

**New Jersey Department of Health and Senior Services
Governor's Council for Medical Research and Treatment of Autism**

Meeting Minutes – October 5, 2009

6:00pm – 8:00pm

**Location: Department of Human Services, Division of Developmental Disability Services
Conference Room 199A
5 Commerce Way, Hamilton, NJ 08691**

Council Members Present

Caroline Eggerding, MD, Vice President Clinical Services, Bancroft NeuroHealth,
Assembly Speaker Appointee,
Chair of Governor's Council for Medical Research and Treatment of Autism

Susan P. Evans, EdD, Education Program Specialist for Early Intervention Program,
Commissioner of Health and Senior Services Appointee

Ms. B. Madeleine Goldfarb, MA, Founder/Director of the Noah's Ark Children's Association, Autism
Organization Representative

Jessica C. Guberman, PhD, Executive Director for Community Options, Inc., Autism Organization
Representative

Yvette Janvier, MD, FAAP, Medical Director for the Children's Specialized Hospital in Toms River,
Healthcare Organization Representative

Linda S. Meyer, EdD, MPA, BCBA-D Executive Directory of Autism New Jersey (formerly COSAC),
Autism Organization Representative

Kendell R. Sprott, MD, JD, Acting Director of Pediatrics, University of Medicine and Dentistry New
Jersey Medical School, Academic Institution Representative

Barbie Zimmerman-Bier, MD, Appointment at Rutgers University, clinician at St. Peter's University,
Academic Institution Representative

Absent

Grace M. Reilly, RN, MSN, APN-C, Adult Nurse Practitioner for Riverview Medical Center, Individual
with Autism or Family Member Representative

Mr. Judah Zeigler, Associate Vice President of Sharp's Retail and Consumer Marketing, Senate President
Appointee

NJ Department of Health and Senior Services (DHSS) Attendees

Gloria M. Rodriguez, DSW, Director
Special Child Health and Early Intervention Services

Michael A. Gallo, Jr., PhD, Executive Director,
Governor's Council for Medical Research and Treatment of Autism

Lori Garg, MD, MPH, Senior Public Health Physician
Special Child Health and Early Intervention Services

Diane DiGiovacchino, Administrative Assistant 3
Special Child Health and Early Intervention Services

Public Attendees

Audrey Mars, MD, Hunterdon Medical Center

Kathy Patrick, Easter Seals

Elizabeth Bell

Susan Freedman, Hunterdon Regional Autism Center and Special Child Health Services Case Mgmt.

Julie Caliwan, Department of Human Services, Division of Developmental Disabilities

I. Welcome

Meeting called to order at 6:08pm by Council Chair, Dr. Eggerding.

A. Introductory Comments by DHSS

Dr. Gloria Rodriguez welcomed and thanked everyone for attending.

II. Chair's Report

A. Approval of the August 3, 2009 Council Meeting Minutes

MOTION by Ms. Goldfarb: to approve the August 3, 2009 Council meeting minutes with no changes.

Seconded by Dr. Guberman.

B. Approval of the September 15, 2009 Conference Call Council Meeting Minutes

MOTION by Dr. Guberman: to approve the September 15, 2009 Council Meeting Minutes with no changes.

Seconded by Dr. Evans.

C. Conducting a Council-sponsored Needs Assessment

Dr. Eggerding stated that the October 5th meeting is the third time in which the Council will discuss conducting a needs assessment in order to better inform the Council in developing its strategic plan, and in developing RFAs for the next round of the Clinical Enhancement and Basic Science and Clinical Research grant programs.

Dr. Eggerding welcomed Drs. Joel Cantor and Dorothy Gaboda from the Rutgers University Center for State Health Policy. Drs. Cantor and Gaboda were in attendance to present a proposal to the Council for conducting a needs assessment. The proposal was structured in a general way, highlighting the techniques and approaches that the Center uses to collect information when conducting a needs assessment for an organization. Dr. Gaboda stated that the proposal will become more focused once the Council decides on the specific goals for the needs assessment.

Needs Assessment Proposal Presentation by Dr. Cantor and Dr. Gaboda

Dr. Cantor thanked the Council for inviting the Center to present its proposal to the Council. Dr. Cantor's presentation began with some background about the Center for State Health Policy, noting that it was established in 1999 with a grant from the Robert Wood Johnson Foundation. Dr. Cantor stated that the Center has a strong service mission "to inform, support and stimulate sound and creative state health policy in New Jersey and around the nation." He also noted the

Center has a history of working with various state agencies and the work they do is available on their website. The Center for State Health Policy has a staff of about 25.

Dr. Cantor presented a list of current research areas, a partial list of current funding areas, major funding sources, and also presented information about an ongoing project that focuses on issues that are similar to those present in the Governor's Council's proposed project.

As noted from previous conference calls, Dr. Gaboda presented the Council's objectives for a needs assessment:

- assist in identifying potential grant making priorities
- examine unique role of the Governor's Council in promoting excellence in clinical research studies and clinical diagnosis and treatment initiatives in New Jersey
- conduct a structured review of autism research in New Jersey and identify the existing gaps in research
- synthesize existing stakeholder perceptions
- compare funding strategies and results in selected states
- review published literature to identify knowledge gaps

Dr. Gaboda also proposed that the Council project activities take place in the following two phases:

Phase 1: includes activities that could inform the Council's deliberation and planning.

Phase 2: includes more detailed information in specific areas of interest.

A timeline of tentative dates and projected budget were also given to include the activities outlined in the presentation. However, Dr. Gaboda stated that the timeline and cost could change depending upon the size and scope of the project requested by the Council.

Questions and Comments

- Dr. Janvier, who is a member of the NIH's IACC (Interagency Autism Coordinating Committee), suggested that the needs assessment determine what is New Jersey's expertise in the field of autism. Dr. Janvier further stated that a comparison of funding strategies with other states may not be needed due to the amount of funding available in New Jersey.
- Dr. Bier would like to see an internal and external review of the Council's funded research and clinical projects. Dr. Bier would like the needs assessment address the question of how can the Council advance research in New Jersey? She suggested that the assessment review other programs and model New Jersey on existing programs.
- Dr. Cantor stated this type of analysis can be done; however, at the appropriate time more detailed information would be needed to do so.
- Dr Eggerding noted that in the past, grants were awarded based on quality of the grant process rather than on building blocks. She suggested both areas be looked at to help further the understanding of autism.
- Ms. Goldfarb expressed concern and hope that a needs assessment would help the Council to fulfill Legislation PL 2007, c.168 in establishing a Center of Excellence.

- Dr. Sprott noted that nothing has been done to assess the quality of research done. His concern with a needs assessment also applies to the Clinical Enhancement Centers. Additionally, from a policy perspective, he would like the assessment to inform the Council regarding some of the existing gaps in research and treatment. He would like the needs of providers looked at to determine gaps within the state, with an emphasis on how poverty and socioeconomic status impacts access. He would also like the assessment to give the Council a sense of the current, and expanding need for medical services.
- Dr. Bier reiterated that the purpose of a needs assessment is to look at what is currently funded and to outline what gaps can be filled through Council Request for Applications (RFAs). In order to move forward, an organization of programs is needed. Dr. Bier stated that currently there is a Clinical Enhancement Center Program without a coordinating center, and that there needs to be a review of the Council's manpower needs. She would like the needs assessment to address what can be expected from the Council as it is currently configured and how, given its current resources, can it best structure a granting process and strategy to fill existing gaps in research and treatment. The issue of which mechanisms should be developed to bring about funding initiatives to target areas of concern in research should also be addressed, and the PL 2007, c.168 legislation should be reviewed to interpret the meaning of a Center of Excellence.
- Dr. Eggerding noted that in regard to defining a Center of Excellence, this may be an opportunity to look at other states' experiences and see how they provide services and better determine how we can use our resources to become a Center of Excellence that can become a resource to all individuals that provide services.
- Dr. Gaboda suggested a combination of conducting interviews with stakeholders and reviewing existing information already available would be useful.
- Dr. Evans noted that part of the work of the IACC's strategic plan involved stakeholder input. She would like to see a comparison of research agendas and how New Jersey is fitting or not fitting into the national strategic plan. Dr. Evans noted that this type of approach could also help in defining a Center of Excellence for New Jersey.
- It was noted by Dr. Meyer that the data received from Rutgers would help shape the strategic plan developed by the Council and in order to get the optimal data the Council needs to define outcome, discuss what has been done to clarify timetable, and cost it out.
- Dr. Gaboda added that defining the Council's project would be a very interactive process between the Center for State Health Policy and the Council. The Center is depending on the Council for input.
- Dr. Meyer requested the names of other groups the Center for State Health Policy has done similar work for so that the Council can contact them. The Center will put together a list of three or four groups for the Council to contact.

Drs. Cantor and Gaboda take leave of the meeting.

MOTION by Dr. Janvier: To work with Rutgers University's Center for State Health Policy to develop a needs assessment, recognizing that it will be an interactive work in progress.

Seconded by Dr. Sprott.

Council Discussion

- Dr. Guberman asked if Rutgers was the only New Jersey provider and, if not, who else can present.
- Dr. Gallo explained that by using a quasi state agency the DHSS can use the Memorandum of Agreement (MOA) process which will allow the Council to move forward quickly with a needs assessment. He stated that if the Council were to go through the competitive bid process the timeframe would be at least one year before something is in place. Therefore, including Rutgers, there was a pool of three quasi state agencies considered. The two other agencies looked at were Rutgers University's School of Social Work, and UMDNJ's School of Public Health. Dr. Gallo commented that given that the Council was once housed at UMDNJ this could be a conflict of interest, and that the School of Social Work's focus would likely be more on the support services necessary for ASD individuals, and not on the research and treatment needed in the field.

Dr. Gallo stated that the Center for State Health Policy is a policy research center that works with organizations to take them from point A to point B, and that of these three agencies, the Center for State Health Policy was judged to best fit the needs of the Council. Dr. Gallo also added that he spoke with state employees who at one time were employed with the Center for State Health Policy and the feedback was that the Center was highly reputable.

- Dr. Meyer expressed her concern with voting prior to seeing a formal reference and with making a decision to work with the Center for State Health Policy because the process would be delayed six months by looking at other vendors. She stated that the fact is the Council could get wonderful information on process from other vendors and other opinions on what data collection process should look like. The Council has not had conversations with outside vendors.
- Dr. Rodriguez stated if the competitive bid process was undertaken, the Council would need to write the specifications for the proposal and would be unable to speak with any vendors. Speaking with a vendor would be perceived as the vendor receiving inside information, thereby disqualifying them from bidding on the project and compromising the bid process. Dr. Rodriguez asked the Council members to keep this in mind.
- Dr. Sprott expressed concern with the timeline. January 2010 doesn't look to be a realistic start time. Data needs to be provided and decisions on what the project will be must be determined. Additional meeting time is needed.
- Dr. Garg stated that the Center for State Health Policy has agreed to assist in the MOA development process.
- Dr. Eggerding also added that in addition to what the Council requests from a needs assessment the Council needs to think about what happens when the information is received. The Council's next step will be to develop goals and direction, and that this next step will take time.
- Dr. Rodriguez added that a MOA is a formal document. Specific and step by step information of what DHSS requires from the Center for State Health Policy, what the Center will do, and a detailed budget will need to be included. She further stated that it is the Council's responsibility

to develop specific activities for the Center. The MOA will be reviewed by DHSS' legal department and when signed by the Deputy Commissioner it will be forwarded to Rutgers for their legal and administrative staff to review. The process of writing an MOA and approval with signatures by both parties takes approximately six to eight months and is a legally binding document. If an MOA were already written the approval process would take approximately three months.

- Dr. Eggerding noted that the Council has a significant amount of work to address and asked the Council to consider scheduling additional meeting time together to work out issues relating to the needs assessment. Additional meeting time will allow the Council to determine how to move from the needs assessment results to a strategic plan, and to address issues the Council has tried to address through subcommittees work. To move a strategic plan forward, Dr. Eggerding suggested having a detailed discussion of what the Council specifically wants to address in the needs assessment. She wants to be sure Council members have an opportunity to be heard as everyone needs information to make decisions.
- Dr. Eggerding called for a vote to talk about the next step in accepting proposal from Rutgers. The vote was on moving forward with the Council being responsible for creating an MOA so Council can work on specifics of what the Council wants the Center for State Health Policy to do in conducting the needs assessment. This vote was proposed with the understanding that the Council will discuss how best to bring together the Council's ideas and get them on paper, and that moving forward was contingent upon checking the references that will be provided by the Center for State Health Policy.

Vote

Approve – 6

Oppose – 2

Motion passes.

- Dr. Rodriguez reminded the Council of their responsibility to determine the goals and objectives of a needs assessment, draft what it is they want the Center for State Health Policy to do, and ask the Center to cost it out.
- Dr. Janvier suggested an outline of areas to include:
 - The Council - not all Council seats are filled. The seats that are filled include professionals, individuals from agencies, and family representation. More input from family representation needed.
 - Research - research analysis of past projects and outcomes. Make recommendations for future projects and how do they fit in with the national strategic plan, and do we have issues in New Jersey of particular importance.
 - Clinical Center(s) - how does the Council create a Center of Excellence. There are many definitions for a center of excellence, and most include clinical research as a key component. Dr. Janvier believes the Council is looking for minimal common standards.
- Dr. Bier suggested that the Council members' own resources in bringing projects to completion be thought about. The resources being referred to are work with the clinical centers and with research projects. Dr. Bier also stated that the Council needs to consider what it needs in terms of infrastructure and administration.

- In order to fulfill the Council's obligation under legislation Ch 2007, c.168, Dr. Eggerding proposed the Council invest a greater amount of time together to address significant issues.
- Dr. Sprott suggested a retreat and Council members are in agreement. Dr. Gallo is to give some proposals so that the Council can conduct its retreat before year's end.
- Dr. Jessica Guberman is highly uncomfortable with the language of having a retreat. She would like to see funding spent elsewhere.

Dr. Linda Meyer extended an invitation to everyone to attend Autism New Jersey's 27th Annual Conference on Friday, October 9, 2009, as it is likely that Governor Corzine will be in attendance at 12:45pm.

III. Executive Director's Report

A. Future Funding of the Clinical Enhancement Grant Program

Dr. Gallo asked Council members affiliated with any of the Clinical Enhancement Centers to recuse themselves. This included: Ms. Goldfarb, Dr. Janvier, Dr. Sprott and Dr. Bier
Council members remaining: Dr. Eggerding, Dr. Evans, Dr. Guberman and Dr. Meyer

- Dr. Gallo noted that DHSS proposed a non-competitive renewal to the current six grantees so that the agencies would have more time to develop their programs. Dr. Gallo stated that in renewing the grants it will be of paramount importance that the DHSS provide ongoing monitoring of the Centers to ensure that the grantees meet their goals and fulfill their obligations.
- Dr. Gallo stated that he did receive an email from Dr. Meyer asking why the current six Clinical Enhancement Centers are being looked at as a block. Dr. Gallo responded by noting DHSS' grant management manual indicates that just cause (for example, inappropriate use of funds) is needed to drop a grant. He noted that some grantees have had more difficulties than others, but that without just cause to remove a given grant, the DHSS' position is to work with the grantee to help it succeed. Support will be provided by DHSS to what is currently in place to enable the Centers to reach their goals and serve the community.
- Dr. Gallo continued to state that the main charge of the Council is to create a Center of Excellence in New Jersey. The Council is working on what that definition means, but at this time, the current model is that of a collection of six centers.
- Dr. Gallo presented the funding options for the Clinical Enhancement Grant Program which include the following approaches:
 - Retain current model. Make no changes to scope of grant program.
 - Two Options: non-competitive renewal or open RFA.
 - Retain the six Centers with major modifications to the terms and scope of the grants.
 - Two Options: non-competitive renewal of 1, 2 or 3 years or open RFA incorporating modifications.
 - Pursue a new model for a Center of Excellence.
 - One Option: develop an RFA for a new model of a Center of Excellence in New Jersey.

Comments

- Dr. Susan Evans does not see it as a model that needs major modification, but refining of model as the grant program continues. She noted the Clinical Enhancement grant process began before the Council moved to DHSS, and that she does not want to see the program dismantled. Rather, she would like to see one year of a non-competitive renewal with the grants undergoing refinement, and then at the end of year 3 announce grants to be awarded through the competitive process. She wants to see the program succeed and to have DHSS help make that happen.
- Dr. Guberman asked about option 3 which includes a 9-12 month extension to the current Centers, and stated that if the current Centers can respond to an open RFA, then services would essentially continue.
- Dr. Gallo responded by saying yes the current Centers would be able to apply and that other agencies would also be able to apply.
- Dr. Eggerding voiced her concern with options 2 and 3 because in order to continue with major modifications to the program, the Council would need to be ready to agree on what those modifications will be. She struggles with what the goals of a Center of Excellence are. For example, she wonders whether the Centers were meant to see all individuals with autism in the state of New Jersey.

She noted that the Centers could not support this as currently funded. Each Center has a different view of its obligation and each Center has its own area of expertise. There is no uniform process within the six Centers with regard to serving individuals with autism in New Jersey. Core agreements to what the Centers need to do must be determined, as well as how individuals with autism in New Jersey will have equal access to excellent care. She would like to see the Centers move toward ensuring equal access and providing quality services. She believes that to do so requires retooling of grant. Also, Dr. Eggerding is concerned with the small number of Council members present in making this large decision.

- Dr. Evans noted that a non-competitive renewal allows the Council time. Time to review data from the Centers and from the needs assessment. All of this information will help enable the Council to formulate what it would like the Centers to look like.
- Dr. Guberman asked about meeting the Principal Investigators from each Center. This issue was discussed on the Council's September 15, 2009 conference call.
- It was reiterated by Drs. Eggerding and Gallo that this could potentially be problematic from the stand point of having each individual Principal Investigator talk about their program in front of the Council that funded them. Time constraints are also an issue.
- Dr. Susan Evans asked the Council members to have faith and trust with DHSS monitoring the grants. The intent of the monitoring process is to safeguard state resources. If problem areas are identified by the DHSS, corrective action will be taken.
- Dr. Meyer stated she does not think that the trust is there. She stated that she does not have enough information and noted she did request a one page summary from each Center which was to be signed by the Principle Investigator and immediate supervisor. The one page summary was to include a list of grant activities, areas where grantees fell short, and an outline of the plan

to correct problems. She does not want to deny services and is willing to agree to a one year non-competitive renewal. However, in order to support this motion she would like for the public to know, via the Council's website, which Centers are falling short, and what they agreed to in their grant applications.

- Dr. Rodriguez noted that the six Centers currently funded were not funded as a Center of Excellence, but as Clinical Enhancement Centers to increase and enhance services. When the Council was moved from UMDNJ to DHSS the Clinical Enhancement grants were also moved. The Council at this time does not have in place the criteria for what constitutes a Center of Excellence.
- Dr. Meyer questioned, even if the Center of Excellence were removed, did the grantees meet their goals? She noted that some grantees did not and some sites did not meet milestones.
- Dr. Gallo noted that performance benchmarks have not yet been developed.
- Dr. Evans stated that though data is not consistent across sites it is similar and is in keeping with the overall goal of enhancing services. Even for those agencies that are not data rich many activities reported are enhancement of clinical services.

MOTION by Dr. Meyer: grant a non-competitive extension of one year to the six Centers with increased transparency and accountability to the Council and public.

Seconded: Dr. Evans

Vote

Approve – 3

Oppose – 1

Motion passes.

- Dr. Rodriguez noted that information is available under OPRA (Open Public Records Act). Individuals from the public can submit a request to DHSS in writing and by law a response must be given within seven days. There is a minimal charge involved.
- Dr. Meyer does not see this as transparency. Responses to requests can take longer than seven days and it can be difficult to interpret data. She would like to see the status of each funded agency posted on the Council's website in easily described language.

IV. Public Comments

Kathy Patrick

Ms. Patrick is a parent of a child with PDD-NOS (Pervasive Developmental Disorder – Not Otherwise Specified). She supports Dr. Meyer's call for Council transparency and accountability. She stated that she accessed the Council's website and noted that a large amount of money is being granted to agencies. From a provider's perspective she encourages Council members to have clear, consistent and executable expectations and that the sites receiving funds are in need and reputable.

Elizabeth Bell

Ms. Bell is a parent of a 16 year old with autism. She expressed parental frustration with the desire to get more information and to tighten things up, but also caution not to slow the process down so

much. She is in favor of the commitment the Council made to get together more often. Ms. Bell is concerned with a needs assessment as there is no state that has a statewide Center. Rather, she stated, centers are usually institution-based and tied closely to a principal investigator. So, the idea of looking at New Jersey as compared, for example, to the University of Washington, is a challenging one to accept. The Council has an opportunity to look at what is a Center of Excellence and determine gaps. Ms. Bell suggested focusing on translational research. She also asked the Council to move faster.

Julie Caliwan

Ms. Caliwan noted that one-half of the Council members in attendance had to recuse themselves from the meeting during the discussion of renewing the Clinical Enhancement Centers. She questions if this is something that is acceptable were it to also occur at the Council's retreat. She suggested the Council's by-laws be checked.

Dr. Audrey Mars

Dr. Mars asked if the public would be able to take part in the development of a strategic plan.

Note: Dr. Gallo responded by saying testimony will probably be taken from the public.

V. Action Items

- Dr. Eggerding asked that those issues independent of the vote be made available to those Council members that needed to recuse themselves from the meeting.
- Drs. Gallo, Guberman and Meyer will develop parameters for transparency and once the report is completed Dr. Gallo is to have it posted on the Council's website.
- Dr. Guberman, a member of the subcommittee formulating Council policies and procedures for supporting other autism organizations, asked that the unsolicited application request process and the public relations plan that she drafted be addressed at the next Council meeting. She noted that if the agency funding proposal is not addressed by the Council, the subcommittee can not move forward in its work.
- A letter to the Governor is to be developed which will address the need for the remaining vacant Council seats to be filled. Dr. Rodriguez suggested that this letter be signed by all of the Council members.

VI. Next Meeting

The next meeting of the Governor's Council for Medical Research and Treatment of Autism is scheduled for December 7, 2009, 6pm – 8pm at the Department of Human Services, Division of Developmental Disability Services, 5 Commerce Way, Hamilton, New Jersey.

MOTION by Dr. Eggerding: adjourn meeting.

Meeting adjourned at 8:13pm.