



Arkansas Legislative Task Force On Autism

FINAL REPORT

August 29, 2008

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Task Force Membership

Non-Legislative Members

Dianna Varady, Chairman
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Mary Carol Roach - Committee Staff member
Gina Mercer - Secretary

Final Report: Arkansas Legislative Task Force On Autism

Executive Summary

According to the Autism Society of America, Autism is a complex developmental disability that typically appears during the first three years of life and affects a person's ability to communicate and interact with others. Autism is defined by a certain set of behaviors and is a "spectrum disorder" in that it affects individuals differently and to varying degrees. Autism spectrum disorders include autistic disorder, Asperger's syndrome, childhood disintegrative disorder, Rett Syndrome, and pervasive developmental disorder not otherwise specified (PDD-NOS), but for the purposes of this report, all autism spectrum disorders will furthermore collectively be referred to as "autism". There is no known single cause for autism, but increased awareness and funding can help families today. The Arkansas Legislative Task Force on Autism was created with the passage of Act 1016 of 2007, sponsored by Representative David Johnson from District 38. The Task Force was charged with examining how the state of Arkansas responds to autism and to accomplish the following:

- Determine best practices to treat autism spectrum disorders.
- Recommend more efficient methods for treatment of autism spectrum disorders.
- Recommend how to obtain more federal funds for treating autism spectrum disorders.
- Recommend to the General Assembly specific changes to the law that will improve the treatment and special education of children with autism spectrum disorders.

Task Force Process

The task force consists of seventeen volunteer citizens, including parents of individuals with autism, service providers to individuals with autism, and state agency officials charged with developing the infrastructure necessary to assist individuals and families living with autism. There were fifteen voting members and two ex-officio members. The task force began holding monthly meetings in 2007, the first of which was held on August 30th.

In Arkansas, the age of an individual who has autism in part determines what services that individual may receive and which state agencies are responsible for providing these services. For these reasons, the task force created four subcommittees based on the age of the individual being served. These subcommittees were 0-3 years, 3-10 years, 11-21 years, and 22 years and older. Each subcommittee began working with the same goals as provided within the original legislation

Task Force Findings

The prevalence of autism has been on a dramatic and steady rise over the last 20 years, both nationally and in Arkansas, and the Autism Society of America reports in the 2008 State Autism Profiles that autism is the fastest growing developmental disability in the world¹. A 2004 report examining prevalence in Arkansas using data from the Individuals with Disabilities Education Act (IDEA) found that the number of children identified with an autism spectrum disorder skyrocketed from 88 in 1993 to 1114 in 2003² (figure 1), an increase of 2319%³ (figure 2). In 2007 the Centers for Disease Control and Prevention (CDC) released a report that found that the prevalence of autism in Arkansas is 1 in 145 children, with 1 in every 93 boys and 1 in every 345 girls identified as having an autism spectrum disorder (figure 3)⁴. This rate is somewhat higher than the national rate of 1 in 150, and among the 14 states participating in the CDC study Arkansas had the 4th highest prevalence rate. The Autism Society of America reports that autism is growing at a rate of ten to seventeen percent annually, and is four times more prevalent in boys than in girls⁵. While this increase may to some degree be due to changes in identification and classification of autism spectrum disorder, most experts agree that this factor alone could not account for the dramatic increase in prevalence over the last two decades.

The range and intensity of services and supports to enable individuals with autism to prepare for, survive, and thrive in life are simply not present across Arkansas. An increase in the level of support and services provided for individuals and families living with autism is imperative. One result of the lack of services available within Arkansas is that families are sometimes forced to seek placement and services in other states, and if the family is Medicaid eligible, Arkansas pays an even higher cost for this lack of services by sending Medicaid dollars to out-of-state service providers. These funds could be invested in building a system in Arkansas for Arkansas families. Intensive, early intervention that develops communication skills and pro-social behaviors in people with autism can avert the crisis that comes when communication skills have not been developed and frustration reaches the breaking point, resulting in extreme forms of behavior.

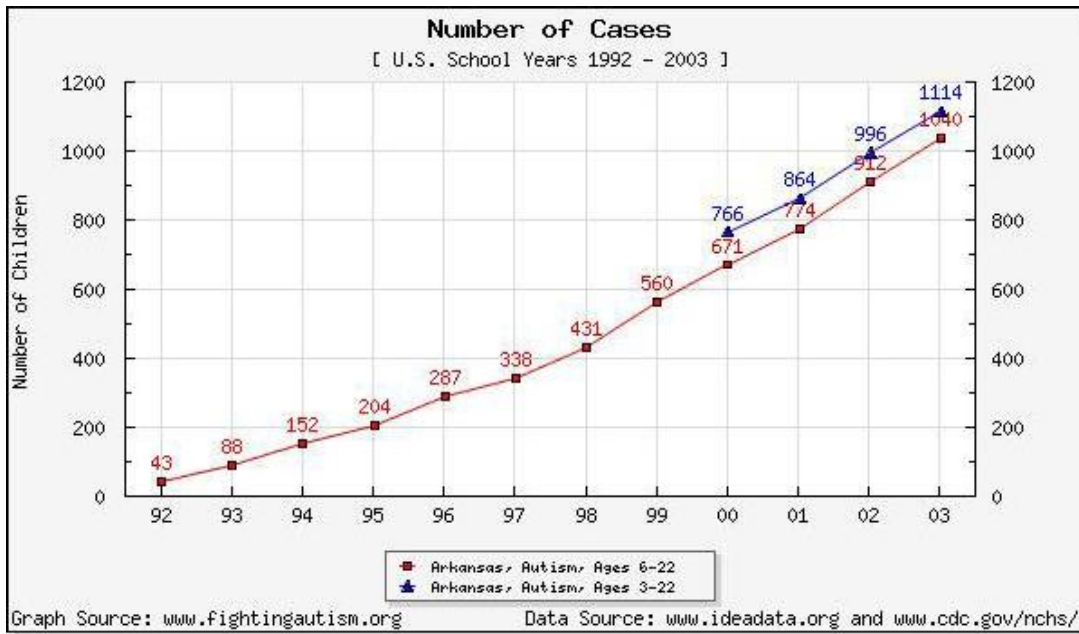


Figure 1

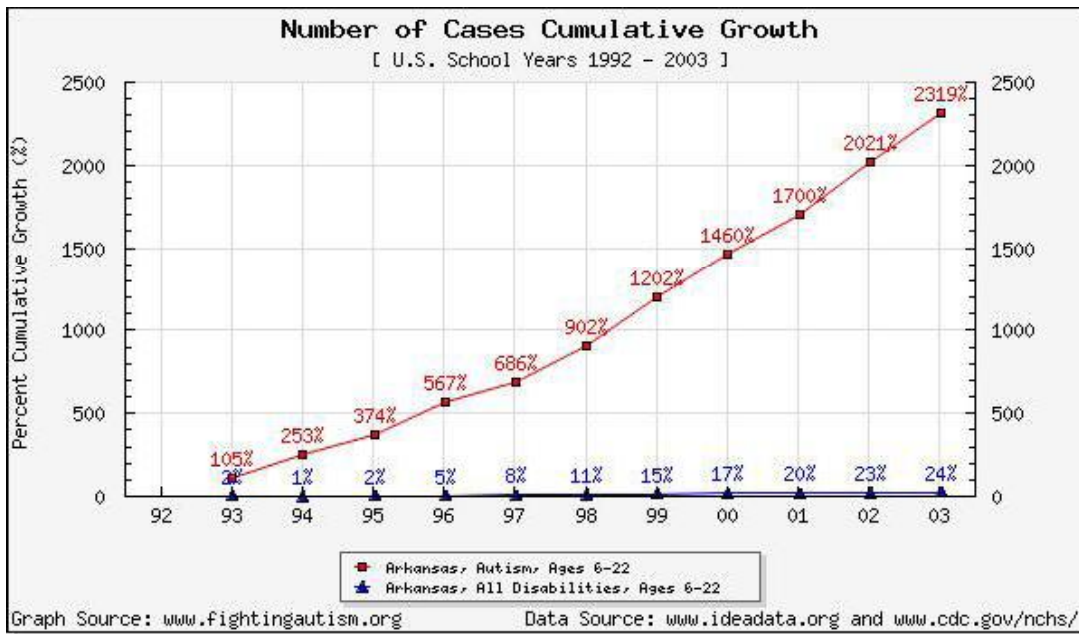


Figure 2

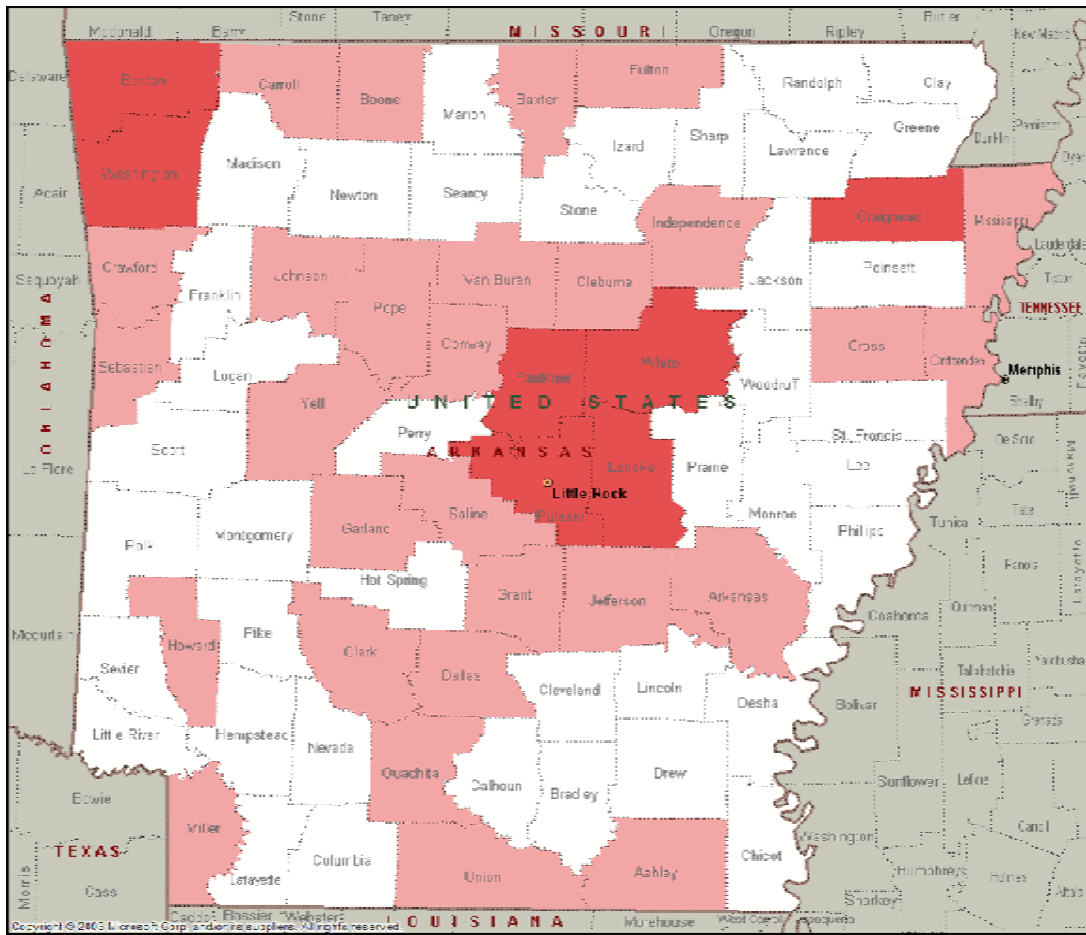





Figure 3: Incidence in Arkansas by County, CDC

-  Indicates highest incidence
-  Indicates moderate incidence
-  Indicates lower incidence

Arkansas has only two clinics offering comprehensive evaluations for children with developmental disabilities: the James L. Dennis Developmental Center located in Little Rock, and the Schmieding Developmental Center in Springdale, both of which are programs of the University of Arkansas for Medical Sciences (UAMS), Department of Pediatrics. These clinics are unable to meet the growing demand for comprehensive evaluations. While over seven thousand children were screened by Dennis Developmental Center in 2007, families who are desperate for help for their young children must sometimes wait as long as sixteen months for an appointment for a developmental evaluation.

A framework exists to support the infrastructure and supply the resources needed for the services required to assist children and families living with autism in Arkansas. However, the existing system of care is complex, and a significant number of families encounter major barriers in accessing and navigating the services that are available. In addition, families report problems accessing autism services through their health insurance coverage.

Recommendations

The Task Force has prioritized the recommendations based upon the experiences of families who live with the disorder and providers who serve Arkansas citizens living with Autism Spectrum Disorder. They are listed as follows:

1. Families report problems accessing autism treatment services.

a) Provide funding for an Early Intervention Medicaid waiver program to provide intensive one-on-one therapy for young children with autism as outlined in Act 1198 of 2007

- A 1998 cost benefit analysis of early intensive behavioral intervention for children with autism concluded that by providing 3 years of a sufficiently intensive intervention program at a cost of \$33,000 per year society will save as much as \$1,081,984 over the lifetime of that child⁶. The program outlined in Act 1198 would provide up to three years of intensive therapy (25 – 40 hours/week) per child at a maximum cost per year of \$50,000/child. Of the \$50,000/year/child needed to provide early intensive intervention, approximately 75% would be federal matching funds, which means that the approximate investment from the state to implement such a program would be \$12,500 per child served per year

b) Enact legislation that results in insurance companies recognizing autism as a neurobiological disorder

- Many private insurance plans deny coverage for diagnostic services and treatment for autism, by erroneously classifying it as a “psychiatric disorder” or by classifying treatments for autism as “educational”. Currently, eight states⁷ have laws requiring insurers to cover treatments for autism. Six additional states have recently introduced legislation to address the issue of health insurance coverage for autism related services,⁸ and twenty-one states are in the process of drafting legislation to address autism insurance reform⁹.

c) Create a billing mechanism for treatment of individuals with autism, addressing billing code issues with Medicaid and private insurance companies to include diagnostic services, applied behavior analysis, medication management, therapy sessions, and crisis intervention.

- Currently, there is no mechanism to fund applied behavior analysis (ABA) through Medicaid or private insurance in Arkansas. TriCare, the insurance program for U.S. Military, does provide ABA for children of active-duty military, when provided by a Board Certified Behavior Analyst (BCBA). Using the TriCare program as a model would be beneficial.

- There is a significant shortage of Speech-Language, Occupational, and Physical therapists in many locations of the state. Even in locations where these therapies are available, many families find it difficult to access sufficiently intensive hours to meet their child's needs.
 - There is no mechanism currently to allow mental health professionals to bill for treatment of individuals with autism, unless there exists an additional diagnosis of a mental health condition. This prevents many professionals from being able to provide services to families living with autism and encourages additional assessment and labeling that may be unnecessary.
- d) **Many of the services listed above are available to individuals who qualify for Medicaid Home and Community Based (HCB) waiver. However, there are currently over 900 individuals waiting for waiver services, resulting in a waiting time of several years. In 2006, Centers for Medicaid and Medicare Services (CMS) approved a mechanism to provide many of the above mentioned services under a state plan option¹⁰. States that wish to take advantage of this option to provide home and community based services will have the ability, unlike other state plan benefits, to limit the number of recipients of these services, and/or limit the amount of funding for these services under such an option. Arkansas has, to date, not taken advantage of this option.**
- e) **Expand the family support option in the state to include subsidy for assistance with out of pocket expenses associated with maintaining a child with a disability in the home.**
- Families often endure overwhelming stress associated with the financial, mental, and emotional demands of caring for a child with autism. The divorce rate for parents of children with autism is estimated between 75-80%, meaning that the majority of children with autism are living in single-parent households and are most likely living near or below poverty levels. In fact, a recent study at the University of North Carolina Chapel Hill found that 40 percent of the surveyed families with disabled children who earned between two to three times the federal poverty level experienced at least one food hardship, including worrying that food would run out or skipping meals because of a lack of money, and fifteen percent of families with incomes at three or more times the federal poverty level experienced housing instability, meaning they were unable to pay their rent or had to move in with others¹¹.
- f) **Provide complete funding for the Home and Community Based (HCB) Medicaid waiver program to cover all eligible current and future applicants. A fully funded Medicaid waiver program providing services to all eligible individuals with developmental**

disabilities in the state is estimated to cost an additional fifteen million dollars annually.

2. The CDC reports the median age of diagnosis for children with autism in Arkansas is 4 years, 11 months, which suggests that a significant number of children in have not been screened, assessed or referred to Early Intervention Services in an appropriate and timely manner. These delays are longer and occur with more frequency in rural areas.

a) Build the capacity to diagnose and treat autism within local communities through the Arkansas Area Health Education Centers (AHEC) system and by recruitment of faculty from other colleges and universities in Arkansas and other interested professionals, utilizing consensus standards for diagnosis and treatment.

- The key to providing early interventions for children with autism is identifying them as soon as possible and referring them to appropriate services. The AHECs provide teaching opportunities for medical students in communities around the state. Physicians at AHECs could partner with professionals in speech pathology, psychology, occupational and physical therapy, and social work within these communities to deliver interdisciplinary evaluations to children suspected of having autism.

b) Intensify and expand public awareness, education and outreach efforts regarding autism services.

- Many state agencies already conduct disability awareness campaigns as part of their efforts in various programs. Current information on autism and appropriate diagnosis/treatment needs to be infused into any of those efforts where it may not currently exist.
- Additional efforts need to be developed to reach families in rural, impoverished areas of the state where citizens may not have access to new research and information via the internet and may have limited transportation to reach needed professionals and treatments. Utilizing the vast network of local churches in the state might be an avenue for information dissemination and outreach that has not been utilized to date.

c) Educate pediatricians and primary care physicians, nurses, and support staff in recognizing symptoms of autism, and provide them with contact information for services available in their community.

- Arkansas Foundation for Medical Care (AFMC) and the Department of Human Services (DHS) have partnered with physicians from the Department of Pediatrics at UAMS to develop

and implement an autism-specific screening tool to be utilized by pediatricians and primary care physicians at well-child checkups.

- The American Academy of Pediatrics has developed a physician tool kit designed to help pediatricians and primary care physicians identify children with autism. This kit is available to physicians at a cost of approximately \$80.
- The Centers for Disease Control and Prevention (CDC) has developed a “Learn the Signs: Act Early” campaign and corresponding literature and materials targeting primary care providers and early childhood providers. These materials are available free of charge and could be disseminated to physicians and early childhood providers statewide.

d) Integrate information and training on medical conditions commonly associated with autism into continuing education for pediatricians and family practice physicians.

- Many individuals with autism have medical conditions that often go undiagnosed because the signs/symptoms of these conditions are interpreted as maladaptive behavior. Gastrointestinal inflammation, nutritional deficiencies, frequent headaches, and other troubling and painful conditions may be contributing to troubling behaviors. Once these corresponding conditions are adequately addressed, behavior and the ability to focus and attend to one’s surroundings may improve. At a minimum, physicians and providers should examine whether or not an individual’s behavior may be influenced by the pain or discomfort resulting from another medical problem.

e) Improve the infrastructure and resources in the Department of Human Services (DHS) and the Department of Education (DOE) to meet the needs of all individuals with autism and their families.

- One component that seems to be critically important to meeting the needs of families with autism is family-centered service coordination, sometimes referred to as “case management”. While a number of state agencies (DHS, DOE, Department of Health) provide service coordination, there is limited or no integration of across agencies when families are served by multiple agencies/programs. Each agency focuses on the needs related to their particular agency, rather than the overall needs of the family. Additionally, the resources available to these agencies for this purpose seem insufficient to allow reasonable caseloads for the staff providing the service. Individuals in these positions are often functioning in crisis management mode rather than proactive service coordination.
- One of the primary systems providing services for individuals with autism (3-21 years of age) is the Department of Education (DOE), via local school districts and educational cooperatives. The DOE is

utilizing federal funds authorized via the Individuals with Disabilities Education Improvement Act (IDEA), the federal law that requires individualized special education and related services for all eligible children with disabilities. The IDEA regulations require states to provide services under very strict guidelines addressing individualized interventions, locations for services, qualifications for staff delivering services, protections for individual rights, etc. While the regulations propose that services should be “designed to meet the unique needs” of the child, the funding that accompanies these regulations has been inadequate from its inception for accomplishing these requirements, thus creating a financial and legal hardship for the state and local school districts as they attempt to provide special education and related services. The National Education Association estimates that the current funding level is 17% of what would have been required (see figure 4).¹²

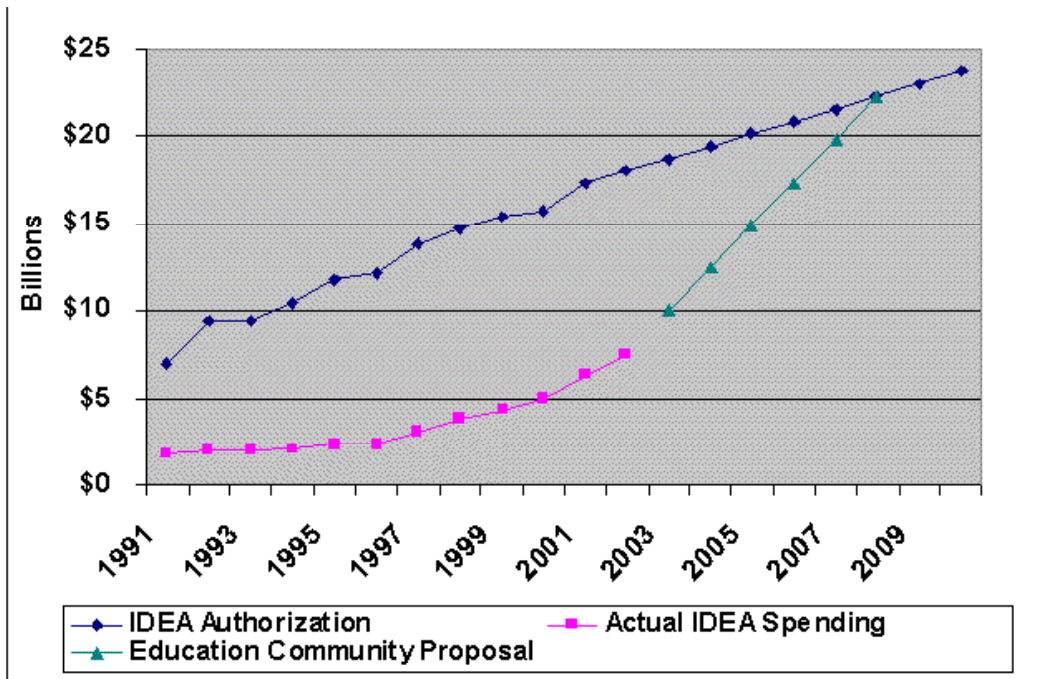


Figure 4:

- 3. The existing systems of care for individuals with autism are complex, and families report major barriers in accessing and navigating the limited services that are available.**
- a) Create a state commission on autism to be responsible for ongoing oversight and continuous improvement activities pertinent to Arkansas families living with ASD and to develop a website or toll free hotline to provide immediate answers on available resources in the state.**
- A website or hotline could direct families to clinical and educational providers in their region.
 - A state commission could also provide guidance to state agencies on issues such as interagency coordination of services, and provide a mechanism for disseminating new developments in medical and educational interventions for autism to providers and families.
- b) Provide comprehensive interagency service coordination for people with autism.**
- As has been mentioned earlier in this report, many agencies are involved in some form of service coordination that is restricted to agency boundaries associated with programmatic or funding parameters. This segmented approach does not meet the needs of families living with autism. Autism does not recognize the parameters of program, location, type of service. A child with autism has communication, social, sensory and behavioral difficulties at home, school, church, the grocery store, Wal-Mart, etc. without regard for the time of day or whom is responsible for the service at that moment. Due to the intense and comprehensive nature of the impact of autism on families, they need access to a service coordinator who is responsible to that child and family and free to coordinate the big picture, removed from restrictions or incentives for any one piece.
- c) Provide training for staff at local Department of Human Services' County Operations Offices and school districts to be available to answer parent questions and provide information about local services.**
- d) Provide training for emergency personnel and first responders in recognizing and responding to the needs of individuals with autism.**
- First responders to emergency situations often misinterpret behaviors common to individuals with autism. Often individuals with autism have difficulty responding to spoken commands. Failure of an individual with autism to respond to commands of a peace officer might result in life-threatening situations when the officer has not been trained in how to recognize or respond to individuals with autism in emergency situations. In another

instance, rescue workers may actually hinder their ability to find a lost child who has autism by using bullhorns and other equipment that frightens a child into running further away. These professionals deserve access to resources and training to help them better serve this vulnerable population.

- e) **Provide training and technical assistance to families, school districts, and disability provider agencies on a comprehensive approach to the development of appropriate social skills for children, teens and adults with autism**
4. **Families report that many providers of early intervention and educational programs, particularly those in rural areas, lack the necessary resources to provide programs that are in line with best practices to treat autism.**
- a) **Create higher education curricula for students preparing to practice in professional fields providing services to individuals with autism to require a minimum of three hours college credit at the undergraduate level in understanding and teaching students with autism.**
 - b) **Create funding which could be accessed by school districts, via a grant application process, that have multiple students with autism to provide supplemental funding for hiring paraprofessionals, purchasing adaptive equipment or training personnel**
 - The DOE currently has such a process to assist districts who have catastrophic needs around particular students with disabilities, not restricted to autism. Expansion of the funding for this process would enable more districts and students to benefit.
 - c) **Increase training for teachers in the implementation of classroom and curriculum adaptations and modifications for individuals with autism.**
 - d) **Address staff training and retention issues for direct support professionals (direct care staff) working with people with autism.**
 - Providing a workforce that is well trained and stable to provide front line services for individuals with autism is a critical component to the overall outcome for the individual. The front line workers are often the people who spend the most time with the individual. They are the paraprofessionals in schools, the companions and personal care workers in the Medicaid waiver program, the individuals who implement the recommendations of many other professionals, yet they are compensated at an entry level wage, often without health benefits, and provided the least

education/training and support. These factors contribute to high turn-over and an unstable workforce to staff these critically important positions.

- 5. Families and service providers report adolescents and young adults with autism experience major transitions related to changes in physiology, social demands and expectations, and service system constructs which require an additional level of support.**
 - a) Increase the guidance provided by the Department of Education to local school districts on topics such as grading and graduation for students with disabilities.**
 - b) Provide training and technical assistance to school districts in addressing bullying and victimization, to assist in modifying existing efforts specific to students with autism.**
 - c) Ensure that the full range of options on the continuum, from regular education to self-contained special education classes, are available for secondary level students with autism in all school districts.**
 - d) Expand vocational training opportunities for individuals with autism, with particular emphasis on the supported employment model.**
 - Currently, the majority of the vocational training for individuals with autism is offered through Arkansas Rehabilitation Services in group settings that teach a variety of vocational preparation skills to a group of individuals with varying disabilities. This model does not work well for many individuals with autism due to the nature of the group and the types of jobs commonly utilized. It is common for individuals with autism to demonstrate significant challenging behaviors in such settings and be subsequently dismissed from the program. This leaves individuals with autism, who are capable of being employed, sitting at home with no option for vocational training. The supported employment model, which utilizes “job coaches” to train and support an individual in a job that is selected based on his/her strengths and needs, has proven very successful in ameliorating behavioral difficulties and enabling persons with autism to function in vocational settings.
 - e) Expand opportunities for functional skills development and community living for students with autism.**
 - f) Create a model demonstration project for transition to adulthood for individuals with autism, similar to the assisted living model with one**

stop for residential, social, instructional and recreational opportunities.

g) Create a process for the development and monitoring of a person-centered, multi-agency transition process that facilitates the development of a post high school transition plan with real outcomes that is the responsibility of all state agencies.

- Currently, this transition process begins as part of the Individualized Education Planning that occurs in the school districts for secondary-level students with autism receiving special education services. The difficulty is that the schools are not the only agency required to provide a successful transition for a student into the adult world. Other state agencies and local providers are a necessary part of the equation, yet the schools have no power to ensure their participation. The success of the transition process varies considerably across the state, and leaves families frustrated and in need of assistance. Many report that they transition to “an adult service system that provides nothing” as they exit public education.

Summary

The Autism Society of America estimates that the cost of caring for an individual with autism over his or her lifetime is \$3.5 million. If the 2007 CDC study prevalence rate for autism in Arkansas is applied to the current birth rate, then approximately 282¹³ of the babies born in Arkansas each year will later be diagnosed with autism, and the cost of caring for those children will be \$987 million. **An investment in programs providing early diagnosis and intensive intervention for children with autism** could potentially reduce that cost by up to two-thirds, a savings of \$658 million, according to a 2001 London School of Economics study¹⁴. The Arkansas Task Force on Autism believes that this investment will be a crucial first step in addressing the needs of the autism community.

Additionally, the Task Force believes that an investment in providing continued community supports for individuals with autism will be necessary to ensure that those who cannot benefit from early intervention today will have every opportunity available to become fully included and productive citizens of Arkansas. **Funding for HCB waiver services** and an **expanded family support program** will substantially improve the ability of families to provide appropriate care for individuals with autism. These programs are a vital component of any long-term strategy to address the needs of the autism community.

Of the recommendations made by the Task Force, several require an increase in funding for services and supports. While we understand that prioritizing the multiple competing funding requests is the most challenging responsibility of the Arkansas General Assembly, we believe that an investment in early intervention for children with autism will, in fact, reduce the cost to the state for these children later in life. Early intervention truly is a “pay now” or “pay more later” scenario. Many of the recommendations would require state agencies that are responsible for serving the autism community to examine and modify current policies and procedures already in place. A great deal of progress could be made by addressing the problems that arise from a lack of interagency coordination and consensus on best practices to treat autism. The Task Force believes that coordinated effort among all state agencies, with an agreed upon plan for interagency coordination of services from the time a child is diagnosed and continuing into adulthood, is absolutely necessary.