

The New Hampshire Council on Autism Spectrum Disorders
MINUTES
JANUARY 9, 2009

Bureau of Developmental Services
105 Pleasant Street, Concord, NH
Prepared by Kirsten Murphy

Council Members Present: *Brian Balke, Matthew Ertas, Amy Frechette, Michelle Jarvis, Brian Huckins, Dr. Debra McQuade, Mariellen MacKay, Patty Willis, Mary Schuh*

Council Members Absent: *Robin Abbott, Teresa Bolick, MaryAnn Cooney, Mary Heath, Paul Leather, Jose Montero.*

Others: *Liz Collins, Lorene Reagan, Sheila Lambert, Santana Thibedeau, Trisha Tilly*

Chair Michelle Jarvis called the meeting to order at 11:15 a.m.

It was noted that members from the Department of Education were at an emergency meeting regarding the state budget. Sheila Lambert and Santana Thibedeau were present to participate on their behalf. Dr. Jose Montero sent Trisha Tilly to participate on his behalf.

OLD BUSINESS

The minutes of the Council's November meeting were adopted with 3 corrections.

ROLES AND RESPONSIBILITIES

The Council discussed its obligations under New Hampshire's public meeting law.

As a deliberative body constituted by act of the NH legislature, Council meetings are open to the public and subject to all provisions of Title VI, 91(A) including the obligation to announce meetings in advance in at least two publicly accessible media. The group agreed to place the Council meeting schedule in – at a minimum – the Autism Society of NH's electronic calendar and the informational link that has been provided by the Bureau of Developmental Services. Minutes will also be available on the BDS link once they have been approved by the Council.

Kirsten Murphy noted that the law also stipulates that if a quorum is not present, the meeting cannot be held. There followed a discussion regarding several questions: How would the Council define a quorum? Should Council members be able to appoint an alternate in their place for a specific meeting and would the alternate have voting privileges? Do the provisions of NH's public meeting law – specifically Title VI (Chapter 91-A:2, 4) apply to work groups?

The Council agreed to have Matthew Ertas review these questions with the Department of Health and Human Services attorney and report back to the group.

The Council asked Kirsten to draft a set of guidelines addressing procedural issues such as tenure, membership, rotation, voting privileges, and the status of electronic voting. Brian Balke suggested that she consult the by-laws used by the NH State Advisory Committee for Children with Disabilities (SAC).

Matthew noted that we are trying to find a balance between meeting our obligations under the NH's right to know laws and the need to have work groups where participants feel comfortable exploring controversial issues or tentative.

WORK GROUP UPDATES

1. EDUCATION: Mary Schuh reported that their next meeting will be meeting Jan 15 Rm 12 at the Department of Education, 10 am to 12 noon.
2. HUMAN SERVICES: Brian Huckins reported the group has met once. He noted that planning for several of the recommendations assigned to this group were dependent upon knowing the budget for the next biennium.
3. EARLY SCREENING AND DIAGNOSIS: Liz Collins reported that they have had two well attended meetings. Through the American Academy of Pediatrics (AAP), her group has funding to sponsor two open forums, one on April 15 and the other in the fall, which will serve as an opportunity to promote the AAP's new guidelines for the management of ASD and the Medical home model, as well as NH's new reporting requirements (the Autism Registry).
4. DATA: Matthew reported that there are 12 participants in this group, including three family members. They are charged with developing and periodically publishing a report. Currently they are reviewing the existing relevant data sources.
5. INSURANCE ISSUES: Kirsten reported that the insurance group has not formally met. However, several members attended a meeting with staff from the NH Insurance Department and Rep. Suzanne Butcher (D-Keene). Rep. Butcher has filed an LSR for a bill that would mandate insurance coverage for the diagnosis and treatment of ASD.

REPORT TO THE GOVERNOR AND LEGISLATURE

Michelle advised that the Council is required by HB 1634 to provide the Governor and legislature with a report by April, 2009. To this end, all work groups have been given a common template in order to provide the Council with an initial work plan for each recommendation; an assessment of the resources already available and those that would be necessary to implement each recommendation; and their recommendation as to the sequence or priority of each recommendation

Discussion followed, providing a consensus view that since the Council is relatively new, the report will focus on a summary of the structure established; the individual work plans can be appended to the report. Additionally, the Council should ask that future reports not be due until summer, when the legislature is not in session and hence more available.

The Council charged Kirsten with collating the templates and revising them where needed. She will draft a narrative summarizing the priorities and themes that emerge from this review – draft to be circulated prior to the Council's March 6th meeting so that final revisions can be discussed and subsequently incorporated into the final report by its April 1 due date.

Brian suggested that the Council use the preliminary work plans to develop a strategic plan once the report has been completed.

FUNDING FOR THE COUNCIL

The Department of Education and the Bureau for Developmental Services have contributed approximately \$8500 toward the cost of a part time administrative director. \$28,000 would be needed to fund this level of support for a full year.

The group charged Kirsten with drafting a letter for Michelle's signature that could be used by other Council members to approach their department or organization for a contribution to this pool of funding.

Lorene Reagan, who has been providing much of the administrative support, noted that 2 days/week is the "absolute minimum" necessary to insure that the Council operate effectively.

POLICY REGARDING LEGISLATIVE INITIATIVES

Kirsten requested guidance from the Council as to the appropriate relationship of her work group on Insurance Issues to advocacy efforts on behalf of HB 569, which would mandate insurance coverage for the diagnosis and treatment of ASD.

Discussion followed where several issues were identified that require further research and conversation. These include the distinction between work groups and the Council, and relevant guidelines already established for state employees who serve on the Council.

As interim guidelines, members of the Council and its work groups should, with regard to specific legislative initiatives:

- Work groups do not have any specific legal standing, and so should refrain from advocating for specific legislation as a single, deliberative body. The Council, by contrast, is a legislatively constituted deliberative body that may, from time to time, chose to support specific legislative initiatives that are compatible with its mission and goals. Work groups should therefore not as a whole have a position with regard to specific bills and should therefore refrain from advocacy and should be so advised by their Chairs.
- Work groups are free to conduct research bearing on specific legislation; such research should be used to inform recommendations to the Council.
- Individual member of the Council or any of its work groups are free to advocate for specific legislation as NH citizens, but should refrain from referencing from identifying themselves in such a way as to suggest that their opinion is shared by the Council or any of its work groups as a whole.

The meting was adjourned at 12:30 p.m.

Respectfully submitted by,

Kirsten Murphy, Administrative Director