



# Council on Children and Families

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## Meeting Summary

**Navigating Multiple Systems Advisory Council**  
NYS OASAS, 1450 Western Avenue, Albany – 4<sup>th</sup> Floor Conference Room  
February 18, 2014 – 1:00 p.m. – 3:00 p.m.

## Advisory Council Members Present

**Deborah Benson**, Council on Children and Families

**Christopher Cargain**, NYS Office of Children and Family Services

**Patricia Donohue**, NYS Division of Criminal Justice Services (by telephone)

**Barry Donovan**, NYS Office of Alcoholism and Substance Abuse Services

**Zachary Garafalo**, YOUTH POWER!

**Victoria L. Gray**, NYS Department of Labor

**Robin Hickey**, NYS Developmental Disabilities Planning Council

**Logan Joseph**, NYS Office of Temporary and Disability Assistance

**Michele Juda**, Parent-to-Parent of NYS

**Mary McHugh**, NYS Office of Mental Health

**Cheryl Ohanesian**, State Education Department

**Danielle Olsen**, NYS Office of Alcoholism and Substance Abuse Services

**Stephanie Orlando**, YOUTH POWER!

**Susan Perkins**, Council on Children and Families (by telephone)

**Paige Pierce**, Families Together in New York State, Inc.

**Davin Robinson**, NYS Justice Center for the Protection of People with Special Needs

**Jean M. Sadowy**, NYS Office of Mental Health, Western NY Field Office

**Janet Sapio-Mayta**, Council on Children and Families

**Susan Slade**, NYS Department of Health

**Nicole Suto**, NYS Office for People with Developmental Disabilities

**Kerry Wiley**, NYS Developmental Disabilities Planning Council

## Project Team

**William McLaughlin**, William McLaughlin Associates, L.L.C. (by telephone)

**Fredda Merzon**, Fredda Merzon Associates

**Rebecca Meyers**, Independent Consultant (by telephone)

**Robin Miller**, Council on Children and Families

**Bill Przylucki**, Council on Children and Families

## Initial Project Goal Statement:

**Navigating Multiple Systems (NMS)** is a statewide, collaborative initiative led by the Council on Children and Families in concert with a broad-based advisory council. With initial grant funding from NYS DDPC, NMS will develop information tools and resources (primarily but not necessarily technology-based), aimed at improving the understanding of and access to appropriate services for children/youth with multiple needs and disabling conditions, their parents and other family members needing to investigate or rely on supports and services from multiple child-serving, state agency systems.



**Andrew M. Cuomo**  
Governor

## Council Member Agencies

State Office for the Aging \* Office of Alcoholism and Substance Abuse Services  
Office of Children and Family Services \* Division of Criminal Justice Services \* State Education Department  
Department of Health \* Justice Center for the Protection of People with Special Needs \*  
Department of Labor \* Office of Mental Health \* Office for People With Developmental Disabilities  
Office of Probation and Correctional Alternatives \* Office of Temporary and Disability Assistance



**Deborah A. Benson**  
Executive Director

## ➤ **Welcome and Introductions**

Debbie Benson welcomed everyone. Attendees introduced themselves.

## ➤ **Project Status Report**

Robin Hickey provided an update on NMS funding Issues. Robin told the Council that the project proposal for second year funding passed the first two approvals of the Children’s Issues Committee and the DDPC Executive Committee. The proposal is scheduled to be voted on by the full Developmental Disabilities Planning Council on March 13. All parties remain hopeful for second year funding approval.

Bill Przylucki explained that the information gathering phase of the project has concluded and we are now moving into the solution definition phase. Bill asked the group if they had any comments, questions or concerns about the two survey summaries and the worker/provider interview summary. The group agreed that useful information was gathered and that some of the findings were unexpected. Bill explained that much of the information gathered from our outreach was used in the development of the Proposed Project Approach document.

## ➤ **NMS Project Approach**

Fredda Merzon led this session and began by reminding the group about the importance of the project engagement that occurred as a result of our survey, interviews with front-line staff and in-person meetings, noting that the people we have engaged will become part of the NMS audience and potentially assist in the marketing and direction-setting of the NMS website and any further products.

Fredda then asked for Council members’ reactions to the proposed project approach. She asked what particularly resonated with people – what was good and what, if any concerns existed. She asked if people thought we were on the right track.

There was general agreement among the group that the components listed in the proposed project approach were components that address many of the needs identified by the outreach conducted. One member mentioned that the components listed would address some of the issues experienced recently by a family member. Paige Pierce talked about the length of time this project has been considered and the change in focus from providers to families. She thanked the Council and DDPC for moving this project along so collegially and for being on the road to creating something tangible to help families and youth with the challenges of navigating multiple systems.

### **Some of suggestions in addition to the listed components included:**

- Providing information on how agencies work together.
- Developing a “preview pane” with an image of the website being linked to.
- Being sure to include family support and empowerment tools, things like:
  - information on upcoming trainings,
  - support groups

- information on how to ask the right questions
- guides similar to the autism tool
- peer advocates
- Link to national and regional websites that list services.
- Opportunity to coordinate with the NYS Parenting Education Partnership (NYSPEP), which is building a website that will include a look-up to find coursework, training, etc.
- Phone or contact information when available.
- Interface that contains a series of questions to get users to the right information – a decision tree
- Excellent search feature – Google search was discussed as the best search programming, but should be built into a customized search wizard.
- Information on eligibility and managed care.
- Look at what other states are doing. Fredda explained that we have already started reviewing websites and gathering information. So far, Wisconsin seems to have the best navigating website.
- An evaluation/user satisfaction dimension should be built into the website.

**Some of the concerns voiced by the group included:**

- Families and youth face complex problems. There will still be barriers for families and youth because of rigidity in some policies and rule-bound practices.
- Sustainability in the context of keeping information up-to date was voiced by a few people. Robin Miller addressed this concern by explaining the plan to develop a secure, multiple-user level, web-accessible back-end for staff to log-in to add, edit and update their data. She also discussed a notification process where CCF staff would be notified of updates and review, update and “make live” data uploaded by agency staff and providers. There was also discussion of ensuring a commitment to keep information up-to-date and if the commitment could not be made, then to limit the scope of content to content that has a commitment by agencies to be kept up-to-date.
- A question was asked about ENGAGE and NMS and overlap. The plan is for NMS’ evolution to draw at least partially from ENGAGE. NMS has the same goals and objectives of ENGAGE and will contain multiple tools to assist families in navigating across systems. This is an excellent line of questioning that will continue to be addressed through branding, messaging, marketing and programmatic discussions.

➤ **Advisory Council Work Groups Formation and Next Steps**

The Advisory Council discussed the development of the work groups listed below to be organized over the following month:

- Marketing and Promotion
- Continuous Quality Control and Improvement
- Sustainability
- Content Development

It is expected that each work group will meet monthly, with phone/web meetings as necessary. There may be staggered start-up of work groups and times where work groups will be more and less active depending on tasks at hand. Bill asked Advisory Council members to think about which work groups they would like to participate on. He also asked Council members to think about recommending staff from their agencies and organizations, (both centrally located and from around the state) with specialized expertise.

The point was made that there will be a great deal of overlap between the work groups. To help address this concern, at least one member of the NMS Project Team will be present at each work group meeting. This team member will be informed about tasks undertaken in other work groups. Work groups will report out at quarterly at Advisory Council meetings.

Based on discussion and concurrence among Advisory Council members, sustainability issues will be addressed by each of the other three work groups and a recommendation was made that a separate sustainability work group may not be immediately necessary. However, this discussion will be revisited in light of the possible need to search for financial resources beyond DDPC funding.

The NMS Project Team tweaked the work group descriptions document based on comments from this meeting. *(Revised work group descriptions attached)* The Project Team will reach out to the Advisory Council with a tool to assist members' solicitation of work group involvement.

#### ➤ **Other Business**

Some positive comments were voiced about the direction and work of the NMS project to date. Debbie discussed her commitment to work with agencies and to keep the Governor's Office informed of this initiative. The value of all the policy-directing data that was gathered from our survey and interview outreach phase was also discussed.

#### ➤ **Adjourn**

There being no further business, Advisory Council participants were thanked for their generous contribution of time and talent and for their ongoing commitment.