



# Council on Children and Families

52 Washington Street \* West Building, Suite 99 \* Rensselaer, NY 12144 \* Phone: (518) 473-3652 \* Website: [ccf.ny.gov](http://ccf.ny.gov)  
Facebook: [www.Facebook.com/NYSCCF](http://www.Facebook.com/NYSCCF) and Twitter: <https://Twitter.com/NYSCCF>

## Meeting Summary Navigating Multiple Systems Advisory Council NYS OCFS, 52 Washington Street, Room 102 South Building October 3, 2013 – 1:00 PM – 2:30 PM

### Advisory Members Present

**Deborah Benson**, Council on Children and Families  
**Regina Canuso**, Council on Children and Families  
**Mary Coppola**, NYS Success  
**Barry Donovan**, NYS Office of Alcoholism and Substance Abuse Services  
**Janice Fitzgerald**, Parent-to-Parent of NYS  
**Zachary Garafalo**, YOUTH POWER!  
**Victoria L. Gray**, NYS Department of Labor  
**Kathleen Griffin**, NYS Office of Children and Family Services  
**Robin Hickey**, NYS Developmental Disabilities Planning Council  
**Vicky Hiffa**, NYS Office of Children and Family Services  
**Carrie Holmes**, YOUTH POWER!  
**Tom Homovich**, NYS Office of Temporary and Disability Assistance  
**Gerald Huber**, NYS Office for People with Developmental Disabilities  
**Michele Juda**, Parent-to-Parent of NYS  
**Kathy Kingsley**, NYS Office of Temporary and Disability Assistance  
**Janine Kruiswijk**, Autism Society of America, Albany Chapter

**Heather Lacis**, NYS Office of Alcoholism and Substance Abuse Services  
**Elana Marton**, Council on Children and Families  
**Mary McHugh**, NYS Office of Mental Health  
**Maria Morris-Groves**, NYS Office of Alcoholism and Substance Abuse Services  
**Stephanie Orlando**, YOUTH POWER!  
**Susan Perkins**, Council on Children and Families  
**Paige Pierce**, Families Together in New York State, Inc.  
**Jean M. Sadowy**, NYS Office of Mental Health, Western NY Field Office  
**Susan Slade**, NYS Department of Health

### Project Team

**William McLaughlin**, William McLaughlin Associates, L.L.C.  
**Fredda Merzon**, Fredda Merzon Associates  
**Rebecca Meyers**, Independent Consultant  
**Robin Miller**, Council on Children and Families  
**Bill Przulucki**, Council on Children and Families

### 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 various 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 of People With Developmental Disabilities  
Office of Probation and Correctional Alternatives \* Office of Temporary and Disability Assistance



**Deborah A. Benson**  
Executive Director

## ➤ **Welcome/Introductions/History Purpose and Progress**

- Attendees introduced themselves and Debbie Benson provided a recap of the project and reiterated the primary focus of this initiative being family and youth.

## ➤ **Activities Reports and Discussion**

### • **Project Work Plan – Rebecca (Becky) Meyers**

Becky Meyers, the Navigating Multiple Systems (NMS) Project Management Advisor, guided the group through the attached overview of the work plan and project schedule. Becky explained that the document she shared with the group was a high-level plan and should be viewed as a schema. The project will proceed in a series of overlapping steps and will be adjusted as more is learned about the needs assessment and solution definitions.

Becky identified product procurement time as a foreseeable risk. Procurement is contingent on the design and development strategies and cannot be defined until the NMS team's information gathering outreach activities are completed and evaluated.

### • **Adult Engagement, Outreach and Survey – Fredda Merzon**

Fredda Merzon discussed four parent interviews she conducted and noted that she heard consistent themes in the interviews. Listed below are some of the most prevalent themes:

- The process of getting assistance was difficult and frustrating.
- The process required an enormous amount of persistence.
- Agency staff was not always familiar with the range of services/supports available and there was a gap between requesting services and receiving them.

Working with parent organizations, it was determined that development of a survey would be the most effective way to reach families. The interview responses along with input from parent and family organizations were used to develop the parent/caregiver survey instrument. The survey was launched on September 11, 2013 and the attached survey summary was developed based on the 211 responses received as of September 24, 2013. Parent/caregiver outreach continues while we are also focusing on the youth/young adult population as well as the "third cohort" – professionals/providers.

The group discussed the inclusion of doctor's offices and schools in NMS marketing efforts, as well as the availability of up-to-date printable resources.

- **Youth Engagement, Outreach and Survey – William (Bill) McLaughlin**

Bill McLaughlin began by discussing the dual purpose of this outreach phase of the project – information collection and engagement. Receiving feedback and engaging the appropriate individuals and organizations is vital to the implementation and success of this project.

Bill discussed his experience with youth focus groups and his quick realization that the same interview questions and survey tool used for parents and caregivers could not be used for youth and young adults. During the focus groups that Bill facilitated, he altered the discussion with youth by phrasing the questions hypothetically and as such received a much more positive response.

A draft youth survey was distributed to the Advisory Council before the meeting and Bill asked for and received feedback on that draft. Bill is working with youth organizations to be sure that the final survey is “youth-friendly.”

Bill asked about the best way to reach youth and handed out index cards for Advisory Council members to provide outreach ideas to reach each of the three cohort groups:  
1) Parents/Caregivers; 2) Youth; 3) Mixed Population (Professionals/Providers)

Youth organizations felt strongly that in order to receive maximum youth participation, the survey should be developed in a printable version for youth to fill out at meetings. The NMS team will provide both a printable and an electronic version of the survey.

A suggestion was made to add recovery supports as an option to the question related to challenges youth/young adults may need help with. (This option has been added to the survey.)

- **Third Cohort (Professionals/Providers) Engagement, Outreach and Survey – Bill McLaughlin**

Due to time constraints, it was determined that this topic could not be addressed in this meeting. Bill asked attendees to list ideas for third cohort engagement on the back side of the distributed index cards.

In addition, a conference telephone call meeting will be convened for Advisory Council members wishing to participate in a discussion about outreach plans with a third cohort. The Project work team will meet in advance to prepare staff and Advisors for that conversation.

- **Advisory Council Members Participation to Date and Future Involvement**

Debbie thanked Advisory Council members for their engagement and participation to date and advised them that as this project advances, the project team will be reaching out to many of them for more specific involvement.

➤ **Primary Funding Partner Remarks**

Robin Hickey (DDPC) discussed one of the biggest challenges facing this project is determining exactly what tools need to be developed and how people will use them. Robin mentioned that DDPC will work to figure out how to better reach doctor's offices with information about DDPC services based on what was learned from the survey's high response rate indicating that doctor's offices were primarily the first place parents and caregivers looked for assistance and information.

➤ **New Business/Next Meeting/Adjourn**

A suggestion was made to keep future Advisory Council meetings to at least two hours – this meeting was shortened due to unanticipated circumstances. The next (2-hour) meeting of the Advisory Council will be scheduled for January, 2014 – a meeting notice will be sent in the near future.

A suggestion was also made for the Project Team to engage the NYC Oversight Committee for better representation from the New York City region. That work has begun.

Finally, ideas relative to maintaining cultural and linguistic sensitivities throughout the NMS life cycle derived from comments shared earlier in the meeting were reiterated, elaborated upon and taken under advisement.

The following documents are attached:

- Overview of the Work Plan and Project Schedule (most recent – this document was adjusted slightly based on discussion from the Advisory Council)
- Parent/Caregiver Survey Description and Link to Survey
- Youth/Young Adult Survey Description and Link to Survey
- Printable Version of Young/Adult Survey