

Meeting Summary

Navigating Multiple Systems Advisory Council

NYS OASAS, 4th Floor Conference Room 2B

June 26, 2013 – 9:30 AM – 11:30 AM

Advisory Members Present

Debbie Benson, Council on Children and Families
Donna Bradbury, NYS Office of Mental Health
Regina Canuso, Council on Children and Families
James DeLorenzo, NYS Education Department
Mary Ann DiChristopher, NYS Office of Alcoholism and Substance Abuse Services
Kris Freitag, Parent Representative
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 (by phone)
Gerald Huber, NYS Office for People with Developmental Disabilities

Dan Hulihan, NYS Office of Children and Family Services
Michelle Juda, Parent-to-Parent of NYS
Logan Joseph, NYS Office of Temporary and Disability Assistance (by phone)
Kathy Kingsley, NYS Office of Temporary and Disability Assistance (by phone)
Janine Kruiswijk, Autism Society of America Albany Chapter
Phyllis Morris, NYS Office of Temporary and Disability Assistance
Liz Morrisey, NYS Department of Labor
Cheryl Ohanesian, NYS Education Department
Stephanie Orlando, YOUTH POWER!
Janet Sapio-Mayta, Council on Children and Families

Project Team

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

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 exclusively 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.

This Advisory Council meeting was the official launch of the Navigating Multiple Systems (NMS) project. The meeting was both productive and informative. The rich discussion contributed to the development of the project goal statement written above. In response to some concerns raised during the meeting, staff were asked to make a few distinctions among the topics discussed, as well as clarify what the project **IS** and what the project **IS NOT**. This project **IS** a collection of tools to make navigating systems easier for our main audience – **parents, youth and families** – it **IS NOT** an active form of advocacy or policy change. NMS may produce information, data and anecdotes that at times may enter policy discussions. Two of the vehicles for addressing policy change are the *Senior Staff and Family and Youth Partners Workgroup* and the *Commissioners' Cross-Systems Workgroup*. Throughout this project we expect to learn more about desired policy changes. Issues will be collected and addressed through the vehicles mentioned above as warranted.

➤ Welcome and Introductions and Overview of the Project

- Debbie Benson (CCF) gave an overview and history of the project.
- Robin Hickey (DDPC) discussed her interest in the project both as a funder and as a parent. She discussed the lack of “good” information and the “silos” that exist and the difficulties connecting different systems.

Participants were asked to introduce themselves and their affiliation and mention their hopes for the project. Below is a sampling of some of the themes mentioned as hopes for this project.

- Development of a technological solution that meets the needs of youth and families.
- A final product that provides easy access to all children and families and supports cultural diversity.
- Development of a solution focused on the family and child health first, opposed to expertise or silos that are driven by agency policy.
- Development of online tools that support agency staff and families and the increasing foster care population.
- Learn from mistakes of the past. Develop something creative that looks at issues differently.
- Develop a tool that provides positive outcomes for youth and families.
- Hope is that systems can be more flexible. Find a way to work with complex kids across time. Learn to avoid situations and be proactive. Stop repeating the same mistakes.
- Build something that is unique and useful and provides some assistance to struggling families.

➤ Vision of the Project: The Results We Want to Achieve

Participants were asked to write on index cards what products and resources they envisioned being developed through this project. Below is a sample of some of the more popular themes and suggestions.

Suggestions that were more policy-focused have been documented and retained for future reference.

- Cross-systems resource directory including a mapping feature to help locate resources in the community–web-based and a cell phone application with real-time information.
- Development of mobile apps for youth, families and frontline workers.
- Printed resource guides.
- Webinars for families and front-line workers that provide information from multiple systems and can be easily accessed.
- Web Portal and/or Telephone Assistance.
- Long-term data system for tracking outcomes – what worked and what didn’t for decision-making and resource allocation decisions.
- Screening tool to connect youth and families to each system.
- Transition tool – e.g., a tool to assist youth transitioning to adult services.
- Text and Talk Support Line.
- Tools and or navigators that are linguistically and culturally sensitive, competent, or have access to translation/interpretation services.
- Expanding and/or informing 211 call centers regarding cross-system resources.
- Communication tools – newsletters and social media.
- Videos

- An admin area for agency staff to keep resource information up-to-date.
- An acronym dictionary.
- Cross-systems triage – a method to obtain assistance when users are unable to find what they need from Navigating Multiple Systems resources.

➤ Collecting the Perspectives of Users

Participants were asked to identify groups of people to conduct focus groups, interviews and possibly on-line surveys. From the long list of suggestions provided, the project team will begin with the following groups:

- Parent-to-Parent of NYS
- **YOUTH POWER!**
- Families Together, Inc.
- Youth in Progress
- SED Parent Information Centers
- NYS Success-Systems of Care Expansion Counties – CCSI – Local-Regional Cross-Systems groups (*i.e., RiTAT Leaders*)
- Global Majority/Racial and Cultural Minority Populations
- Autism Society

Positive Thoughts

- Part of the value of this project is its involvement in pathways to policy change and collaboration, especially for children and families involved in multiple systems.
- Many tools already exist and could be incorporated, linked to or built upon. Mapping on KWIC, MyBenefits, Text4Baby, NY-Connects, NY-ACTS.
- Consider apps for kids. Most kids have phones. Most kids text. Keep in mind the youth component and how comfortable they are using technology.
- This project goes hand-in-hand with managed care.
- This project is an opportunity to create new partnerships to provide better services.

Cautions

- Need to incorporate a means to keep information up-to-date.
- Information isn't lacking – information needs to fit reality. Need navigation tools to get something that is actually helpful.
- If we don't think broadly, we won't create something that works.
- Everyone has to agree that health is the primary concern.
- Need to consider front-line workers.
- Must build tools that are culturally sensitive.
- Substance abuse intersects with all agencies. Everyone is struggling with managed care.
- Training won't work. Need a tool – videos, texting.
- Navigating can have multiple meanings.
- Although we are in the exploration phase, we need move steadily towards producing products.

Action Steps/Progress

- Project team will meet to digest meeting findings and distribute findings and next steps to the Advisory Council. *The project team met and this meeting summary details the findings and next steps for this project.*
- Need to get the Department of Health at the table. *The Council has started conversations with the Department of Health to ensure their involvement with this project.*
- Need to leverage agency resources. *The Council is researching potential agency resources to learn more about what is currently available.*
- The project team will define a project goal statement that is manageable and leads to real products. *Please see Project Goal statement on page one of this document.*
- The project team will gather input from potential NMS users through focus groups, surveys, and interviews. *The Project Team has identified initial outreach groups and has begun communicating with these groups to develop methods for gathering valuable input.*

➤ Next Meeting/Adjourn

- **October 3, 2013**
1:00 – 2:30 p.m.
NYS OCFS, 52 Washington Street, Rensselaer, Room 102 South