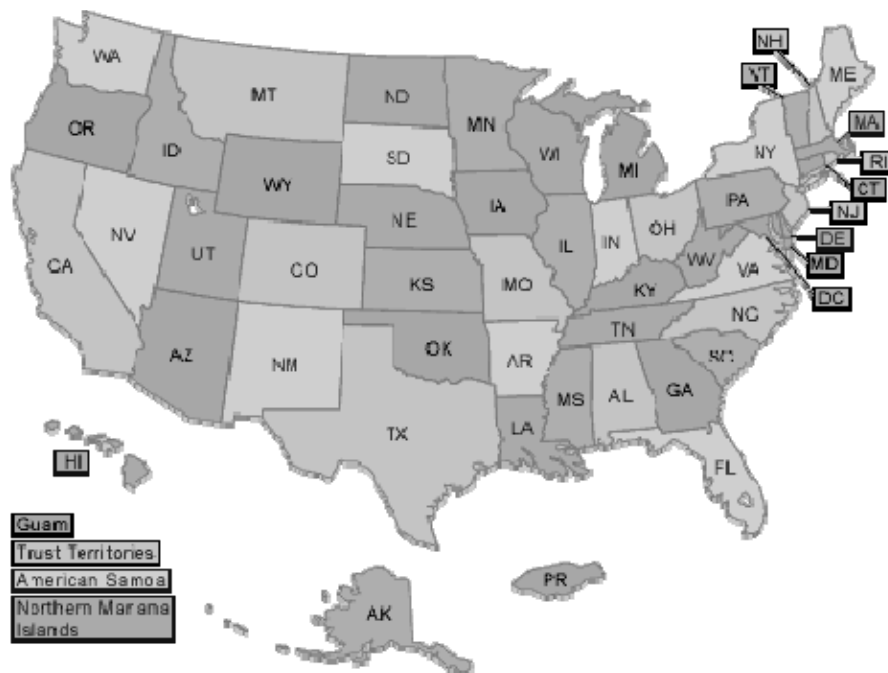


National Association of Councils on Developmental Disabilities

April is Autism Awareness Month. The United States recognizes April as a special opportunity for everyone to educate the public about autism and issues within the autism community.

Councils on Developmental Disabilities have been working within their States/Territories on initiatives that directly affect people with autism and their families.

We would like to share a few Council achievements as we join the national efforts to share information and education about the autism community.





Alabama Council
Myra Jones-Banks, Executive Director

The Alabama Council financially supported the University of Alabama Autism Spectrum Disorder College Transition and Support (UA-ACTS) program that was developed in 2006 and continues today. This program is designed to provide academic and social transition and support services for students with ASD. The program provides individualized services to help students develop appropriate skills for self-advocacy, daily living, and social interactions that will contribute to their success as an independent adult in their chosen career field. UA-ACTS program seeks to provide support for transition into a large, traditional university campus and to guide students toward achieving their goals for the future. Also, the program seeks to promote awareness and understanding of ASD throughout the campus community through education, training, and collaborations with University programs, faculty, staff and students.

The Council Chair was appointed by the Governor to participate on the Autism Task Force to review the state's response to the increase in the rate of Pervasive Developmental Disorders (PDD) commonly referred to as Autism or Autism Spectrum Disorders (ASD) in Alabama. To further assist the Task Force, the Alabama Council collaborated with the Alabama Autism Collaborative Group, the University of Alabama at Birmingham and the University of South Alabama, College of Education and the USA Polling Group to conduct a Needs Assessment. A Final Report was submitted to the Legislature and the Alabama Interagency Autism Coordinating Council (AIACC) was created by the Legislature in 2009. The ACDD is a member of this Council and continues to participate in its efforts to develop a long-term plan for a comprehensive statewide system of care for people with ASD.

The Alabama Council is a Co-sponsor of the Annual Alabama Autism Conference. The Conference is designed to present the very latest research regarding diagnosis and treatment to Autism Spectrum Disorder. The Conference reaches from 350-400 people annually and is beneficial to advocates, parents, professionals, educators, students, etc. The 2011 conference focused on early screening, diagnosis, and intervention for children from birth to five years.

The Council supported the Alabama Autism Society in raising the awareness of Autism Disorders to families in rural communities. The activities included: Training physicians and nurse practitioners to use First Signs Screening Kits, Public Service Announcements, Billboards, and Train Case Managers at Family Guidance Centers to be familiar with First Signs identifications, provided books about Autism for mini-libraries, Presented to Local Groups, and organized Family Support Groups.

The Council supported a project with The University of Alabama and The University of Alabama in Birmingham entitled "Preschool Social Skills Education Curriculum for Children with Autism Spectrum Disorders. This research was utilized to facilitate social skills development in preschoolers with autism spectrum disorders by developing, implementing, and disseminating a comprehensive social skills curriculum.

The Council partnered with the Alabama Department of Mental Health and the Alabama Department of Public Health to host a "First Responders and Autism Training Symposium".

The Council is partnering with the Alabama Autism Society in their effort to establish Autism Spectrum Disorder Satellite Learning Libraries in 29 Alabama cities. Also, a parent information 101 series of podcasts that will provide information about parenting children with ASD in Alabama.

The Council has included several articles on Autism in its quarterly Advocate magazine.



Alaska
Millie Ryan, Executive Director

After hearing from a variety of stakeholders about the dearth of services for people with autism, the Council convened an Ad Hoc Committee on Autism comprised of Council members, state agencies, the university and service providers to develop policy recommendations for the administration and legislature. After a year of meeting, the committee developed a set of recommendations in 2006 of which 4 and ultimately 5 were bundled into an interrelated 5-Part Autism Initiative consisting of universal screening, expanded diagnostic clinics, enhanced referral and consultation services, time-limited intensive early intervention services and workforce development capacity building. The Council then proceeded to "shop" the initiative with the administration and the legislature. As a result, state and Alaska Mental Health Trust Authority funding has been secured for expanded diagnostic clinics, enhanced referral and consultation services and workforce development capacity building. Policy change has been made or is underway. In addition, the Council and the UCEDD helped the Division of Public Mental Health, Section on Women, Children and Family Health write and secure a Combating Autism Grant to develop a system for better meeting the needs of children in rural and remote areas of the state who are typically diagnosed with autism 1 to 2 to 3 years after children residing in rural areas. The Council also identified a sponsor of a bill requiring private insurance coverage of autism diagnosis and treatment.

Children referred to the Children's Hospital at Providence now have a more comprehensive evaluation process with more specific treatment recommendations being provided; the backlog of older children was eliminated and screening and assessment clinics are available in a variety of locations statewide. Families have access to more information about available options and support groups. Screening and assessment clinics are now held statewide instead of people having to travel to Anchorage. In addition, Combating Autism grant funds are being used to develop a system where if children living in rural and remote areas of the state, who are currently diagnosed 1 to 2 to 3 years later than children living in urban areas, are suspected of having autism, they can be filmed in their natural environment; the films are then reviewed by

the staff at The Children's Hospital, who will determine if the child needs to come in for a full evaluation.

Significant inroads have been made in terms of workforce development capacity building. Funds were awarded to the UCEDD, which 1) is supporting 15 masters-level Alaskans to secure board certification in Applied Behavior Analysis (ABA); 2) negotiated an agreement with Northern Arizona University to offer a distance-delivered ABA program to develop an Alaska-specific program for a new cohort of master-level Alaskans; 3) is working with the University of Alaska Anchorage to develop a bachelor level program and an occupational endorsement program for paraprofessional staff; and 4) is now offering a week-long Summer Institute on autism.

Systemic changes were made in terms of the progress for diagnosing children with autism both in terms of there being a more comprehensive evaluation process and holding screening and assessment clinics statewide instead of requiring everyone to come to Anchorage. The State Board of Education & Early Development passed regulations adding advanced nurse practitioners to the list of medical personnel who can make autism diagnoses for the purposes of special education; this was important since the expanded autism clinics are using an advanced nurse practitioner to make autism diagnoses and these diagnoses needed to be recognized by local school districts.

The Council continues to support the Ad Hoc Committee on Autism. The committee was recently re-convened to develop a strategic action plan for resources and funding. Once the strategic action plan is developed, the Council will assume responsibility for implementation in coordination with identified stakeholders.



Colorado DD Council
Marcia Tewell, Executive Director

The Colorado Council voted in September 2010 to support an ad hoc Autism Committee to follow up on the work and recommendations of the Autism Commission. The Commission was created by the state legislature in 2008. The Commission was to obtain information on people with Autism Spectrum Disorders (ASD) in Colorado. The Commission was also to identify existing services and gaps in services for people with ASD, determine actions to remedy the gaps in services, and to detail their recommendations and action plan by issuing a Ten-Year Strategic Plan for Colorado. The Council's ad hoc Autism Committee is continuing the work of the Commission to implement the Ten-Year Plan.

Also, the Council funds a statewide self-advocacy organization, Watch Our Words (WOW) that is lead by people with developmental disabilities, many of whom are on the autism spectrum.

They have developed a curriculum and implement it when they do trainings around the state on facilitated communication, and aspects of living with disability in school, work and community.



Florida DD Council
Debra Dowds, Executive Director

Many of the Florida Council initiatives involve multiple disabilities, including autism. For example, their Program for Inclusive Early Care and Education includes many children on the autism spectrum. They are assisted to be successful in early care. Also, Project DISCOVER has been expanded and is working with two classes of students on the autism spectrum. Implementation of Universal Educational Practices includes children on the autism spectrum. In particular, the Florida Council is providing classroom technology to ensure children with disabilities can access regular course curriculum.

The Florida Council's Executive Director was appointed by Governor Crist to serve on the Governor's Task Force on Autism Spectrum Disorder. The Council ED served on this task force for two years during which time she worked with the task force in subcommittees and the full task force to prepare recommendations for the Governor for a unified and coordinated agenda for addressing autism in Florida.

During the 2011 Florida legislative session, the Council is supporting the Autism Screening Bill. This bill requires a physician to refer a minor to an appropriate specialist for screening for autism spectrum disorder under certain circumstances



Iowa DD Council
Becky Harker, Executive Director

The Council Executive Director serves on the Iowa Autism Council which was created in legislation with members appointed by the Governor to advise the Governor and the legislature.

The DD Council Public Policy Manager provides training, advice, mentoring and modeling for members of the Council and the state Autism Society to help advocates prepare their agenda, develop messages and deliver those to decision makers. The DD Council also publishes and disseminates a bi-weekly newsletter with legislation and other policy discussions related to developmental disabilities, including Autism.



Kentucky Council
Pat Seybold, Executive Director

The Kentucky Council was given the role of providing oversight to an Autism Commission that was formed by the Governor in 2006. The Commission had a limited timeframe to develop a 10 year plan. Once the plan was completed and presented to the Governor, the Commission ended. The second phase of the Council's responsibility was to form a committee within the Council to provide oversight to the implementation of the plan and to send an update to the Governor at least bi-annually.



Louisiana Council
Santee Winchell, Executive Director

The Louisiana Developmental Disabilities council supported The Autism Early Behavioral Intervention Project was an innovative practice initiative that succeeded in developing a coaching model for family members and Early Steps' providers to provide appropriate evidence-based interventions for young children with autism. The Autism Project was a joint effort between LSU Human Development Center, the Office for Citizens with Developmental Disabilities and the DD Council. The Council supported the project from October 2008 through September 2010 with \$120,000 of total funding.

Louisiana Council members and staff played a leadership role on the Act 648 of 2008 task force. This task force facilitated the interpretation and implementation of Act 648 of 2008 that required certain insurance coverage for the diagnosis and treatment of autism spectrum disorders for children under the age of seventeen.

Louisiana DD Council members and staff participate on the Louisiana State Autism Team of the Louisiana Department of Education. In addition to providing feedback on pending issues this team has developed and begun to implement action plans to address professional development needs for educators and others working with students with autism. Through these efforts a set of competencies for a tiered approach to professional development to train staff has been developed, and multiple training opportunities have been provided to build the skills of educators and pupil appraisal staff in the identification of autism and effective instructional practices and initial steps to build university programs and coursework to build skill sets across the comprehensive array of competencies have begun.



Maryland DD Council
Brian Cox, Executive Director

A Council representative was appointed by the Governor to the Maryland Commission on Autism, which was established by legislation to: advise and make recommendations about services and supports effecting people with autism spectrum disorders; develop a comprehensive statewide plan for an integrated system of training, treatment and services for people of all ages; and promote awareness. The Commission operates with subgroups and the Council participates on the Funding and Resources workgroup, ACT Early subgroup which looks at early intervention services, and the evidenced-based practices workgroup. When appropriate, we have discussed issues and ideas in the context of the needs of the broader developmental disabilities community. An interim report is due to the Governor and General Assembly in June. The focus will be on a comprehensive, state-wide plan to support children and adults with autism spectrum disorders across the lifespan.



Massachusetts Council
Dan Shannon, Executive Director

The Massachusetts Council has been involved in a number of autism specific activities/initiatives including:

- 1) Staffing and coordinating the newly formed MA Autism Commission.
- 2) Facilitating four task forces (by age group) to identify service and support needs and develop recommendations for the Autism Commission.
- 3) Conducting research and data analysis for policymakers on autism services, supports and funding mechanisms in other states.
- 4) Providing information and referral resources about the Autism Insurance law that took effect on January 1, 2011 and will require private insurance coverage by July 1, 2011.
- 3) Establishing on-line autism insurance resources in partnership with New England Index.
- 4) Supporting an Autism information specialist position at the MA Network of Information Providers.
- 5) Supporting two Autism advocacy organizations to participate in our cross-disability advocacy coalition.



Minnesota DD Council
Colleen Wieck, Executive Director

The Minnesota Council collaborated with the State Vocational Rehabilitation agency to develop an online employment resource for people on the autism spectrum ; the section contains 150 resources about employment/ASD/tech fields. The web-site address is:

<http://www.mncdd.org/asd-employment/index.html>

Additionally, the Minnesota Council is working on a different state grant re: emergency planning and individuals with ASD.



Nebraska Council
Mary Gordon, Executive Director

The Nebraska Council provided funding for two projects that involve autism. The first focused on training parents whose children are involved in a group therapy session that taught social skills to the children/youth with autism. The Council grant funded the development of a curriculum that was piloted with the parents so they could reinforce the skills being taught to their children outside of the treatment session.

The second grant funded by the Council supported the development of a curriculum as well as training to respite providers in the central part of the State. This training was directed at teaching respite providers the skills needed to care for individuals with behavioral issues, primarily autism, as it was very difficult for families to find respite providers willing to care for their family member.



New Hampshire DD Council
Carol Stamatakis, Interim Executive Director

The Council has provided financial support for the NH Council on Autism Spectrum Disorders, and multi-disciplinary, staffed state agency. This agency was established as a result of a commission that worked very diligently and made numerous recommendations to better serve people on the autism spectrum.. The NH Council on DD was a major player in getting the autism council established.



New York Council
Sheila Carey, Executive Director

The New York council has been active in working on initiatives related to early identification of ASD as an outcome of the Region II Act Early Summit. In addition, the Council has also participated in an Interagency Task Force on ASD which resulted in a report.

The DDPC developed a position paper that indicates that person-centered planning, not diagnostic categories, should be the focus. The Council will continue work related to helping the State meet the needs of people with complex medical and behavioral challenges.



Ohio Council
Carolyn Knight, Executive Director

The Ohio Council continues to collaborate on several initiatives to improve the lives of people with autism statewide. Work to revise and update the 2004 ODDC funded Autism Service Guidelines was completed. The revision extends the focus of the Autism Service Guidelines for Individuals with Autism Spectrum Disorder and Pervasive Developmental Disorder (ASD/PDD): Birth Through Twenty-One to include consideration for services for adults. http://www.ocali.org/up_doc/Autism_Service_Guidelines.pdf

In addition, the Ohio Council is a participating stakeholder in the Ohio "Act Early" action plan to enhance the capacity to respond to the increasing demand for evidence-based practices for children with ASD and related disabilities.



Oregon Council
Kathryn Weit, Interim Executive Director

The Council in Oregon has been actively involved in Autism initiatives. Council staff served on a legislative workgroup through 2009 and drafted an initial report that resulted in the Governor creating a state level Autism Commission. The DD Council received financial support from our Department of Human Services and the Department of Education to support the work of the Commission. Council staff provided their service to the Commission. Over 100 stakeholders were involved in subcommittee work. The Report to the Governor is posted on the Commission

website at www.orcommission.sd. The new Governor is in the process of developing another executive order to continue the work of the Commission and the Council will continue to facilitate and support the activities.



The South Carolina DD Council
Valarie Bishop, Executive Director

The SCDDC is very involved in autism projects. We are part of the ACT Early Team and have supported grant requests that were successful. We helped develop a roadmap to services and provide STAT training for a set of qualified providers statewide. Additionally, we are supporting the following initiatives:

- 1) Key Autism Indicators and Training (capacity to develop model program based on 8 key autism indicators that reflect quality programming & best practices)
- 2) Autism Training Collaborative (staff training across the life span - developing a roadmap, developing resources, etc.)
- 3) All are Welcome (develop a turnkey curriculum for faith communities to be a welcoming & supportive community for individuals with autism and other developmental disabilities)
- 4) Life Lessons (an after-school program for individuals with autism - teaching age appropriate social skill development in prep for successful employment)
- 5) Emergence & Stability of Autism in High Risk Infants (research project to study two high risk groups; will use as leverage to secure other funds)
- 6) Responsive Robot-Assisted Therapy for Children with Autism (research project to develop an adaptive robot system)
- 7) Child Health Services - evaluating pediatric health disparities (research project to explore state and national issues surrounding ASD and health disparities; will use as leverage to secure other funds).



South Dakota Council on DD
Arlene Poncelet, Executive Director

The South Dakota Council on DD has been a sponsor for the "Lighting the Way Conference: Autism in Our Community". This conference reaches 300-350 people annually. Attendees include parents, people with autism, educators, university education students, law enforcement, etc. Augustana College, SD Parent Connection, the Center for Disabilities and other organizations collaborate to plan the conference held each year in mid-June.

The SD Council on DD funded a project working with the Autism Society of the Black Hills on a recreation project, "Exploring Sports". Children and youth with autism were provided an

opportunity to learn about sports and practice in a non-competitive setting. The desired outcome was to enable children to experience sports and the “rules of the game” so that they will feel comfortable moving to inclusive sports settings.

The SD Council on DD is currently working with parents of children with autism in the Rapid City area to develop a post-secondary pilot program with one or two universities.



Vermont Council
Karen Schwartz, Executive Director

The Vermont Council is involved in the following initiatives: **MULTI-YEAR DEMONSTRATION GRANT:** Youth Employment Specialist (YES! Project) supports young adults with ASD and similar disorders through the youth employment specialist model to participate in work experiences that lead to successful vocational outcomes. YES had a 100% placement rate for participants who are young adults with autism or similar disorders not eligible for developmental services in VT. It created a promotional DVD that it uses with presentations about its successes. Initiatives also include social skills group & training for participants; PowerPoint for prospective employers; and Support Guidelines for hiring and maintaining employment of people with ASD & similar disabilities.

TRAINING: The Council co-sponsored with VT Dept. of Disabilities, Aging & Independent Living & Voc Rehab Division: "Developing Employment Opportunities for People with Autism", featuring self advocates describing what is needed to find and retain employment. Co-sponsor of Puppets in Education training "Helping Children Understand Autism Spectrum Disorder", that provides a foundation in supporting peers to connect with other children who happen to have autism through the Friend to Friend model. Co-sponsor with VT Dept. of Disabilities, Aging & Independent Living & Voc Rehab Division: "Bi-annual Communication Conference" to address needs of Vermonters with communication challenges that featured film *Wretches & Jabberers*, which follows 2 Vermonters with autism on a global tour to meet and support people using facilitated communication. The Executive Committee Fund grants to individuals with developmental disabilities & family members support attendance at conferences & trainings related to autism to learn more & be better advocates.

PUBLIC AWARENESS: The Council is a co-sponsor with Green Mountain Self Advocates and VT Center for Independent Living of 2 sold out showings of *Wretches & Jabberers* at the Green Mountain Film Festival, March 19 and March 27, 2011. That included advertising in Vermont's largely weekly newspaper *Seven Days* as well as website and program recognition. Co-sponsor of annual Disability Awareness Day on March 23, 2011, with theme and showing of film *Wretches & Jabberers*.

COALITION EFFORTS: There is a VTDDC member on the statewide Autism Task Force. We are also recruiting a member to serve on the Advisory Board focused on dissemination of information for a new federal grant for autism information, referral and assistance.



Virginia Board for People with Disabilities
Heidi Lawyer, Executive Director

The Virginia Board has been integrally involved in various state level initiatives including a legislative study, a workgroup convened to discuss an autism waiver, workgroups related to educational services for individuals with autism and employment initiatives among others. The Board is a partner and collaborator on autism specific initiatives as the Board has focused its initiatives on developmental disabilities broadly.



Washington State DD Council
Ed Holen, Executive Director

The DDC was instrumental in creating and implementing a waiver for children with DD needing intensive in-home behavioral supports that now serves about 60 families. To implement the CIIBS Waiver, the DDC met with policymakers to clarify certification and licensing barriers to contracting with professionals in the field. As a result, legislation was introduced to address workforce issues.

The DDC assisted the House Human Services Committee with obtaining testimony on best practices for diagnosing and treatment for individuals with Autism and their families. To educate policymakers, we assembled a panel of Medical professionals, parents, providers, and individuals with Autism.

Additionally, the DDC is an active participant on the Combating Autism Advisory Council. The CAAC has:

- improved communication between schools, parents, and professionals;
- streamlined the diagnostic process and referrals from communities;
- produced a community mapping tool that identifies local resources for screening, evaluation, diagnosis, and treatment of Autism and related disorders;
- conducted training on screening tools; and
- worked on insurance coverage for diagnosis and treatment.

The DDC and UCEDD communicate and collaborate frequently on the operation of Leadership Education in Neuro-developmental and Related Disabilities (LEND) that provides training to health professionals. The DDC works closely with the UCEDD's Community Disability Policy Initiative to identify the need for further research, training, educational opportunities, and policy development regarding Autism.

The Council publishes several magazines and have featured specific stories on Autism in our Crossroads and Kids' Crossroads Magazines. Crossroads reaches tens of thousands of people in the state every year while the Kids' Crossroads reaches thousands of kids in grade schools twice a year.

One Council member, a parent of three boys living with autism teaches Autism awareness at the local school and utilizes the Kids Crossroads magazine as a resource.

In addition, the Council has provided funding for Conference speakers featuring information and education on Autism.