

## NH Council on Autism Spectrum Disorders

### Meeting Notes

November 7, 2008

Bureau of Developmental Services  
105 Pleasant Street, Concord, NH  
Main Building, South Function Room  
Minute Taker: Virginia Smith, SMS

Council Members Present: Mary Heath, Matthew Ertas, Brian Balke, Kirsten Murphy, Michelle Jarvis, Amy Frechette, Brian Huckins, Teresa Bolick, Mary Schuh, Patty Willis, Debra McQuade, Robin Abbott, Paul Leather.

Others Present: Alan Greene, Sheila Lambert, Elizabeth Collins, Sue Langlois, Candace Lord, Santina Thibedeau, Julie Smith, Mary Lane, Suzanne Wichland Swett, Susan Covert, Lorene Reagan.

The NH Council on ASD held its second meeting on November 7<sup>th</sup> at the Bureau of Developmental Services.

### **GUIDING PRINCIPLES AND RECOMMENDATIONS**

Brian Balke made a motion, seconded by Theresa Bolick, that the NH Council on ASD vote to formally adopted both the Guiding Principles and Recommendations of the HB 396 Legislative Commission on Autism Spectrum Disorders that are found in the Commission's final report. These recommendations are essentially the work plan for the Council.

### **WORKGROUP REPORTS**

Council workgroups are in the process of being established. As new members are being sought, people were asked to try and make sure that there is good geographic representation on their committee. Committee chairs provide the following reports.

***PUBLIC AWARENESS COMMITTEE:*** Michelle Jarvis, reported that she has invited Dr. Langlois and representatives from PTAN, Headstart Education Center, IOD, and the ASNH to become members of the Public Awareness Group.

***SAFETY COMMITTEE:*** Michelle Jarvis reported that this committee is co-chaired by Elizabeth Webster and that DHHS, DOE, and NH Easter Seal Society are represented on this workgroup. The Committee will be contacting the NH Department of Safety, Police Standards and Training, and Fire Standards concerning implementation of Commission recommendations that involve their departments. The Safety Committee will be meeting in December at Easter Seals in Manchester.

***DATA COMMITTEE:*** Matthew Ertas reported that the committee will be breaking into smaller work groups to determine what types of data are needed and how to collect and disseminate this information. He said that the group is in the process of pulling together members and is still looking for representation from the DOE and IOD. Kathy Murphy said she will try to get someone from DOE, and Mary Schuh recommended that Peter Antal be asked to represent the IOD on this committee. Matthew shared information about data collection being done by the Area Agency in Nashua. In Nashua 21% of those served were identified as having ASD with 33% of those under 21 having this diagnosis. Council member Deb McQuade reported that these figures are a sharp increase from 1987 data for Nashua that indicated approximately 10% of those served had ASD.

Lorene Regan gave an update on the *NH AUTISM REGISTRY*. Stakeholders have been notified regarding the information being requested by the registry, information is available on the Bureau's website, and a brochure is being printed. Council members and workgroups will be asked to help get the word out. The Child Development Network has a meeting scheduled on December 4, 2008 and Lorene will attend to be sure those providers are familiar with Autism Registry Requirements.

Michelle Jarvis and Kirsten Murphy noted that the Autism Registry captures only those with a new diagnosis. The Council discussed having ASNH host a voluntary registry. Matthew suggested that once the mandatory registry was in place that efforts be directed to establishing an expanded voluntary registry.

***HUMAN SERVICES COMMITTEE:*** Brian Huckins reported that the committee will meet in November at Community Bridges. The committee includes representatives from Behavioral Health, ASNH, DHMC, and the Area Agencies. They are still looking for a representative from Public Health (Brian has a call into Audrey Knight and hopes that she will join the group.)

***SCREENING AND DIAGNOSIS COMMITTEE:*** Liz Collins said the group will meet November 13, 2008. Most committee members have been identified, however, they still need to connect with the IOD/LEND Program. Julie Smith, a new part-time employee of IOD/LEND, offered to join the committee. Michelle volunteered to help identify ASNH family members who might be interested in working with this group and said that she would attend meetings when she could. Teresa suggested asking Ruth Littlefield of DOE and Ted Wingate, a Child Psychologist in North Conway, to join this workgroup.

Liz reported that her agency has a small American Academy of Pediatrics grant to convene two "Open Forums" for providers, governmental and public stakeholders on early identification and screening and developmental resources for children 0-5 years of age. The first forum is planned for Spring 09 with one of the authors of Bright Futures and Dr. Carl Cooley on the agenda. These forums are open to Council members.

***EMPLOYMENT AND INDEPENDENT LIVING COMMITTEE:*** Sheila Lambert report that there are 15 individuals who have volunteered to serve on this committee. They are still hoping to get representatives from People First and the Council on Developmental Disabilities. Kirsten is a member of the Council on DD and will bring this item up at the Council's November meeting. Amy Frechette also recommended that Kathy Berger, UNH Director of Students with Disabilities, Stacy Shannon, M. McLeod, Maureen Lorden, and Wendy Watts be invited to join the committee. Other council members asked that this workgroup consider the needs of adults with Asperger's syndrome; many of whom also have secondary depression/anxiety disorders.

***EDUCATION COMMITTEE:*** Mary Shuh reported that the Committee is still being formed and will meet in December. Suggested members included: Sharee Sullivan from the NH Technical Institute in Concord, Bruce Mallory from UNH, and Carolyn Woodman from SERESC. Other representatives will be sought from Keene State College and Plymouth State University. Brian Balke offered to find a representative from public education to participate on this committee.

***INSURANCE COMMITTEE:*** Kirsten Murphy reported that the committee membership currently includes Michelle Winchester from the Health Law and Ethics Center at Franklin Pierce Law School; two parents; the Director of Kidz Play Janet Wright, which bills insurance for some of

their service; and representatives from Gateways Community Services, which has been experimenting with billing insurance for families enrolled in their new autism program. Kirsten plans to have the committee use a dual strategy in pursuing more comprehensive coverage for common treatment protocols: Working with legislators to introduce an autism insurance reform bill; and at the same time reaching out to insurance industry representatives to educate them regarding the need for better coverage and that fact that the impact on premiums has been shown to be minimal.

## **COUNCIL FUNDING**

Matthew Ertas reported that while there is a request in next year's budget for Council staffing, given the State's current fiscal crisis it is unlikely there will be funds for a full time executive director. At the request of the Bureau of Developmental Services, Kirsten Murphy has submit a proposal for the cost associated with buying out 16 hours a week of her time to provide professional support to the Council. Mary Heath of DOE said she will work with Matthew to fund a portion of the proposed amount. Council members suggested that the Endowment for Health could also be approached for funding.

## **COUNCIL LEADERSHIP**

The Council outlined the following responsibilities for the Council Chairperson

- Setting the agenda for Council meetings
- Facilitating Council meetings
- Helping to ensure that the workgroups are coordinating their efforts
- Overseeing the management of Council and workgroup minutes, reports, and other official paperwork

Teresa Bolick asked Michelle Jarvis if she would consider serving as Council Chairperson. Michelle said she was interested, but would like some time before making a decision. Mary Heath moved that if Michelle decided to accept the nomination prior to the next Council meeting, that Michelle become Chair and Brian Balke be Vice Chair. Mary Schuh seconded and the Council voted unanimously to approve this motion.

## **SETTING THE CALENDAR FOR THE YEAR**

Beginning in 2009, the NH Council on ASD will meet from 11:00 to 1:00 on the first Friday of every other month (with the exception of the first meeting which will be held on January 9<sup>th</sup>). The Coordinating Council, comprised of the chairs of the workgroups, will meet on November 21<sup>st</sup> and will set a calendar for their monthly meetings.

## **COMMUNICATING COUNCIL BUSINESS**

Council members agreed that every effort should be made to ensure that Council business and that of the work committees be transparent and easily accessible. Kirsten said that she has created folders for each workgroup on the E-Studio Website. BDS will send out information about how to access these. If you do not receive an email about this, please contact Lorene Regan at [LReagan@dhhs.state.nh.us](mailto:LReagan@dhhs.state.nh.us).