the communities where they live. There are currently 16 active parent-led organizations that support individuals with ASD and their families.

# Need

#### 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, <a href="http://www.cdc.gov/ncbddd/autism/index.html">http://www.cdc.gov/ncbddd/autism/index.html</a>).

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 2010, 3,062 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.

#### Children served under Autism Category in Oklahoma Child Count by Age Group

	98-99	02-03	06-07	09-10	10-11	Percent Change
Age 3-5	*	15	65	130	164	1,722.22
Age 6-11	305	511	857	1,281	1,405	360.66
Age 12-17	135	280	688	1,106	1,346	897.04
Age 18-21	14	38	53	134	147	950.00
TOTAL (Age 3-21)	454	844	1,663	2,651	3,062	576.45

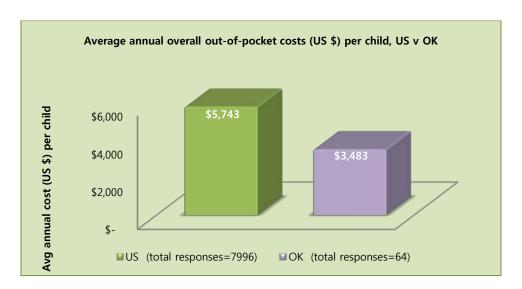
<sup>\*</sup> not reported

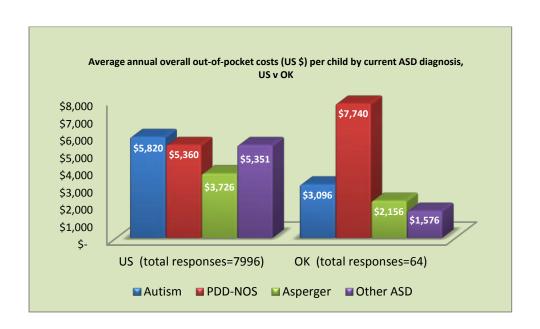
Prevalence data provides information on the estimates of individuals with ASD who require education and health intervention, allows agencies and programs to plan for funding and resources (ADDM, 2009), shows the magnitude of the problem, and describes the characteristics, such as race, ethnicity, and 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.

#### Costs

Michael Ganz (2007) described the costs of autism across the lifespan of individuals in the United States. He estimates the age-specific and lifetime incremental societal costs are \$3.2 million per person and \$35 billion annually. A recent study (Wang and Leslie, 2010) examined the trends in health care expenditures for individuals with ASD aged 17 and under in 42 Medicaid state programs, including Oklahoma. The individuals were continuously enrolled in the fee-for-service Medicaid. The authors found the average annual healthcare expenditure per child in 2003 was \$22,772. Leslie and Martin (2007) and Shimabukuro et al. (2008) studied data from 2003 private insurance claims and estimated the expenditures to be \$7,003 and \$6,830, respectively. The difference between Medicaid and private insurance expenditures may be due to wider coverage by Medicaid (Wang and Leslie, 2010).

The Interactive Autism Network at Kennedy Krieger Institute recruits families nationwide to participate in research about autism. To date 64 individuals from Oklahoma have participated in their research. Below is data about the average annual overall out-of-pocket costs per child, by diagnosis and by treatment in Oklahoma and nationally (retrieved January 29, 2012).





Average annual out-of-pocket cost (US \$) per treatment among Top Ten Treatments, US v OK

	• •			
Treatments	US avg cost	US	OK avg cost	ОК
	US \$	responses	US \$	responses
Speech and Language Therapy	\$887	4872	\$1091	32
Occupational Therapy	\$708	3902	\$707	28
Medications	\$357	3347	\$307	41
Applied Behavior Analysis (ABA)	\$5372	2027	\$3850	8
Social Skills Group	\$1017	1242	\$574	10
Physical Therapy	\$440	1004	\$720	8
Picture Exchange Communication System	\$246	972	\$336	6
Visual Schedules	\$112	938	\$29	8
Sensory Integration Therapy	\$1239	932	\$0	9
All-Purpose Multivitamin Supplement	\$246	888	\$156	4

To better inform state agencies and programs in Oklahoma, a systematic and collaborative effort is needed to collect data on the costs of autism in Oklahoma.

#### **Early Identification and Intervention**

Early identification and intervention has been a focus of the Combating Autism Act of 2006 (P.L. 109-416) and more recently the Combating Autism Reauthorization Act of 2011 (H.R. 2005). While the state has made progress in this area, more progress is needed for public awareness, the use of validated and reliable screening tools for ASD, promotion of early screening, increase of professionals who can confirm or rule out a diagnosis of ASD, increase of professionals who provide evidence-based interventions and promote as early as possible the use of evidence-based interventions. Stakeholders in Oklahoma have outlined activities to address these outcomes as evidenced in the Council logic models (see appendix B).

#### **Access to Services**

The 2011 Interagency Autism Coordinating Committee (IACC) Strategic Plan for Autism Spectrum Disorders addresses the need for services at a state and national level, including the variability of services in communities and local school districts, and the delay between identifying best practice through research and implementation of these practices into services provided within communities. Children and individuals with ASD in Oklahoma experience similar challenges. The availability of services continues to be insufficient to meet the growing needs, particularly in rural areas of the state where children and families have very limited access to professional resources outside of those provided through the local education system. Funding for services can be limited and several key services, such as behavioral therapy, are not recognized as a reimbursable service by SoonerCare, the state's Medicaid program, or by other third party payers.

There is a continued need to identify ways to increase timeliness and availability of services to individuals across the state, including increased coordination of services between agencies and programs; increased access to professional services and information to families, particularly in rural areas of the state, and additional options for funding evidence-based interventions for individuals across the autism spectrum.

#### **Secondary Transition and Adult Life**

Because information about long-term outcomes and lifetime supports for people with ASD is lacking, attention to transition from high school and adult outcomes is increasing nationally. One can hardly disagree that if the goal is for all individuals to lead self-determined lives, we must then invest in activities that will inform us. The Interagency Autism Coordinating Committee (IACC) 2011 Strategic Plan for Autism Spectrum Disorder Research identifies the need to conduct longitudinal studies of treatments, interventions, services and supports; increase understanding by the public; improve post high school options developmental disabilities and vocational systems. The IACC also identifies the need to understand quality of life and health outcomes, the number of individuals with ASD in the criminal system, the direct support needed for employment, and the supports and

services to live in the community. Finally, the IACC recommended the need for research on the use and safety of psychopharmaceutical medications. Several of these needs are being addressed in Oklahoma as described below.

Established in 2000, The Zarrow Center's (ZC) mission is to facilitate successful secondary and postsecondary educational, vocational and personal outcomes for students and adults with disabilities. ZC faculty, staff, and students do this through self-determination oriented evaluation, research, development, transition education instruction, and dissemination of best educational and support practices. The ZC also prepares undergraduate and graduate students to assume leadership roles in schools, universities, and support organizations.

Since 2002, The Oklahoma Transition Council (OTC) has conducted activities to improve transition education, planning, and services that lead to successful post school outcomes for students with disabilities. The OTC consists of 34 members representing diverse interests and includes representatives from the Oklahoma State Department of Education, Oklahoma Department of Rehabilitation Services, Oklahoma Family Network, Public School educators, Oklahoma Department of Human Services, the Parent Training and Information Center of Oklahoma, and university representatives.

The Department of Rehabilitation Services has partnered with Goodwill Industries, Inc. and Tulsa Public Schools to develop and implement an autism work study pilot program. DRS also facilitates partnerships between private and public organizations to implement Project SEARCH. Project SEARCH is dedicated to providing education and training to young adults with intellectual and developmental disabilities through an innovative workforce and career development model that benefits the individual, workplace, and community. The primary goal is to secure competitive employment outcomes for each of the student graduates. They currently have five programs in Oklahoma including: 1) St. John Medical Center and Jenks Public Schools; 2) Valley View Regional Hospital and Byng Public Schools; 3) INTEGRIS Bass Baptist Health Center and Enid Public Schools; 4) Chesapeake Energy Corporation and Metro Technology Centers; and 5) Mercy Health System and Francis Tuttle Technology Center.

These are important projects to improve transition for high school students, and they highlight collaborative efforts among programs. In addition to the needs addressed by these projects, continued planning of an Oklahoma agenda is needed to understand the needs of adults.

#### **Crisis Intervention**

Currently families in Oklahoma do not have an integrated, seamless, continuum of options for assistance when in a crisis. Individuals receiving services through Developmental Disabilities Services Division (DDSD), Department of Human Services (DHS) may receive crisis intervention services as part of their plan of care. However there are

many individuals with ASD who do not meet the eligibility criteria for DDSD. Through the Oklahoma Department of Mental Health and Substance Abuse (ODMHSAS), Mobile Crisis Response Teams are addressing the needs of youth in crisis in 24 of the 77 Oklahoma counties; however, they may lack training about the needs of children, youth, and adults with ASD. School teams are struggling with placement for children with ASD and challenging behavior. The Oklahoma State Department of Education (OSDE) has provided a mechanism for school personnel to receive crisis prevention and management training. Children with ASD are being asked to leave some child care settings when they have engaged in challenging behavior. Mental Health Consultation is available for childcare facilities who accept the DHS childcare subsidy. However, this does not include all childcare options. Funding for childcare providers to receive training on ASD and challenging behavior through the Training Inclusive Childcare = Terrific Opportunities for Children program has disappeared. Nationwide there are training programs that support police, fire and emergency responders to recognize and respond to the needs of individuals with ASD, but currently there is no statewide mechanism to provide such training or support.

#### Research

The need for research is recognized nationally. The Interagency Autism Coordinating Committee (IACC) 2011 Strategic Plan for Autism Spectrum Disorder Research outlines a framework for biomedical and services research (IACC, 2011). Their aspirational goals include:

- 1. Child at risk for ASD will be identified through reliable methods before ASD behavioral characteristics fully manifest;
- 2. Discover how ASD affects development, which will lead to targeted and personalized interventions;
- Causes of ASD will be discovered that inform prognosis and treatments and lead to prevention/preemption of the challenges and disabilities of ASD;
- 4. Interventions will be developed that are effective for reducing both core and associated symptoms, for building adaptive skills, and for maximizing quality of life and health for people with ASD;
- 5. Communities will access and implement necessary high-quality, evidence-based services and supports that maximize quality of life and health across the lifespan for all people with ASD;
- 6. All people with ASD will have the opportunity to lead self-determined lives in the community of their choice through school, work, community participation, meaningful relationships, and access to necessary and individualized services and supports; and
- 7. Develop and support infrastructure and surveillance systems that advance the speed, efficacy, and dissemination of autism research.

Oklahoma has a role to fulfill in addressing the research agenda. Currently, research underway in Oklahoma includes two intervention models: 1) ConnectedKids: Training Parents to Use Developmental and Behavioral Strategies with their Children with Autism Spectrum Disorder (Daman and Smith); and 2) Evaluation of a

Comprehensive Community-based Intervention for Toddlers with ASD (McBride). Another on-going research project is the study of cultural and linguistic diversity of ASD within the state of Oklahoma for children birth to 5 years old (DeGrace). Conducting such research requires continued support, collaboration and development of partnerships across agencies, programs, private providers and families. It requires identifying and pursuing viable private and public funding streams. Additionally, to move research forward in Oklahoma, a research agenda needs to be developed.

#### **Needs Assessment**

The original Individuals with Autism and Their Families, 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 (2009/2010). The number of Oklahoma parents that reported that their child 2-17 years currently have Autism, Asperger's Disorder, pervasive developmental disorder (PDD), or other autism spectrum disorder (ASD) on the NSCH 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.

In 2010, The Oklahoma Family and Interagency Autism Council recommended the Oklahoma Autism Network design and implement a needs survey for parents, caregivers, individuals with autism spectrum disorders and professionals within the state of Oklahoma. The Oklahoma Autism Network is developing the methodology and exploring grant opportunities for 2012. Such a survey will assist 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.

# References

- Centers for Disease Control and Prevention (CDC). Prevalence of —Autism Spectrum Disorders --- Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2002. MMWR SS 2007;56(SS-1)(2)
- Centers for Disease Control and Prevention. Prevalence of autism spectrum disorders: Autism and Developmental Disabilities Monitoring Network, United States. MMWR Surveillance Summaries 2009:58(SS10);1-20.
- Daman, R. and Smith, J. (in progress), *ConnectedKids: Training Parents to Use Developmental and Behavioral Strategies with their Children with Autism Spectrum Disorder.* Research Project, University of Oklahoma Health Sciences Center, Oklahoma Autism Network, Oklahoma City, OK.
- DeGrace, E. (in progress). *Cultural and linguistic diversity of ASD within the state of Oklahoma for children birth to 5 years old.* Research Project, University of Oklahoma Health Sciences Center, Oklahoma Autism Network, Oklahoma City, OK.
- Data Accountability Center, Individuals with Disabilities Education Act data. Data tables for OSEP State Reported Data, Part B child count. Accessed on January 26, 2012.
- Ganz ML. (2007). The lifetime distribution of incremental societal costs of autism. *Archives of Pediatrics and Adolescent Medicine*, 161, 343-349.
- IAN Community State Statistics. <a href="http://dashboard.ianexchange.org/StateStatsAdvanced.aspx?A1=OK">http://dashboard.ianexchange.org/StateStatsAdvanced.aspx?A1=OK</a>. Accessed on January 29, 2012.
- Individuals with Autism and Their Families, Oklahoma Plan, July 29, 2002. http://okautism.org/okplan/progress\_reports.asp
- Individuals with Autism and Their Families, Oklahoma Plan, Progress Report, May 2009. http://okautism.org/okplan/progress\_reports.asp
- Interagency Autism Coordinating Committee. 2011 IACC Strategic Plan for Autism Spectrum Disorder Research.

  2011 Jan. Retrieved from the Department of Health and Human Services Interagency Autism

  Coordinating Committee website at <a href="http://iacc.hhs.gov/strategic-plan/2011/index.shtml">http://iacc.hhs.gov/strategic-plan/2011/index.shtml</a>.
- Leslie D.L. and Martin A. (2007). Health care expenditures associated with autism spectrum disorders. *Archives of Pediatrics and Adolescent Medicine*, 161, 350-355.

- McBride, B. (in progress). *Evaluation of a Comprehensive Community-based Intervention for Toddlers with ASD.*(McBride). Research Project, University of Oklahoma Health Sciences Center, Child Study Center,
  Oklahoma City, OK.
- National Survey of Children's Health. NSCH 2007. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved January 29, 2012 from www.childhealthdata.org.
- National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved January 29, 2012 from www.childhealthdata.org.
- Shimabukuro, T.T., Grosse, S.D., and Rice, C. (2008). Medical expenditures for children with an autism spectrum disorder in a privately insured population. *Journal of Autism and Developmental Disorders*, 38, 546-552.

# APPENDIX A

### Committee Members

#### **Crisis Intervention Committee**

#### Jennifer Moyano, OTR/L, Committee Chair

Training and Outreach Coordinator, Oklahoma Autism Network, College of Allied Health

#### **Department of Education**

Jenny Giles, Coordinator, Special Education Services

# Department of Human Services, Developmental Disabilities Services Division

Michaela Bishop, Director, Human Resource Development

# Department of Mental Health and Substance Abuse

Traci Brownlow, Communication and Events Specialist, Children, Youth and Family Services Brian Hiel, Access Specialist, Children, Youth and Family Services

#### **Higher Education**

University of Oklahoma Health Sciences Center
Julie D. Smith, MS, OTR/L, Assistant Director,
Oklahoma Autism Network, College of Allied
Health

#### **Parents**

Deborah Decker, AutismOKC.org Shawna Muns Jenifer Jones, Oklahoma Family Support 360 Project

#### **Early Childhood Committee**

#### Bonnie McBride, PhD, BCBA, Committee Chair

Assistant Professor Pediatrics, Child Study Center, Department of Pediatrics, University of Oklahoma Health Sciences Center

#### **Child Care Resource Center**

Lesley Gudgel, LINK Project, JumpStart Coordinator, Early Childhood Planner

#### **Department of Education**

Cynthia Bernardi-Valenzuela, Associate Director,
Special Education Services

Jenny Giles, Coordinator, Special Education Services

Erin Gray Nation, Early Childhood Education
Coordinator

Michele Presley, Regional Coordinator, SoonerStart Early Intervention

#### **Department of Health**

John Corpolongo, MS, Chief

#### **Higher Education**

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

Melissa Fenrick, MSW, Dissemination and Academic Partnerships Coordinator, Center for Learning and Leadership

Seth Kastner, Research Assistant, Early Foundations: Autism Model and Outreach Project, Child Study Center

Jennifer Lockhart, Director, SoonerSUCCESS, Child Study Center

# APPENDIX A

### Committee Members

Laura McGuinn, MD, 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

Gay Snyder, Project PEAK, Child Study Center
Linda M. Wilson, PhD, Training Director, Oklahoma
LEND, Section on Developmental - Behavioral
Pediatrics, Department of Pediatrics, Child
Study Center

# Oklahoma Association of Community Action Agencies

Tamara Brickey, Early Childhood Education Center Manager, South Plains Community Action Association

Kay C. Floyd, Director, Head Start State Collaboration Office

#### **Parents**

Angela Donley, Oklahoma Family Network, Autism Coordinator

Jennifer Miller, Co-Founder, Resource Director, Autism Center of Tulsa

Michelle Wilkerson, Co-Founder, Program Director, Autism Center of Tulsa

### Regional Supports and Access to Services Committee

#### Rene' Daman, PT, MS, Committee Chair

Director, Oklahoma Autism Network, College of Allied Health, University of Oklahoma Health Sciences Center

#### **Department of Education**

Cynthia Bernardi-Valenzuela, Associate Director,
Special Education Services
Jenny Giles, Coordinator, Special Education Services

#### **Department of Health**

John Corpolongo, MS, Chief

#### Oklahoma Health Care Authority

Jennifer King, Behavioral Health Jolene Ring, Behavioral Health, retired

#### **Parents**

Christina Newendorp
Michelle Wilkerson, Co-Founder, Program Director,
Autism Center of Tulsa

# Secondary Transition and Adult Life Committee

#### Judy Pluess, Committee Chair

Family Services Coordinator, Oklahoma Autism Network, College of Allied Health, University of Oklahoma Health Sciences Center

# APPENDIX A

### Committee Members

#### **Department of Rehabilitation Services**

Marla Baker, External Relations Coordinator Robert Eames, CRC, Transition Rehabilitation Counselor

#### **Higher Education**

University of Oklahoma

James Martin, PhD, Zarrow Family Professor of
Learning Enrichment, Zarrow Center, College of
Education

University of Oklahoma Health Sciences Center
Rene' Daman, PT, MS, Director, Oklahoma Autism
Network, College of Allied Health
Julie D. Smith, MS, OTR/L, Assistant Director,
Oklahoma Autism Network, College of Allied
Health

#### **Parents**

Joni Bruce, Executive Director, Oklahoma Family Network

#### **Youth and Family Services**

Dee Blose, Executive Director

### Crisis Intervention Committee

**Committee Purpose:** The Crisis Intervention Committee has focused on identification of existing resources for crisis intervention, identification of existing gaps in services, and development of a plan to improve the response to crisis for people with autism and their family in Oklahoma.

**Oklahoma Plan Priority:** In Oklahoma all people with autism are safe and not are denied services. A seamless continuum of effective, integrated options for assistance, including crisis intervention, is available for every person across his or her lifespan.

Situation Statement: Crisis comes in many forms. Families do not have an integrated, seamless, continuum of options for assistance. Youth with ASD are ending up in the juvenile justice system. Adults with ASD may be lost in the corrections system. Mobile crisis teams are addressing the needs of youth in crisis but may lack training about the needs of children/youth/adults with ASD. School teams are struggling with placement for children with ASD and challenging behavior. Placement options often include OJA, self-contained, home-bound, alternative school. Children with ASD are being asked to leave some child care settings when they have engaged in challenging behavior. Emergency Room/medical personnel /hospitals are not addressing the needs of children/ adults in crisis. First responders (fire/police/EMT) need more information about recognizing individuals with ASD and de-escalating individuals with ASD in crisis. Prevention and de-escalation are the keys to crisis intervention. Last year community mental-health consultants served 112 licensed facilities in 29 counties. Seventeen childcare family homes requested services. A total of 1763 hours of services were delivered and this represented a 45 percent increase from the previous year. Avenues for training exist (Oklahoma Autism Network, Project Peak, Registry Training, others). Two training programs are no longer funded including Training Inclusive Childcare = Terrific Opportunities for Children (TIC-TOC) and Statewide Training and Regional Supports (for families and providers serving individuals with disabilities) programs. Current CLEET training exists but needs more information about responding to individuals with ASD. Dennis Debbaudt has training videos for police, fire and EMT.

#### **Impact**

- 1. Individuals with ASD will be able to safely function (work, play, learn, participate) in their environments/communities
- 2. The state will have a plan for tiered crisis intervention across the lifespan
- 3. Families will be able to stay together

### Crisis Intervention Committee

#### **Long-Term Outcomes**

- 1. Individuals with ASD will be educated and supported in the least restrictive environment.
- 2. Children with ASD and challenging behavior will be safely included in typical childcare environments.
- 3. First responders will appropriately address the needs of individuals with ASD in crisis.
- 4. Health systems will recognize and address the needs of individuals with ASD in crisis.

#### **Long-Term Outcomes**

- Service providers (private occupational therapist, speech-language pathologist, physical therapist, licensed professional counselor, psychologist) will provide support to individuals/families in crisis.
- 6. A continuum of options for crisis intervention will be available.
- 7. Families will access community based services that will support the family unit staying together.

#### **Short Term Outcomes**

- 1. Fewer children with ASD will have home-bound, self-contained, or residential school placements.
- School teams will receive training (increase knowledge/skill development) on how to support children with ASD in inclusive classroom settings including PBIS (skill development).
- Schools teams will receive technical assistance to support children with ASD in inclusive classroom settings.
- 4. Families will receive training/information about support strategies/PBIS along with the school teams.
- 5. Children with ASD will have the training/skills and support they need to function in inclusive classroom settings.
- 6. Childcare providers will have the knowledge and skills necessary to include children with ASD.
- 7. Families of typically developing children will be flexible and more tolerant.
- Childcare providers will receive technical assistance to support children with ASD in inclusive childcare settings.
- 9. Families will receive training/information about support strategies/PBIS along with the childcare teams.
- 10. Children with ASD will have the training/skills and support they need to function in inclusive childcare settings.
- 11. First responders will have a greater awareness of recognizing when a person has ASD.

### Crisis Intervention Committee

- 12. First responders will receive training / learn how to respond to a person with ASD in crisis.
- 13. Families will receive information about ways they can support the first responders (911 registry, fire decal on house, medication sticker on the car "Safe and Sound" program, ASA).
- 14. Community Mental Health Agencies (including mobile crisis teams) will have increased knowledge of the needs of individuals with ASD.
- 15. Health systems (hospitals/ERs) will recognize when they are serving individuals with ASD.
- 16. Health systems (hospitals/ERs) will understand the needs of individuals with ASD in crisis.
- 17. Healthcare systems will have guidelines/policies for serving individuals with ASD in crisis. (hospitals are governed by hospital boards).
- 18. Service providers will assist families to identify resources available for crisis intervention.
- 19. Service providers will increase knowledge of the crisis cycle and how to support and individual in crisis.
- 20. A continuum of options for crisis intervention will be identified.

#### **Activities**

- Oklahoma State Department of Education (OSDE) will identify the current numbers of children with ASD with home-bound, self-contained, or residential school placements.
- 2. OSDE will develop Seclusion and Restraint Guidelines.
  - a. OSDE will provide training on the Seclusion and Restraint Guidelines.
  - b. OSDE will provide training on non-crisis intervention for special education.
- 3. OSDE will have a Positive Behavior Intervention and Supports (PBIS) Coordinator.
  - a. OSDE will provide PBIS Team Training (Building Behavioral Expertise).
  - b. OSDE will provide for School-wide PBIS Teams (by Dr. Riffle).
  - Crisis Intervention committee to schedule meeting with OSDE PBIS Coordinator to discuss OSDE's vision for PBIS training for families.
- 4. Provide training to childcare providers on how to support children with

ASD in inclusive childcare settings, including PBIS.

- a. Crisis Intervention committee to schedule a meeting with OKDHS
   Child Care Licensing /Center for Early Childhood Professional
   Development to find out what are the avenues for training child care providers now that TIC-TOC and STARS are unfunded.
- Create and provide general public awareness program targeting parents of children developing typically to increase their awareness of the needs of children with ASD.
  - a. Crisis Intervention committee to identify if materials are available to disseminate to parents regarding response to challenging behavior PBIS.
- Child care licensing specialists will distribute brochures on about the Mental Health Consultation program to childcare providers.
  - a. Crisis Intervention committee to identify other avenues to distribute brochures on about the Mental Health Consultation program to childcare providers.
    - Child care providers will access Mental Health Consultation program.
- 7. Crisis Intervention committee to create and distribute information for first responders on recognizing and responding to individuals with ASD.
  - a. Project ALEC will provide training to fire fighters during May 2012.
- Crisis Intervention committee to create an "Emergency ID Card" for families.
  - a. Review existing materials
  - b. Disseminate on the okautism.org website (Oklahoma Autism Network)
  - c. Identify other avenues to disseminate the "Emergency ID Card"
- Crisis Intervention committee to develop one page fact sheet/folder for inclusion in the mobile crisis teams which could be included in the class materials.
- 10. Provide training for community mental health providers on ASD.
  - a. Crisis Intervention committee to develop a needs survey for Community Mental Health Providers (Systems of Care).
    - i. Create survey in Survey Monkey
    - ii. Submit survey for OKDMHSAS approval
    - iii. Disseminate survey through OKDMHSAS
    - iv. Coordinate with ODMHSAS to develop training to meet

the needs of Community Mental Health Providers (SOC)

- 11. Crisis Intervention committee to design single page "poster" for Emergency Room charting areas (ASD in the ER).
  - a. Review poster design by ER physicians/nurses
  - b. Print poster
  - c. Disseminate to ERs statewide
- 12. Crisis Intervention committee to develop a crisis intervention decision tree outlining a continuum of crisis intervention options.
  - a. Identify continuum of options of crisis intervention currently available
  - b. Develop needs survey for parents: What defines a crisis?
    - i. Create survey in Survey Monkey
    - ii. Distribute survey
  - c. Disseminate decision tree (911, 211, physicians)

# 2012 Priorities / Resources Needed

- 1. Training for child care providers
  - a. Collaboration with OKDHS Child Care Licensing /Center for Early Childhood Professional Development representatives
- Programs and organizations to disseminate the "Emergency ID Card" for families
- 3. Needs survey for community health providers (Systems of Care)
  - a. Collaboration with ODMHSAS
    - i. SOC Training Coordinator
    - ii. Approval of survey
    - iii. Dissemination of survey
- 4. Emergency Room poster (ASD in the ER)
  - a. ER physicians/nurses to review
  - b. Funding for printing
  - c. Means of dissemination
  - d. Funding for postage
- 5. Crisis Intervention Decision Tree
  - a. Dissemination of family needs survey
  - b. Dissemination of decision tree

#### **Progress**

1. OSDE reported data from the 2010 Child Count about placements for students under the Autism category. 1,048 students are in self-contained

classrooms, 18 are in residential placements, and 22 are home-bound. Note the count only represents students in the 6-21 age group and only the 3-5 year olds who are placed in a category only school for early childhood students. This does not reflect the number of children placed in the Developmental Delay/DD category who may be placed under the autism category at the age of 9. Currently 16,245 children 3-9 years old placed in DD.

- 2. OSDE reported the Seclusion and Restraint Guidelines developed and posted to their website January 2010.
  - a. OSDE provided training on the Seclusion and Restraint Guidelines at the 2010 Oklahoma Statewide Autism Conference and the 2010 Oklahoma Special Education Conference.
  - OSDE provided training on Positive Behavioral Interventions and Supports for 75 attendees at the 2011 OSDE Transportation Conference.
  - c. OSDE providing training on non-crisis intervention for special education
    - i. As of July 2011, 209 school districts have received CPI training resulting in 227 CPI trainers
    - ii. As of July 2011, 92 school districts have received Mandt training.
    - iii. OSDE provided four-day train the trainer CPI workshop January 24-27, 2012.
- 3. OSDE identified Karie Crews St. Yves as the PBIS Coordinator.
  - a. OSDE reported that from January 2010 thru July 2011, 83 of school districts participated in the PBIS Team Training (Building Behavioral Expertise)
  - b. OSDE reported that 62 of schools participated school-wide PBIS Teams (Dr. Riffle)
- Oklahoma Autism Network, during 2009 and 2010, provided training to 224 childcare providers on how to support children with ASD in inclusive childcare settings through the Training Inclusive Childcare = Terrific Opportunities for Children (TIC-TOC) program.
- Oklahoma Autism Network, during 2009 and 2010, provided training to 244 childcare providers on positive behavior supports through the TIC-TOC program.
- 6. OKDHS child care licensing specialists are distributing brochures about the Mental Health Consultation program at licensing monitoring visits when a need is identified and at Voucher Conferences.
  - a. OKDHS reported that during 2010, mental health consultants

delivered 847 consultations totaling 1,786 hours to 97 child care facilities in 24 counties (unknown how many of those are for children w/ ASD).

- 7. OKDMHSAS reported the one page fact/tip sheet for mobile crisis team is completed.
- 8. Oklahoma Autism Network provided training titled School Counselors: an essential piece of the autism puzzle for 45 community mental health providers at the 2010 Children's Behavioral Health Conference.

# Early Childhood Committee

**Committee Purpose:** The focus of the Oklahoma Combating Autism Leadership Team is to enhance state wide early identification and intervention efforts and service provision and coordination for young children with autism spectrum disorder (ASD) and related disabilities and their families.

**Oklahoma Plan Priority:** to expand services related to early identification of ASD, including screening and diagnosis, and expansion of early childhood intervention programs such as early intensive behavioral intervention and child care

Situation Statement: xxx

Impact	1. All children and adults with ASDs reach their full potential.
	2. Enhanced Oklahoma statewide coordinated infrastructure through the
	lifespan.
Long-Term and Short Term	1. Develop a broad based network of individuals that are qualified to provide
Outcomes	evidence-based services.
	2. Develop a broad based network of individuals that can provide training and technical assistance.
	3. Decreased interval between screening and treatment or services
	4. Systematic valid and reliable statewide screening process
	5. Increased access to quality diagnostic services
	6. Key stakeholders know one another and collaborate to develop and
	maintain coordinated service infrastructure Continuous efforts toward
	public education and awareness of ASD.
	7. Increased support and funding for programs
	8. Assure public policies support our goals and objectives.
	9. Centralized information infrastructure
Activities	Statewide effort to disseminate and incorporate Act Early campaign
	materials into public awareness/ child find activities and information across
	agencies and communities is ongoing.
	a. Tracking system for dissemination of Act Early materials
	b. Analyze data from tracking system to identify under-represented
	areas of the state
	2. Identify strategies to address personnel shortages and ongoing workforce
	development
	a. Partner with LEND interns and faculty to distribute Act Early

## Early Childhood Committee

materials and increase awareness of LEND interns

- 3. Regular meetings to coordinate efforts around CAAI
  - a. On-going maintenance Google Group communication system
- 4. Identify strategies to increase screening activities across the state.
  - a. SoonerStart providers receive training to administer the STAT (2<sup>nd</sup> Tier screener for autism).
  - b. Replicate Autism Center of Tulsa screening clinic in OKC.

# 2012 Priorities and Resources Needed

- 1. American Academy of Pediatrics
- 2. Center for Learning and Leadership / UCEDD, OUHSC
- 3. Child Care Resource Center
- 4. Child Study Center, OUHSC
- 5. Developmental Disabilities Council
- 6. Department of Education, SoonerStart (IDEA Part C)
- 7. Department of Health
- 8. Department of Human Services, Child Care Services and Licensing
- 9. Department of Human Services, Child Welfare
- 10. Department of Human Services, Developmental Disabilities Services
  Division
- 11. Department of Mental Health and Substance Abuse
- 12. Faith-based organizations
- 13. Family Organizations (i.e., Autism Center of Tulsa, Autism Oklahoma.Org, Oklahoma Family Network, EFFO)
- 14. Grants
- 15. Head Start and Early Head Start
- 16. LEND, Child Study Center, OUHSC
- 17. Local Education Agencies
- 18. Oklahoma Autism Network-OUHSC (OAN)
- 19. Private Foundations
- 20. Project PEAK, Child Study Center, OUHSC
- 21. PTI 211, OASIS, JOIN
- 22. Smart Start Communities
- 23. Sooner SUCCESS, Child Study Center, OUHSC

#### **Progress**

- Oklahoma Autism Network provided competency-based training on scoring and administration of the Screening Tool for Autism in Two-Year Olds (STAT) (2<sup>nd</sup> Tier screener for autism). Reliability is required for use.
  - a. 43 SoonerStart providers have attained reliability
  - b. 7 occupational therapy and physical therapy students

# Early Childhood Committee

participating in pediatric specialty coursework have attained reliability.

### Regional Supports and Access to Services Committee

**Committee Purpose:** The purpose of the Regional Supports and Access to Services Committee is to enhance access to services and supports across the lifespan for people with autism throughout the state. This includes working with service systems to increase the number of service providers in urban and rural areas, identifying various options for funding services for individuals and families, and improving the continuity of services between the various service systems.

Oklahoma Plan Priority: Regional Supports and Access to Services

**Situation Statement:** The Regional Education Service Centers (RESC) that were originally included in the Oklahoma Plan as the foundation for the development of regional hubs were closed in fiscal year 2004, and the system has not been replaced. Closure of the RESCs requires new plans for providing regional supports. The role of the RESC was to support local school districts with testing, resource materials, and assistive technology. Closure may have impacted school districts ability to identify and provide services, as well as resources for professionals and families. The Oklahoma State Department of Education continues to provide training and professional development, however current budget deficits impact attendance. State budget cuts are affecting service systems for training, recruitment and retention of professionals, and services. OSDE does provide reimbursement of some degree programs such as Board Certified Behavior Analysts, special education, and speech-language pathology to encourage students to be trained in these professions. High school transition and post-secondary educational opportunities continue to be very limited.

Access to services also includes a need for a continuum of services that addresses health needs, crisis intervention, and support in the home and community across the lifespan and across the autism spectrum. Access to primary care providers, therapists, dieticians, specialists and insurance coverage and payment of services needs to improve. Many families in rural areas are driving a considerable distance to access services in the OKC and Tulsa metro areas or the states larger communities that have services available, such as Duncan or Muskogee.

There are multiple organizations that are currently providing training for families, professionals, educators, physicians, students, and community organizations. However, there is still not enough training to meet the needs and availability of training is limited in rural areas of the state. Parents need better access to materials and resources such as books, videos, journal articles, and other materials either locally or regionally. Access to information electronically has improved considerably over the past several years, however this can also be limited in rural areas of the state where high speed internet is not available.

Oklahoma has an on-going dialogue about autism and needs with a broad range of agencies, families and other programs. State agencies have committees and/or projects focused on autism. However several of the agencies do not include individuals across the ASD spectrum due to eligibility criteria based on level of severity of disability. Currently approximately 15-20 parent-led organizations focused on autism exist in the state that are at varying levels of maturity and provide different supports based on each group. The Oklahoma legislature is engaged in addressing the needs of individuals with autism and their families through several

## Regional Supports and Access to Services Committee

interim studies and passage of several bills, including SB 2071, SB 135, SB 2045, SB3393 (teacher training, UCO BCBA certificate program, BCBA licensure, physician training, ABA pilot treatment project, replication of Early Foundations, scholarship program). Families and other key stakeholders continue to be engaged with the legislature to work towards further reform aimed at improving services for ASD. However there remains much to be done with regards to coordination of services, access to and availability of services, and access to multiple funding sources for intervention.

The emphasis remains on services / supports in the individual's community / region; however, the services / supports are lacking in many areas of the state.

### **Impact**

- 1. Oklahoma has a system of support and services for people with autism spectrum disorders and their families.
- 2. People with autism are safe.
- 3. Individuals with ASD are not denied services.
- 4. People with autism and their families are accepted and actively participate in their community.

### **Long-Term Outcomes**

- A statewide infrastructure is in place to provide a seamless continuum of effective, integrated options for timely and easily accessed assistance available for every person across his or her life span, and for their families and caregivers.
- 2. Professionals working with people with autism provide contemporary and effective services.
- 3. Individuals with ASD, families, and caregivers are provided effective support, training and technical assistance.
- 4. Students with autism receive an appropriate, individualized education based on current best practices (e.g., NRC, 2001; Dunlap et al., 2003).
- 5. Safe and time-effective substitute (e.g., child care, respite, day services) care is available for all ages.
- Oklahoma's system of support for people with autism and their families is monitored with oversight and grievance procedures that ensure accountability and effectiveness that will be regularly measured and reported. Family members are involved in this process.
- 7. Families access parent-led organizations, natural supports, and training opportunities within their community.

## APPENDIX B

## Regional Supports and Access to Services Committee

#### **Short Term Outcomes**

- Professionals who identify, diagnose, and provide services give comprehensive, standardized information to families and individuals with ASD based on current best practice guidelines.
- All service coordinators communicate and collaborate for continuity and continuum of care between systems.
- 3. Individuals and families in rural areas of the state have increased services and resources available to them within a reasonable distance from their home
- 4. Individuals with ASD and their families have flexibly-funded options available to pay for services.
- 5. Professionals (including all school personnel) working with people with autism learn about the most up-to-date evidence-based information specific to their discipline and are competent.
- 6. Families are aware of parent-led organizations, natural supports, and training opportunities within their community.
- 7. Students and parents know about IDEA and other laws, effective educational practices, and how to advocate effectively.
- 8. Substitute care providers are aware of existing incentives for providing care for individuals with ASD (e.g., DHS reimbursed rate, respite vouchers).

### **Activities**

- 1. Create a comprehensive, standardized Autism Guide about ASD and Oklahoma resources.
- 2. Identify service coordinators within existing services and how they function.
- 3. A workgroup, including service coordinators will create a technical assistance document to be used with the Autism Guide for service coordination for individuals with ASD.
- 4. Identify a source for updates of both the Guide and technical assistance documents.
- 5. Identify a method for ongoing communication between service coordinators (forum, SKYPE, webcasts, conference, existing groups, etc.).
- 6. Develop partnerships with rural community programs and professionals.
- 7. Provide and continue to expand on-line training through Oklahoma Autism Network, OUHSC including the Life first series, Navigating the World of Autism, and family life training series.
- 8. Implement ASD module through the SoonerStart web-based orientation.
- 9. Develop and implement the PDD-aide web-based orientation module for paraprofessional through Oklahoma Health Care Authority.

## Regional Supports and Access to Services Committee

- Provide professional development for educators and other professionals through Project Peak, Child Study Center, University of Oklahoma Health Sciences Center.
- 11. Provide professional development and family training through the Oklahoma Autism Network, OUHSC.
- 12. Provide family training and support through parent-led organizations.
- 13. Provide the Oklahoma Statewide Autism Conference coordinated through the Oklahoma Autism Network, OUHSC with assistance from a steering committee that includes families, agencies, and community organizations.
- 14. Provide physician training to evaluate children with autism through SoonerSUCCESS, Child Study Center, University of Oklahoma Health Sciences Center
- 15. Work with the OHCA to recognize board certified behavior analysts as licensed providers and create a mechanism for reimbursement of their services
- 16. Work with the legislature to identify other options for funding therapy for individuals with autism, including consideration of an insurance mandate such as those passed by neighboring states.
- 17. Identify additional members to participate on the committee and assist in achieving the identified goals and creating new goals as needed.

# 2012 Priorities/Resources Needed

- 1. Complete development of the comprehensive, standardized autism guide.
  - a. Input needed from Oklahoma State Department of Education, Department of Rehabilitation Services, Developmental Disabilities Services Division.
  - b. Identify group to review document and provide feedback.
  - c. Identify group to assist in dissemination of document.
- 2. Identify and invite additional members needed for committee.
- 3. Identify additional priorities and outcomes needed.

### **Progress**

- 1. A rough draft of the comprehensive, standardized autism guide is in process with additional information that needs to be gathered and incorporated into the document before a final proof is ready for review.
- 2. The availability of on-line training continues to increase, through the Oklahoma Autism Network Life First training, along with other programs such as the Autism Internet Modules.
- 3. Project Peak continues to offer training for educators, paraprofessionals, and other related services providers.
- 4. The Oklahoma Autism Network continues to provide training for parents

## Regional Supports and Access to Services Committee

- and professionals (visit okautism.org for training calendar).
- 5. Parent-led organizations offer access to resources and other information within their communities. Many of the parent-led organizations collaborate with local professionals to offer training to families.
- The Oklahoma Statewide Autism Conference has been held for three years in a row, with over 500 attendees each year and presentations on a variety of evidence-based topics. The fourth annual conference is scheduled for October 2012.
- SoonerSUCCESS at the Child Study Center, University of Oklahoma Health Sciences Center has provided the STAT-MD training to 30 physicians, with approximately 15 who have completed reliability.

**Committee Purpose:** The focus of the secondary transition and adult life committee is to expand and enhance the services and supports available to assure people with autism have options and experience success as adults.

**Oklahoma Plan Priority:** Improve the transition education and processes across the state to achieve meaningful post-school outcomes.

**Situation Statement:** Employers/businesses need to be open to including people with autism spectrum disorder so need supports to understand liability, help with fear, bring about attitude change and create community awareness. Education needs to translate into employment; need higher education and career counselors to work together for employment placement. School systems are system driven and need to be person driven, based on the interests, strengths, and skills of the student. Persons in key state leadership positions need to be identified to advocate for the needs of the autism spectrum disorder community.

#### **Impact**

- 1. Each person with autism spectrum disorder resides in the least restrictive setting capable of providing that individual with consistent safety, security and maximum independence.
- People with autism spectrum disorder will gain employment or meaningful activities that match their interests and skills along with the needed supports.
- 3. People with autism spectrum disorder and their families are fully accepted and actively participate in their community network, interacting naturally with their friends, neighbors, co-workers, and other supports.
- 4. All professionals working with people with autism spectrum disorder are competent, educated to provide contemporary and effective services and receive ongoing professional development which is based on the most upto-date evidence-based information.
- Every person with autism spectrum disorder receives an appropriate, individualized education which assures that he or she masters the skills necessary for further education including enrollment and completion of post-secondary education to achieve his or her personal goals.

### **Long-Term Outcomes**

- 1. Key legislators become champions for post-secondary transition outcomes and the autism spectrum disorder community.
- 2. Quality school based transition education programs throughout the state
- 3. Quality transition education programs in Oklahoma's post-secondary education system
- 4. Individuals with autism spectrum disorder employed in jobs that match their interests and skills.
- 5. Individuals with autism spectrum disorder living and having fun doing what they want and wish in the community of their choice with those who care about them
- 6. Individuals with autism spectrum disorder understand their strengths and needs
- 7. Individuals with autism spectrum disorder have increased selfdetermination skills.

#### **Short Term Outcomes**

- 1. Individuals with autism spectrum disorder know their strengths and needs relevant to their disability.
- 2. Individuals with autism spectrum disorder have self-determination skills.

### Activities

- Provide professional development about secondary transition for individuals with ASD, including teaching students about self-determination, and self-advocacy.
  - a. Oklahoma Autism Network
  - b. Oklahoma Department of Rehabilitation Services
  - c. Oklahoma Statewide Autism Conference
  - d. Oklahoma Transition Institute
  - e. Zarrow Center
- 2. Develop plan for increasing family / parental involvement in secondary transition
- University of Central Oklahoma, AutismOklahoma, Oklahoma Autism
  Network, and others to design and implement a pilot college orientation
  program for high-school students and young adults interested in
  attending college.
- 4. Department of Rehabilitation Services, Goodwill Industries, Inc. and Tulsa Public Schools to design and implement an autism work study program for students with ASD.
  - a. Provide training about ASD
- 5. Engage with the Oklahoma Transition Council and their activities
  - a. Establish post-secondary goals with focus on social needs

- 6. Identify how the needs of individuals with ASD are different from those with other disabilities in terms of employment, health, housing, post-secondary education, relationships, and supports and services
- 7. Identify needs of educators and services providers
  - a. Identify committee members
  - b. Look at existing programs needs assessments, evaluations, etc.
  - c. Develop needs survey
  - d. Disseminate survey
- 8. Identify needs of providers in Department of Rehabilitation Services to work with and help individuals with ASD
  - a. Develop interview for focus groups or needs survey
  - b. Conduct focus groups or disseminate survey

# 2012 Priorities / Resources Needed

- 1. Expand committee membership.
  - a. Commitment from adults with ASD, Autism Center of Tulsa, Bee's Knees coordinator, college / university disability coordinator, Development Disabilities Foundation, TARC, Wings, OKDHS-Aging, OKDHS-Developmental Disabilities Services Division
- 2. Identify 2012 priorities and resources needed.

## **Progress**

- Several programs provided professional development about secondary transition for individuals with ASD, including teaching students about selfdetermination, and self-advocacy.
  - Oklahoma Autism Network provided training on Supporting Individuals with ASD in Employment for 32 providers at the Career Tech Summer Conference, Tulsa, OK
  - b. Department of Rehabilitation Services provided a one-day training on autism and transition in March 2011 for 130 providers.
  - c. Oklahoma Autism Network reported that Oklahoma Statewide Autism Conference included sessions focused on secondary transition and adult life during 2009, 2010, and 2011. Each conference had over 500 participants. Two keynote speakers provided their personal perspectives of being an individual with ASD and shared needs, supports, and successes. During 2010, Peter F. Gerhardt, Ed.D. Director of Education, Upper School for the McCarton School, New York City; President & Chair, Scientific Council Organization for Autism Research was a featured keynote sharing evidence-based research and practices about secondary transition and adult life.

- d. Oklahoma Transition Institute included sessions on supporting individuals with autism at the 2010 and 2011 conferences.
- e. Zarrow Center posted transition education materials on their website http://www.ou.edu/content/education/centers-and-partnerships/zarrow/trasition-education-materials.html.
- 2. University of Central Oklahoma, AutismOklahoma, Oklahoma Autism Network, and others designed and implemented the Summer Advance: Get Ready for College in June 2011. A college experience at UCO was offered to young adults with autism interested in attending college. The experience featured 7 young adults, a 2-night stay in college dorms, and 3 days of orientation information and social activities. Additionally, parents of the participating young adults were provided with valuable information in regard to assisting their young adults transition into a college lifestyle.
- Department of Rehabilitation Services, Goodwill Industries, Inc. and Tulsa Public Schools designed and implemented an autism work study program for students with ASD.
  - a. The Oklahoma Autism Network provided training about ASD for 15 Goodwill Industries' staff in August 2011.

## Oklahoma Services and Supports

### **Community Providers**

Many providers in Oklahoma serve individuals with autism spectrum disorder. Please visit <a href="www.okautism.org">www.okautism.org</a> and <a href="http://www.autismtulsa.org">http://www.autismtulsa.org</a> for a list of providers in Oklahoma that have indicated that they specialize or have expertise in serving individuals with autism spectrum disorders.

## Early Foundations: Autism Model and Outreach Project

Early Foundations: Autism Model and Outreach Project began in October of 2007. Early Foundations is a program designed to provide a model of intervention for the very youngest children with ASD and their families in the state. This model program is a collaborative project between the OSDE, SoonerStart and the Department of Pediatrics, Child Study Center at the Health Sciences Center. The purpose of this unique project for toddlers with ASD is to address the importance of early, intensive intervention as soon as a child receives a diagnosis and to provide these includes access to typical peers and typical childhood activities. In addition to developing an effective model, Early Foundations is intended to provide replication and outreach support to assist other communities in our state in developing a program with the recommended program components.

### **Good Shepherd Catholic School at Mercy**

#### http://www.mercy.net/oklahomacityok/newsroom/2011-11-11/school-for-autism-blessed

Development and implementation of a school designed to serve children with autism has been accomplished through a partnership of the University of Central Oklahoma, Mercy Health Center, and the Archdiocese School System. The school serves as a training site for future board certified behavior analysts and as a site for children whose parents feel their child needs intensive educational and behavioral services. The school will serve as a model program demonstrating how to implement applied behavior analysis (ABA) in an educational setting. The school is open 11 months of the year, and schools can send teachers or aides to learn, in an applied environment, how to incorporate ABA as part of the Individualized Education Program outlining special education and related services each child receives.

#### **LINK Project**

## http://www.csctulsa.org/content.php?p=117, http://www.autismtulsa.org/index.cfm?id=153

The Autism Center of Tulsa and the Child Care Resource Center LINK Project collaborates to offer free screenings once a month for autism, developmental, speech and hearing. The screenings are provided by trained professionals. The service is available to families with concerns about the development of their children from birth to 6 years of age.

## Oklahoma Services and Supports

### **Oklahoma Assistive Technology Center**

### http://www.ouhsc.edu/oatc/

The Oklahoma Assistive Technology Center (OATC) is dedicated to providing quality assistive technology services to Oklahoman's with disabilities and their families; to providing professional and community education and technical assistance; and to research. In meeting the needs of Oklahoman's with disabilities, the personnel of OATC employ a philosophy of "people first" and "contemporary practices" in habilitation and rehabilitation. Services provided are intended to assist individuals to participate fully in their own communities in the most cost-effective and timely manner possible. Services provided are age-appropriate, scientifically sound, and are designed to result in functional outcomes meaningful to the person and the person's family or caregivers. These services are intended to meet the high quality assurance standards. OATC personnel are committed to education and training for professionals who serve individuals with disabilities, as well as the individual themselves and their families. OATC also provides education and training for colleges and universities, and for public and private agencies. OATC personnel also are committed to research designed to evaluate the outcomes of assistive technology and the cost benefit of the technology services, and to expand knowledge in the application of assistive technology.

#### **Oklahoma Autism Network**

## http://www.okautism.org/

The Oklahoma Autism Network is a center of excellence committed to improving quality of life for individuals with autism and their families. They facilitate and implement Oklahoma's Statewide Autism Plan through research, education, and service while respecting individual preferences and promoting community inclusion. The Oklahoma Autism Network was established in October 2003 as a statewide administrative unit to facilitate the planning, financing and administration of the various recommendations of the Individuals with Autism and Their Families: Oklahoma Plan. They convened the Oklahoma Family and Interagency Autism Council during 2009 with membership from state agencies, families, non-profits, communities, and businesses. The network supports individuals across the full autism spectrum from diagnosis through adulthood. Activities include: 1) serving as the state's information and referral system providing evidence-based information through our toll-free telephone line, a comprehensive website, and trainings and technical assistance to families and professionals; 2) supporting parent-led and community organizations across the state; 3) collaborating with state agencies to understand needs and to provide expertise in assessment, program planning, and intervention for individuals with autism spectrum disorders across the lifespan; 4) coordinating activities with other groups and programs focused on Autism Spectrum Disorders so as to maximize the limited resources in the state versus duplicating programs and services; 5) bringing professionals from the private and public sector together through the coordination of the Oklahoma City Professional Autism Coalition and collaboration with the Tulsa Professional Autism Network; and 6) developing and implementing research such as the ConnectedKids: Applied Behavior Analysis Research Project outlined in Senate Bill 135.

## Oklahoma Services and Supports

The program is sponsored by the Tolbert Center for Developmental Disabilities at the University of Oklahoma Health Sciences Center and funded by the Oklahoma State Department of Education, Special Education Services and the Oklahoma Department of Human Services, Developmental Disabilities Services Division.

## **Oklahoma Combating Autism Leadership Team**

Originally called the Act Early Summit team, the Oklahoma Combating Autism Leadership Team is a state team initiated by the Centers for Disease Control, National Center on Birth Defects and Developmental Disabilities that includes key stakeholders including state agencies, parents, physicians, and service providers. The focus of the team is to enhance state wide early identification and intervention efforts and service provision and coordination for young children with autism spectrum disorder (ASD) and related disabilities and their families. The team also serves as the Early Childhood Committee of the Oklahoma Family and Interagency Autism Council.

#### Oklahoma Department of Human Services, Childcare Division

http://www.okdhs.org/divisionsoffices/visd/dcc/

Oklahoma Child Care Services (OCCS) has the responsibility of making sure Oklahoma's children and their parents have access to licensed, affordable, high-quality child care where children have the opportunity to develop to their fullest potential in a safe, healthy and nurturing environment.

## Oklahoma Department of Human Services, Developmental Disabilities Services Division

http://www.okdhs.org/divisionsoffices/visd/ddsd/

The mission of the Oklahoma Department of Human Services, Developmental Disabilities Services Division is to help individuals and families in need help themselves lead safer, healthier, more independent and productive lives. DDSD provides services to persons ages 3 and older who have an intellectual disability (IQ of 70 or below). Persons served may also have other developmental or physical disabilities. OKDHS Developmental Disabilities Services Division (DDSD) consists of the State Office in Oklahoma City, the Area I office in Oklahoma City and a satellite office in Enid, the Area II office in Tulsa, and the Area III office in Pauls Valley. The state office staff provides direction and support to the area offices through program and policy developmental and over-sight.

#### Oklahoma Department of Mental Health and Substance Abuse

http://www.ok.gov/odmhsas/

The mission of the Oklahoma Department of Mental Health and Substance Abuse Services is to promote healthy communities and provide the highest quality care to enhance the well-being of all Oklahomans. Services available through the Oklahoma Department of Mental Health and Substance Abuse Services will promote productive lifestyles and set the national standard for prevention, treatment, and recovery for those affected by mental illnesses, substance abuse disorders, and domestic and sexual violence.

## Oklahoma Services and Supports

### **Oklahoma Department of Rehabilitation Services**

### http://www.okrehab.org/org/index.htm

The Oklahoma Department of Rehabilitation Services (DRS) expands opportunities for employment, independent life and economic self-sufficiency by helping Oklahomans with disabilities bridge barriers to success in the workplace, school and at home. Some of the divisions include: 1) Division of Vocational Rehabilitation (DVR): employment services for people with any disability, except blindness; 2) Division of Visual Services (DVS): employment and independent living services for people who are blind or visually impaired; 3) Disability Determination Division: Determines medical eligibility for Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI), 4) Oklahoma School for the Deaf: educational programs for children who are deaf or hard of hearing; 5) Oklahoma School for the Blind: educational programs for children who are blind or visually impaired; and 6) OK Library for the Blind and Physically Handicapped: Free services to Oklahomans who are blind or visually impaired and those with learning disabilities or physical limitations that make it difficult to use standard print.

DRS have partnered with Goodwill Industries, Inc. and Tulsa Public Schools to develop and implement an autism work study pilot program. DRS also facilitate partnerships between private and public organizations to implement Project SEARCH. Currently, five Project Search exist in Oklahoma including: 1) St. John Medical Center and Jenks Public Schools; 2) Valley View Regional Hospital and Byng Public Schools; 3) INTEGRIS Bass Baptist Health Center and Enid Public Schools; 4) Chesapeake Energy Corporation and Metro Technology Centers; and 5) Mercy Health System and Francis Tuttle Technology Center. Project SEARCH is dedicated to providing education and training to young adults with intellectual and developmental disabilities through an innovative workforce and career development model that benefits the individual, workplace, and community. The primary goal is to secure competitive employment outcomes for each of the student graduates.

## **Oklahoma Early Access Autism Project**

## http://earlyaccessok.org/

The goal of the Oklahoma Early Access Autism project is to provide and promote autism awareness and early detection of autism spectrum disorders. Early Access seeks to reach underserved populations who may not have access to traditional developmental screening services by partner with local communities throughout the state to offer free autism screening and awareness. Early Access is family oriented and is designed to provide services, resources, and an environment tailored to the needs of each child, family, and community. The Oklahoma Early Access Autism Project is a service of the OUHSC, Child Study Center, funded in part through a contract with the Oklahoma Developmental Disabilities Council. We work together with child and social services, local schools, and community organizations as well as partners with the autism community

## Oklahoma Services and Supports

#### Oklahoma Family Network (OFN)

### http://www.oklahomafamilynetwork.org/

The Oklahoma Family Network (OFN) Family-to-Family Health Information Center informs and connects individuals with special health care needs and disabilities, their families and professionals to services and supports in their communities. OFN provides opportunities for individuals and families to strengthen their communities through leadership development and volunteering. The OFN Mentorship Program is the flagship program of the center. Families may receive connections to: parent-to-parent support, support groups, support in navigating the maze of health care and other supports in the community, and opportunities to strengthen the community through leadership development and volunteering.

### Oklahoma Health Care Authority, Autism Workgroup

The Oklahoma Health Care Authority in collaboration with the Oklahoma Department of Human Services – Developmental Disabilities Service Division, the Oklahoma Autism Network, Oklahoma Department of Education – Special Education Services, the University of Central Oklahoma, the Child Study Center and parents are investigating the options for expanding Medicaid coverage for services related to autism including behavioral therapy.

#### **Oklahoma Professional Autism Coalition**

### http://www.okautism.org/professionals/opac.asp

Oklahoma Professional Autism Coalition is coordinated by the Oklahoma Autism Network and brings professionals in the Oklahoma City metro together to share information, network, and learn about resources.

### Oklahoma State Department of Education, Local Education Agencies

## http://sde.state.ok.us/Default.aspx

The mission at the Oklahoma State Department of Education is to improve student success through: service to schools, parents and students; leadership for education reform; and regulation/deregulation of state and federal laws to provide accountability while removing any barriers to student success. By working with parents, business/community leaders, and CareerTech and higher education officials, the State Department of Education (SDE) puts state education policies and programs into action to support the efforts of public schools. The SDE's vision is to make children Oklahoma's top priority through the Department's mission of: 1) quality services to students, schools and communities; 2) leadership for education reform and school improvement; and 3) regulatory flexibility focused on accountability and improving student success.

Each local school district provides special education services to students (3-21 years) who are eligible. For a directory visit: http://sde.state.ok.us/Services/Directory/oklaschools.html

## Oklahoma Services and Supports

#### Oklahoma State Department of Education, SoonerStart Early Intervention

http://sde.state.ok.us/Curriculum/SpecEd/SoonerStart.html

The mission of the SoonerStart Early Intervention Program is to use an individualized, comprehensive, coordinated system of services and supports to enhance the abilities of Oklahoma infants and toddlers with disabilities and developmental delays and strengthen the capacity of their families to support their development. The Oklahoma State Department of Education is the lead agency. During November 2008, SoonerStart implemented policies and procedures for autism screening of children 18 months and older.

### **Parent-led Organizations**

See appendix D

### Programming and Evaluation for Kids with Autism (Project PEAK)

http://www.oumedicine.com/body.cfm?id=1545

Autism Support Services are provided through a collaborative effort of the Child Study Center and the Oklahoma State Department of Education. Project PEAK is a training and support network for educating children (age 3 through 21 years) with Autism Spectrum Disorders, which 1) coordinates with existing professional development and technical assistance programs; 2) supports local efforts to build capacity within school districts; 3) employs evidence-based/research-based practices; and 4) partners with local parent support groups. Services include training, technical assistance, on-site collaborative consultation, mentoring, coaching and demonstration teaching, information dissemination, program evaluation and quality assurance, and links to educators and professionals from other disciplines.

## Rose Rock Academy, a program of Sequel Youth and Family Services

http://www.sequelyouthservices.com/html/autism-roserock.html

Rose Rock Academy, formally known as Camelot of Oklahoma, was established in April 2007 as a residential treatment facility for children diagnosed with Autism or any diagnosis on the Autism Spectrum. With a licensed capacity of 51 residents, Rose Rock Academy is a Joint Commission accredited program. They offer 1:1 resident-staff ratio when needed (standard ratio is 1:2, not to exceed 1:3). RNs and LPNs provide 24-hour nursing care.

Rose Rock Academy is tailored for children/adolescents with special needs that are best met in a highly structured environment with 24-hour care. Rose Rock Academy provides therapy and academic instruction for children and adolescents ages 5 to 17 with a diagnosis of Autism or disorders on the Autism Spectrum. Residents typically demonstrate impairment in socialization, communication and restricted repetitive behaviors. These symptoms are intrusive and severe enough that management and treatment in a residential treatment setting is necessary. A resident must be medically stable.

## Oklahoma Services and Supports

#### **Shadow Mountain Behavioral Health System**

### http://www.shadowmountainbhs.com/

Shadow Mountain Behavioral Health System is a psychiatric hospital offering a comprehensive continuum of behavioral healthcare services, including acute, residential, therapeutic foster care, school-based, and outpatient programs for children, adolescents and their families. Shadow Mountain Behavioral Health System provides treatment for a wide variety of psychiatric disorders in a safe, secure, and nurturing environment. Other services include neurological evaluation, psychological evaluation, speech and language assessments, medical history, physical examination, medication management, dietary consultation, and an individualized treatment plan.

#### SoonerSUCCESS

### http://www.oumedicine.com/body.cfm?id=1517

SoonerSUCCESS provides support to families of children or youth with a developmental disability, mental health need, chronic health care need, or abuse/neglect issues. SoonerSUCCESS provides assistance to families in accessing services and supports through county coordinators currently located in nine Oklahoma counties.

### Summer Advance: Get Ready for College

## http://www.autismoklahoma.org

In 2010, a college experience at the University of Central Oklahoma was offered to young adults with autism interested in attending college. The experience featured 7 young adults, a 2-night stay in college dorms, and 3 days packed full of orientation information and social activities. Additionally, parents of the participating young adults were provided with valuable information in regard to assisting their young adult's transition into a college lifestyle.

## **Teacher Registry Project**

http://sde.state.ok.us/Curriculum/SpecEd/Training\_Registry.html, http://www.ouhsc.edu/thecenter/education/education.html

The Special Education Teacher Registry is a training project funded by the Oklahoma State Department of Education and coordinated by The Center for Learning and Leadership/UCEDD. Registry training was created as a mechanism to provide approved training in federal criteria areas for which no special education certification exists. These federal criteria areas include: Autism, Traumatic Brain Injury (TBI), Multiple Disabilities, and Deaf/blindness. Thirty-two-hour trainings have been developed and are coordinated by The Center for Learning and Leadership, OUHSC. Other entities may be approved to offer training by completing an application approval process. Registry trainings are designed to expand special education professionals' knowledge and skills. All training includes the following components: 1) a common base of knowledge regarding the disability or condition; 2) appropriate and effective evaluation and assessment practices; 3) key issues in educational programming; 4) functional curriculum, adaptations and accommodations; 5) information about state and

## Oklahoma Services and Supports

national resources available for this population; 6) information about coordinating with other professionals and families in planning the most appropriate and meaningful service plan for these children.

#### **Tulsa Professional Autism Network**

http://www.autismtulsa.org/index.cfm?id=134

Tulsa Professional Autism Network is coordinated by the Tulsa ARC and the Autism Center for Tulsa and brings professionals in Tulsa metro together to share information, network, and learn about resources.

### University of Central Oklahoma, BCBA program

http://www.uco.edu/ceps/dept/psy/psychology-ma.asp

The University of Central Oklahoma has established a training program for the treatment of autism. Students completing the program can become board-certified behavior analysts specializing in autism. The Behavior Analyst Certification Board, Inc. has approved the coursework requirements for eligibility to take the Board Certified Behavior Analyst Examination. Applicants must meet additional requirements to qualify. In addition to the course sequence and passing the national exam, successful completion of 1600 clock hour supervised internship is required. This course sequence is available only to those with earned Master's Degrees in related fields or those currently enrolled in Master's Degree programs in related fields.

#### University of Oklahoma, Zarrow Center for Learning Enrichment

http://www.ou.edu/content/education/centers-and-partnerships/zarrow.html?rd=1

The Zarrow Center for Learning Enrichment facilitates successful secondary and postsecondary educational, vocational and personal outcomes for students and adults with disabilities. ZC faculty, staff, and students do this through self-determination oriented evaluation, research, development, transition education instruction, and dissemination of best educational and support practices. The ZC also prepares undergraduate and graduate students to assume leadership roles in schools, universities, and support organizations.

## Oklahoma Parent-Led Organizations

### A New Hope-Autism and Related Disabilities Support Group

#### anewhope4autism@yahoo.com

They meet in Tahlequah on the second Thursday of each month, 6:00 PM – 7:30 PM, at the Tahlequah National Guard Center, 100 South Phoenix Ave. Childcare is provided.

## **Autism and Special Needs Support Group**

### jamesmom92@yahoo.com

Meets every third Monday of the month from 7-9 P.M. at the Alva Public Library.

### AutismCanadianValley.org

### http://autismoklahoma.org/CanadianValley

This support group is for parents of children that have Autism spectrum disorders in the Yukon, Mustang, El Reno and Bethany area. They meet the first Tuesday of each month, 7:00 pm – 9:00 pm, at Church of Christ South Yukon, 11700 NW 10th Street, Yukon, OK 73099. Childcare is provided.

#### Autism Center of Tulsa, Inc.

#### http://www.autismtulsa.org/

The Autism Center of Tulsa focuses on providing programming that supports its mission in a variety of ways, including community awareness and outreach, early screening and intervention, safety, parent and professional information and training as well as family support and on-site resources. Their offices are located in the William Medical Building at the NE corner of the traffic light at 66th Street and Yale Avenue.

Regular office hours: Monday - Friday 10am - 2pm. Additional office hours are available by appointment.

#### AutismEdmond.org

### http://autismoklahoma.org/AutismEdmond

Supporting families affected by autism since May 2002. They serve approximately 300 families in the Edmond and NW Oklahoma City areas and offer activities for the entire family. They have child care from babies to teens (See their website for details). Teens can enjoy their Teen 2 Teen group monthly that enhances peer interaction through arts, crafts, movies, recreation activities, etc. Their adult "Friends" on the spectrum group is just for those looking for a time with peers learning together and having fun. They meet the second Tuesday of each month, 6:30 pm – 8:30 pm at the First Presbyterian Church located in Edmond at 1001 S. Rankin.

## Oklahoma Parent-Led Organizations

### AutismMuskogee.org

### http://autismoklahoma.org/AutismMuskogee

Meets the 2nd Monday of each month at 7:00pm at Muskogee First Church of the Nazarene, 2700 E. Peak Blvd. Muskogee, OK, 74403

## AutismOKC.org

### http://autismoklahoma.org/AutismOKC

Dedicated to the education and welfare of all people with autism and other pervasive developmental disorders they help and support people with autism and their families. They meet the 4th Thursday of each month at St. Luke's United Methodist Church, 222 NW 15<sup>th</sup>, Oklahoma City, OK. Childcare for meetings is available.

### AutismOklahoma.org

### http://autismoklahoma.org/

AutismOklahoma.org is a 501c3 charitable organization that supports families affected by autism. The organization is 100% dependent upon donations. Their dream is to create a substantial and positive impact for families affected by autism in the state of Oklahoma and to bring hope, empower our kids, and help Oklahoma become more autism-friendly and aware! They want every person and family affected by autism to have the opportunity to reach their potential and do great things!

AutismOklahoma.org started in 2002 in Edmond, Oklahoma and today they have five parent support groups throughout Oklahoma, an annual PieceWalk & 5K, summer camps, Bees Knees, college, teen, and adult groups as well as many more community events and social opportunities. Their website, e-newsletters, social media, and our mascot Dash provide ways for them to reach out and connect with each other and with the community.

### AutismStillwater.org

#### http://autismoklahoma.org/AutismStillwater

Monthly meetings are every 3rd Tuesday, 6:30pm - 8:00pm. Childcare/Respite provided.

#### **Biomedical Intervention Group (BIG)**

#### bigofokc@yahoogroups.com

For families interested in or currently providing biomedical and dietary interventions for their child on the spectrum including but not limited to DAN! and Yasko protocols. Families can share stories and provide support to one another.

## Oklahoma Parent-Led Organizations

#### Circle Time of Ada

#### www.circletimeofada.com

Circle Time of Ada meets every first Tuesday of the month from 6-8 P.M. at the Glenwood Early Childhood Center on west main in Ada. The meetings are open to all SE Oklahoma families. They welcome anyone wanting to learn more about autism spectrum disorders or have special needs children. Childcare provided. Contact: Lori Gray at (580)-320-4061 or (580)-436-4060.

### **Parents Fighting Autism**

### parentsfightingautism@gmail.com

This group provides encouragement and support for parents considering or doing biomedical treatments for their children on the autism spectrum. They discuss special diets, supplements, interventions and therapies. Meetings are typically held the 3rd Monday of the month at 7pm at the Olive Garden in Norman.

#### **Piedmont Parent Advocates**

### piedmontparentadvocates@yahoo.com

Meets the 2nd Thursday of each month from 6-8 p.m. at Piedmont 1st United Methodist Church, 2525 Piedmont Road. This group is dedicated to providing parents of children with special educational needs and/or disabilities with the knowledge and tools needed to help their child succeed in their educational goals. They also have a Facebook page and offer childcare during their meetings.

#### **Support & Networking Group For Moms**

This is a group made for moms of children with Asperger's Syndrome to network with each other and to mentor with ideas as well as find help in the Tulsa area. A topic-oriented group (each month brings a new topic) with occasional speakers/professionals to talk to the group. Meetings are held on the first Thursday each month from 7-9 P.M. at Asbury United Methodist Church, 6707 S. Mingo Road Room 1506, Tulsa, OK. Contact: Jonni Segnar at (918) 798-2379

# Oklahoma Parent-Led Organizations

## **Supporting the Pieces**

supportingthepieces@gmail.com

Meets the third Thursday of every month from 6:30-7:30 pm at Christ United Methodist Church, 2418 W. Randolph, Enid, OK (The Pumpkin Patch Church).

## Vinita Autism Support Network

buckallewfam@aol.com

This group meets at Helping Hands Daycare, 570 South Fifth Street, and is open to any person needing support regarding special needs.

## **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