

LEGISLATIVE TASK FORCE ON AUTISM MEETING SUMMARIES

August 30, 2007

The Task Force was created by Act 1016 of 2007. Representative David Johnson, sponsor of Act 1016, called the meeting to order. Speaker of the House Benny Petrus addressed the Task Force and thanked the appointees for their willingness to serve. Dianna Varady was elected the first Task Force Chair and Leslie Henson Kita was elected to be the Task Force Co-Chair.

Task Force Members listed the following goals:

- How to provide funding for biomedical treatment of autism
- How to provide funding for undergraduate programs for teacher education training on autism spectrum disorders
- How to create or expand graduate level programs at state universities for specialists in behavioral analysis, and certification or licensure for behavioral specialist
- How to find funding mechanisms such as Medicaid for training program cost
- How to find services to help older adolescents/adults receive supportive living options and opportunities
- Provide access to services in rural communities
- Educating physicians in early diagnosis and intervention
- Need legislative support for possible Autism Treatment Network site
- Need better insurance coverage for children with autism
- Need for respite care
- Find a way for private insurance to help
- State funding for treatment and programs
- Need equal access to group care services
- Need an agency to provide the parents with information on all programs available
- Lower cost of the programs to help support parents
- Be consistent in setting task force priorities
- Focus on comprehensive task force plan to educate Primary Care Physicians on detecting signs of autism at an earlier age and provide treatment options as soon as autism is detected
- Finding the cause of autism and possible prevention measures need to be addressed
- Task Force could help physicians come to a consensus on acceptable complementary and alternative treatments for autism spectrum disorders

September 28, 2007

Karan Burnette explained the 2007 CDC Report Autism Developmental Disabilities Monitoring Network. The multi-state study produced the most recent prevalence data, at the time. Arkansas's rate was 1 out of 93 boys and one out of 345 girls.

Charlie Green gave an overview of current services available to people age 0-21. The Developmental Day Treatment Clinic Services (DDTCS) provide approximately \$67 million in services to children ages 0-5 years. The First Connections program provides approximately \$3 million in non-clinical therapy services and parent training for people not covered by Medicaid. Currently, children with autism are not qualified for Title Five programs designed for special medical needs. Dr. Green listed the following services available for school age children:

- Intermediate Care Facility/Mental Retardation
- Easter Seals
- Brownwood
- Millcreek
- Arkansas Pediatric Facility
- Conway Human Development Center

Krameelah Banks, sitting in for Maureen Bradshaw, reviewed the Centralized Intake and Referral/Consultant Unified Intervention Team Services (CIRCUIT) which began in 2005-2006 school year. She said the program provides training and programs for the student at the request of a parent, teacher or child advocate. There are currently 11 Behavior Intervention Consultants and 16 Early Childhood Behavior Interventionist working around the state to assist school districts. These services are funded by ADE, Special Education Unit.

Jennifer Hennessey said 51% of children identified with autism were found in 7 counties. When a student is diagnosed as a special education student the Behavior Intervention Consultants will drive to the school and teach strategies to the school teacher.

October 26, 2007

Dianna Varady explained that Act 1198 of 2007 is designed to create a program with intensive one on one therapy for children with autism spectrum disorders. Ms. Varady feels the Task Force should explore interventions in Arkansas, what's being done and find the gaps in services provided.

Charlie Green explained the process of submitting a waiver to CMS for approval. Dr. Green said that habilitation service is in the state plan and there is no limitation in the number of spots available within the DDTCS. There are restrictions on new providers but not as many restrictions on expanded providers.

Eldon Shultz said that non-categorical intensive services can be provided without having a specific diagnosis because autism is visible in children under age three.

Chris Ewing suggested pulling funding from interventions and therapies that do not have the research to support their effectiveness and use the funds to support programs that work.

Dusty Maxwell, Pathfinder, said his agency worked during the last session to get funding for the waiver. He is concerned that public school teachers are not aware of the teaching services provided at the day treatment centers for the children who are transitioning from the day treatment centers to the public schools.

Leslie Henson Kita explained that desperately needed services are not being provided at the DDTCS because not all services are eligible for payment. Ms. Henson Kita feels recommendations need to be made to provide services that are needed and research based.

NOVEMBER 30, 2007

The Task Force formed four subcommittees addressing different age groups of individuals with autism spectrum disorder to expedite the development of the Task Force recommendations to be presented to the Governor by May 1, 2008.

Steve Kahler explained there are different degrees of evidence. Dr. Kahler said there is a huge difference between saying something hasn't been demonstrated to work and saying it has never been shown to work.

Tyra Reid believes the Task Force should establish a minimum dollar amount of services to be provided so the State will not pay for services that don't work.

Marilyn Strickland suggested that TF members compare waivers in other states that have been approved by CMS to use as a basis when writing recommendations.

Leslie Henson-Kita said she would like to see an amount of money that's available to the child then let the health care providers and the service providers decide how best that money should be spent on that child's care because children with ASD have different needs.

FEBRUARY, MARCH, APRIL and MAY SUBCOMMITTEES MET TO DEVELOP RECOMMENDATIONS – In April, Eric Moxley was appointed to the Task Force and Dayna Miller addressed the Task Force for the first time regarding the difficulties she has faced with her son's school while trying to help him receive a proper education.

JUNE 6, 2008

Birth to 3 years old Subcommittee Recommendations:

- Educating physicians and nurses on early identification and referral to available services
- Include autism specific screening tool during the 18 month physician visit
- Develop continuing education course for physicians on signs of biomedical conditions found in children with autism
- Provide information and training to families about autism
- Provide training to medical and educational personnel about autism
- Establish a demonstration project at multiple sites that will serve as a template to expand early identification programs
- Implement a statewide public awareness campaign on autism

3 to 10 years old Subcommittee Recommendations:

- Early intervention/Early diagnosis
- Entry into intervention services instead of deferring until a definitive diagnosis is made
- Advertise that intervention services beginning at a later age are still beneficial
- Lower student to teacher ratios for autistic students
- Incorporate a variety of objectively verified practices designed to meet individual needs
- Consideration be given to integrating several intervention approaches
- Early transition planning
- Early intensive behavior intervention
- Functional approach to behavior
- Individualization of services
- Assessments should identify specific strengths and needs of the child and family
- Modify intervention techniques as appropriate based on the child's progress
- Specialized curriculum
- Family involvement
- Structured environment
- Access to natural setting/environments
- Appropriate supervision of line staff and coordination efforts

JUNE 27, 2008 – Task Force Subcommittees continued to meet and development recommendations

JULY 25, 2008

The Task Force discussed the recommendations and their justification. Dr. Kahler believes the Task Force must provide a fiscal impact for the recommendations. Ms. Burnette thinks the

state's capacity to diagnose and treat autism must be increased. Ms. Miller suggested using parents of children with autism to testify before the legislature.

AUGUST 29, 2008 – TASK FORCE FINAL REPORT WAS FILED

AUGUST 21, 2009

The Legislative Task Force on Autism was reestablished by Act 1272 of 2009. Senator Salmon and Rep. Lindsey were elected Task Force officers. Ms. Varady said the biggest legislative success was the funding of \$1.5 million for the Medicaid waiver program. This funding was received from the new tobacco tax. The waiver will provide one-on-one therapy treatment services for individuals with ASD. Ms. Varady requested to have an employee from the Department of Workforce Education attend the next task force meeting to discuss specific education needs.

Dr. Green updated the TF on the waiver development process. He said DDS contracted with Partners to develop and submit the waiver application to CMS. He said the waiver should be approved or denied in October 2009. He said the waiver will explain who is eligible, what age groups, and what services will be provided. He said the number of people who can get on the waiver determines how much service is provided to each individual with autism. There are approximately 500 people on the DDS waiver waiting list. DDS does not have special language allowing them to carry forward funds from the \$1.5 million annually. The state set up a special needs grant program to utilize this money prior to the waiver being approved by CMS. The special needs grants are capped at \$5,000 annually per family.

Ms. Harding will put the special needs grant information and the waiver information on the web site and list serves. This information will be accessible to the public schools, directors of special education and advocacy groups. She said ADE is working with UAMS and Children's Hospital to build a regional partnership to develop diagnostic teams using people from each region of the state.

NOVEMBER 20, 2009

Task Force members list the following concerns:

- The negative impact school discipline policies have on school children diagnosed with ASD
- IDEA law
- Schools need to be educated on ASD and positive outcomes
- Capitalize on past successes and goals to expand services
- Focus on final report
- Look at recommendations that cost less
- Physicians should require more training in ASD

- Due process hearings take too long to get children diagnosed with ASD into the mainstream special education system
- Need a theme for each Task Force meeting
- ESEPT screening at 18 month old check up
- Educating parents on what services are available to them
- Form a collaboration between parents and Department of Education

Dr. Tom Smith, Interim Dean, explained the U of A Autism Graduate Certificate Program. The program is an online program the offers five classes and be accessed by students currently enrolled at the University with a 3.0 GPA.

Marsha Harding stated ADE data show the majority of children diagnosed with ASD are not in self-contained programming but are included in less restricted services because of performance levels. Maureen Bradshaw said the Co-ops provide intensive training at the local district level. She explained how behavior intervention consultants are trained and offer technical assistance in all evidenced based practices.

Dr. Green explained DDS is in the process of development and submission to CMS a proposed waiver program to provide early intensive intervention services to children diagnosed with ASD. Ms. Carole Cromer, ACS Home & Community Based Waiver explained that CMS will make 46 changes to the waiver that will go into effect March 1. One of the major changes to the waiver is the additional funding DDS will obtain for 150 new slots. Another change was the inclusion of a Positive Behavioral Support Specialist to work specifically with autistic individuals.

Robert Trevino and Jim Moreland provided information on two programs, Increasing Capabilities Network and the Arkansas Career Training Institute.

DECEMBER 18, 2009

Marcia Harding, ADE Special Education, explained the Centralized Intake and Referral Consultant Unified Intervention Team (CIRCUIT) is a centralized referral system for students, parents, and school personnel needing problem solving assistance regarding a student's education. These services are available to anyone with a disability. The following services are available through CIRCUIT:

- BICS – Behavior Intervention Consultants
- ESO – Easter Seals Outreach
- ESVI-Education Services for the Visually Impaired
- EARS-Educational Audiology Resources Services
- POISE-Post-school Outcome Intervention for Special Education
- TCC-Technology and Curriculum Access Center
- ARLEARN-Arkansas Local Education Agency Resource Network

Information regarding CIRCUIT and accessing the services can be found at the Department of Education web site. ADE is in the sixth year of using raining and positive behavioral support systems, the third year working with response to intervention for children presenting behavior issues and the fifth year of CIRCUIT and intensive literacy initiative. ADE added highly qualified BCBA's and 18 early childhood behavior consultants serving the three to five year olds. Student progress on the benchmarks has been steady.

Recent data shows that 49 districts each have 10 to 145 students with ASD total approximately 1580 students statewide. 133 districts each have 2 to 9 students for a total of 575 students and 35 districts have identified 1 student. ADE is working on legislation to develop an appropriate policy regarding the use of restraints and seclusion. Currently, the 60 hours of required continuing education does not include training on disabilities.

The Task Force heard testimony from parents and grandparents regarding how school districts have forced some disabled students into home bound schooling due to behaviors associated with their disability.

MARCH 19, 2010

Dr. Cheryl May, Deputy Director of the Criminal Justice Institute requested to work with the Task Force to develop curriculum to educate School Resource Officers to identify and respond to special needs students. Therefore, the Law Enforcement Focus Group Subcommittee was created to provide CJ guidance on curriculum development for School Resource Officers and local police departments.

APRIL 9, 2010 – SUBCOMMITTEE

The Task Force Subcommittee held the first meeting. The following professional development needs were identified:

- How much training is required
- SRO training should be available through CJ
- Basic training classes for new officers should include disability interaction
- Certification designation for SROs
- Coordinating ARLEARN to train law enforcement officers
- Develop identical basic training materials for SROs and law enforcement agencies

CJI is developing a standardized training program for SROs and law enforcement officers emphasizing interaction with people who have a disability. ALETA, State Police, Sheriff's Association, and Chiefs of Police all participated in the Subcommittee discussions and inclusion of additional disability identification and interaction training.

MAY 11, 2010 - SUBCOMMITTEE

The Subcommittee discussed specific needs of first responders in identifying citizens with a developmental disability. The Public Safety Communication Officials recommended using a computer aided dispatch system for voluntary registration for individuals with health problems. However, some HIPPA laws have changed the way some departments flagged their CAD system. The lack of a centralized training class for 9-1-1 operators was identified. The Association of Chiefs of Police hired Dennis Debbaudt to provide 5 training classes statewide. Mr. Debbaudt had a two hour training class each night which was opened to the public.

MAY 21, 2010

Karan Burnette explained the findings from statewide community meetings with parents and on-line surveys to all BCBA and BCBA Assistants in the state and surrounding states regarding the services to be provided under the proposed autism waiver. The top five critical features collected from her survey:

- Use Evidence Based Interventions
- Family/Parental Participation and Training
- Emphasize Social Skills and Communication Development
- View Functional Behavioral Assessment
- Consistent Program Review/Progress Monitoring

Ms. Burnette is proposing to use licensed or certified services provider who provide services in the DDTCS plus other service providers to create a network of service providers. She believes the proposed waiver will provide services to approximately 100 children with a maximum length of service of three years from time of diagnosis.

Marsha Harding said data show 63% of children diagnosed with a mental disability by age three and receive early intervention services no longer require any services by age five. Jamie Morrison, ABC Program Administrator, explained the Better Beginnings program. Better Beginnings is a quality rating improvement system for early childcare providers in the state. There are three thousand licensed providers serving children from age six weeks through six years old. Better Beginnings will help providers know the services that are available for the children they serve.

AUGUST 12, 2010 - SUBCOMMITTEE

The Subcommittee adopted the following recommendations:

- Create a statewide voluntary registry program for citizens with a developmental disability
- Standardize the training opportunities regarding developmental disability recognition and interactions for law enforcement, dispatchers, fire fighters and emergency medical technicians

- Publicize current programs to assist developmentally disabled citizens and families

Dr. May described the three training classes developed by the Criminal Justice Institute. The first class focused on law enforcement issues of policing individuals with mental health and developmental disabilities. The other two classes focused on School Resource Officer training. Dr. May emphasized the need for additional funding to expand the training opportunities by creating a web-based education and training program. The web-based program could be accessed by the smaller law enforcement agencies which cannot afford to send officers to voluntary training due to lack of staff and funding issues.

AUGUST 20, 2010

Marsha Harding explained the Family Educational Rights and Privacy Act (FERPA). It is a federal law protecting the privacy of all student's education records. FERPA permits school officials to disclose, without parental consent, a student's education records to appropriate parties in an emergency, if that knowledge is necessary to protect the health or safety of the student or other individuals.

The Task Force recommended the following legislative changes be presented to the 88th General Assembly:

- Mandate insurance coverage of autism spectrum disorders
- Provide standardized IEP hearing process information to parents weeks prior to their scheduled IEP hearing
- ALETA certification for School Resource Officers
- Require additional special education professional development for all teachers and administrators
- Establish uniform standards for all first responders and dispatchers
- Develop rules and regulations regarding the use of restraints and seclusion in schools
- Establish a state voluntary developmental disability registry to be used by first responders

AUGUST 31, 2010 – REPORT TO LEGISLATIVE COUNCIL

The legislative priorities of the Task Force are as follows:

- Increase funding for the Home and Community Based Medicaid Waiver Program to cover all eligible current and future applicants
- Continue funding the Autism Medicaid Waiver Program
- Provide insurance coverage for autism spectrum disorders
- Build the capacity to diagnose and treat autism spectrum disorders within local communities

- Fund the Community-Based Autism Liaison and Treatment Project within the local communities as created by the University of Arkansas for Medical Sciences and currently funded with federal stimulus money by the Department of Human Services
- Require school district administrators be properly informed of and properly disseminate federal educational rights and privacy act, FERPA, information and guidelines to parents and personnel having the right to know
- Provide block grants to school districts with the highest incidence rate of autism spectrum disorders for providing additional special education services
- Create a statewide voluntary registry program for citizens with a developmental disability
- Standardize the training opportunities regarding developmental disability recognition and interaction for law enforcement, dispatchers, fire fighters and emergency medical technicians
- Adopt federal laws and regulations relating to the use of restraints and seclusion for all students attending public schools in the state
- Expand the autism graduate certificate program at the University of Arkansas to include undergraduate students
- Continue the Arkansas Legislative Task Force on Autism and provide per diem to non-governmental task force members

SEPTEMBER 23, 2010 – SUBCOMMITTEE

CJI presented the estimated biennial cost for the web-based seven hour course on identifying and communicating with a developmentally disabled person. The estimate follows:

- One Time Expense \$60,400
- Continuing Cost \$22,020

This course is designed for law enforcement officers, fire fighters, and emergency medical responders. ALETA provides 4 to 6 hours of training on developmental disabilities as part of their basic training course.

Pam Marshall made a motion to ask the Governor's Council on Developmental Disabilities to continue explore the standardize training for all emergency responders regarding individuals with a disability and the development of a statewide voluntary registry system.

NOVEMBER 12, 2010

Charles Ellis stated ALETA has increased training on autism to the new law enforcement officers and the agency is considering providing advanced training to all law enforcement officers. Dianna Varady said children in the state should start receiving medical services for developmental disabilities under the Autism Medicaid Waiver Program by January 2012.

Charlie Green stated there are approximately 1700 individuals on the waiver waiting list. DHS waiver program budget proposal is \$20 million in general revenues.

The Task Force voted to endorse the Community Service Oversight Counsel's recommendation to the Joint Budget Committee to increase the Home and Community-Based Medicaid Waiver program by 960 new slots each biennium.

JUNE 17, 2011

Martha Kay Asti, Special Education Interim Associate Director, provided information on the services available under the Area Service Grants. The grants are provided to the school districts by DOE for consultants and technical assistance provided to students with a disability.

Ms. Greenberg expressed concerns that the CIRCUIT meeting and reports information is not being provided to the families of students. She feels grade school children with autism are not receiving the benefits of a structured program.

Senator Salmon request that DOE encourage teachers to attend professional development classes on interacting with an autistic child.

Dr. Green discussed a plan to eliminate the Home and Community Based Medicaid Waiver waiting list in four years. He said there is support from the Governor's Office and the General Assembly to provide additional funding as the economy improves and more funds become available. The waiver will cost an additional \$25 million annually to provide services to everyone on the four year waiting list.

Dr. Reid explained the UAMS Community-Based Autism Liaison and Treatment Project (CoBALT). The statewide project will train pediatric health professionals to triage children with ASD into the appropriate services. The Task Force hopes the project will be expanded to include the training of family practice physicians.

AUGUST 19, 2011

Dr. Reid explained the CoBALT trained team of physicians are given knowledge based information about resources for services and introduced to program personnel for EI, EC, DDS and CMS. UAMS expects to train nine teams by the end of the year. Currently, the training is only opened to physicians. If funding for this program is continued, UAMS plans to open the training to Advance Practice Nurses who are knowledgeable about developmental disability issues.

Tonya Russell provided information on the SpecialQuest project. The project is funded by the ARRA. The project provides responsive services and includes a parental involvement component.

Dr. Green stated that DDS had applied for a waiver specific to ABA therapy. The available funds will serve 100 children. He feels the funding will encourage more providers to become ABA therapist.

Dr. Kahler would like to see the ABA therapy available throughout the state.

Dr. Eugene Gessow explained the plan to transform the state's Medicaid program to a more patient centered payment model which would focus on the needs of the individual not the services provided to that individual. Dr. Gessow stated the growth of Arkansas Medicaid spending exceeds the rate of growth of state revenues. The program is built around care coordination between healthcare provider. The transformation is dependent on electronic medical records and health information exchanges being built into the standard of care.

OCTOBER 21, 2011

The Task Force heard a presentation by Todd Miller, Vice President, Public Safety Services, Rave Mobile regarding his company's SMART 911 system.

Booth Rand, Attorney, Insurance Department, said the insurance mandate provides enough clarity to eliminate any concerns insurances companies, providers or consumers may have regarding insurance coverage for autism. The Department had concerns about the \$50,000 state mandated cap on mental health services. However, the federal government informed the department that the cap does not violate mental health parity laws. Mr. Rand addressed the issue that self-funded insurance programs will not be subject to the state mandate.

Dr. Martin announced Blue Cross and Blue Shield is hosting a workshop for BCBA's who have not had any experience in billing insurers. The workshop will explain policies and billing procedures.

Dr. Green discussed the creation of a state certification for ABA providers. The certification is required under the proposed ABA waiver program.

Maureen Bradshaw provided information regarding the educational cooperatives' program to train parents on early intervention services. She said the consultants trained three sets of parents in Conway. The program will be replicated in Helena and DeQueen. This training includes pivotal response and discreet trial methods.

NOVEMBER 18, 2011

Lauren Tankersly a senior at Harding University majoring in Speech Pathology spoke to the Task Force regarding her experiences being diagnosed with severe autism and attention deficit disorder. She explained the challenges with school teachers not understanding how to work

with her disability. Lauren's goal is to become a Speech Pathologist and work with autistic children.

Dr. Green said DDS is rewriting the waiver standards and qualification to include all Board Certified Behavioral Analysts in the new waiver program. DDS will certify BCBAs, but will not certify or license their assistants. DDS will request a criminal background check including the adult and child abuse registry on all BCBAs and their assistance. Actually, anyone who is in contact with a child receiving DDS services directly or indirectly will be subject to the background checks.

Martha Kay Asti explained Act 1223 requires school districts to develop an attendance policy defining the specific number of absences permitted per semester. A student or parent may petition the school or the district administration for additional absences which will be decided by the local district. A student with special needs or highly complex medical needs requiring a shorten school day must have the attendance petition addressed with their IEP.

Karan Burnette has received information that school district IEP teams do not believe they have the authority to alter the attendance or discipline policies set under Act 1223. The school districts need guidance to know that the IEP team is the local decision-making body for students with a disability. Senator Salmon has requested that ADE inform school districts of the disability exceptions within Act 1223 regarding attendance and discipline policy development.