



# **Children's Mental Health Plan Youth Advisory Workgroup**

**Draft Report of Workgroup Proceedings**  
December 17, 2007 – April 15, 2008

Division of Children and Families  
Office of Planning  
New York State Office of Mental Health

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The ideas and recommendations expressed in this draft report reflect those of the individuals participating in the workgroup and not necessarily those of New York State agencies serving children and families. The mention of specific interventions or service models does not imply endorsement by these agencies.

The Office of Mental Health would like to extend its gratitude to each workgroup member and all who contributed to the development of this report.

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Children's Mental Health Plan  
**Youth Advisory Workgroup**  
**“Shifting our focus to ABILITY, not DISability”**

**I. Background**

Involving youth in the development of the Children's Mental Health Plan was always of critical importance. When the Office of Mental Health began to reach out to a wide variety of individuals to participate in workgroups, youth representatives were top on the list. In collaboration with YOUTH POWER!, of Families Together of New York State, a number of youth were asked to become participants of the workgroups to enable there to be two members on each of the four groups. Youth representatives attended our Kick-Off Meeting on December 17, 2007, with the other participants and were asked to become full and active members on all scheduled workgroup meetings and conference calls. The Children's Mental Health Plan process represented an unprecedented level of youth involvement than ever before.

*“Providers should meet with the individual before they read the file so they can know you as an individual first not just what is in your file or the label you have.” “I am not my label.”*

As the workgroups began to meet, it became clear that there were a number of barriers that kept youth from playing active roles. Namely, workgroup calls were scheduled during regular business hours—hours when youth were tied up primarily with educational and work activities; members needed to have access to computers to participate in the web-based conference calls; and, most importantly, the amount of background material to review and e-mails messages related to the work were overwhelming. We realized that there was actually an opportunity to more fully involve youth in the process than we had imagined.

When these challenges were identified, the Office of Mental Health met with Stephanie Orlando, the Director of YOUTH POWER!, to discuss other approaches to involving youth. Collectively, it was decided that a fifth workgroup would be created, comprised solely of youth, known as the Youth Advisory Workgroup. This workgroup would engage in conference calls each week, for six weeks, to discuss the purpose of Children's Mental Health Plan and each of the four other workgroup topics. Through this process, all youth would be able to provide feedback and input into all the recommendations that were beginning to emerge from each workgroup.

To facilitate this process, Stephanie Orlando agreed to serve as chair of the Youth Advisory Workgroup. All youth were provided with a “Youth Guide” to each of the four workgroup topics prior to each conference call. These guides introduced each topic area with background information and explanations of concepts. They also summarized the preliminary recommendations being generated in each workgroup to solicit youth feedback and opinion on the direction the groups were taking. To ensure active participation, conference calls were held at the end of the business day, from 4:00 – 5:00 p.m.

Not surprisingly, attendance and participation on the calls were very impressive. Youth came prepared with ideas, thoughts, and written notes. They identified areas that were missing, language and strategies that needed to be clarified, and suggestions for how to improve all areas of child-serving systems in general. The end result was pages of strategies and approaches that represented a true depiction of “youth voice.” While each workgroup was provided with the feedback from the Youth Advisory Workgroup as it pertained to their topic, below is a summary of the major content areas and subsequent suggestions identified by the workgroup.

*“The way you treat people should be the same for everyone, but understand every one is different.”*

## **II. Problems Identified**

Members of the Youth Advisory

Workgroup were very passionate about dispelling the myths and preconceptions that people had about mental health. They wanted everyone to know that “mental health issues are common and having a mental health challenge is not bad; that good things can come of it.” They wanted to see a different approach to service provision, one that involves them and their families, listens to what they have to say, and focuses on their abilities, not just their disability.

With a focus on developing skills and attaining goals, the youth felt that services should “help children to be healthy and help make them strong for facing life’s challenges.” This includes providing them with the skills to cope and manage their symptoms, but also to “encourage people to do what is important to them so they can go forward in life.” The values of resilience, youth development, empowerment, and recovery were heard time and time again.

As for child-serving systems, they felt services should be seamless. In other words, “Children and their families should not be like ping pong balls bouncing from one place to another to get what they need to be healthy. Doctors and therapists should do their best and not keep on telling kids and parents that they need a better doctor or therapist...constantly being evaluated but not seeing results or getting help.”

The youth identified the frustration they and their families felt when they were unable to get the services they needed. Conversely, if children and families began to make good progress, often staff turnover caused them to start again. One youth shared, “You build a relationship with someone and then you have to start over with someone new. There should be a better transition.”

Most importantly, they indicated that there is no recognition of what they had to offer the system themselves. Having other peers to talk to or walk them through the system was very helpful for many of the youth. Being empowered to help others and share their

*“Be realistic without lowering expectations.”*

ideas to support a peer or improve the system seemed to be better than any treatment they received. They saw a great need to increase the use of peer

support programs and services. In addition, having youth serve as trainers, advocates, and policy makers would not only improve our systems for the better, but enable youth to attain the necessary developmental and professional skills they need for a successful future.

What follows is a listing of key areas for improvement and strategies Youth Workgroup members identified.

### **III. Key Areas for Improvement**

- Increasing Awareness and Reducing Stigma
- Enhancing and Expanding Peer Support and Youth Involvement
- Improving Workforce Education and Training
- Coordinating and Integrating Systems and Services
- Enhancing Individualized Care and Promoting Youth Development
- Enriching School Environments and Opportunities for Learning

### **IV. Strategies**

#### **Increasing Awareness and Reducing Stigma**

- Create a marketing/public education campaign (like the Tobacco TRUTH campaign) to change the culture around mental health and increase competency and tolerance for everyone.

- A task force should be created to focus on developing a campaign and how to implement it successfully
- Change the terms “Special Education” and “Consumer” to something less stigmatizing and isolating.
- Promote and market the youth involvement, what it is, how to do it, what the benefits of youth involvement are for both youth and adults, etc. Marketing should include written materials, posters, a website, etc.

## **Enhancing and Expanding Peer Support and Youth Involvement**

### *Peer Support*

- Expand definition OR create a separate definition of Family Support to include Youth/Peer Support.
- In all recommendations, include youth language when “family” is used for support and engagement. Youth and peer support includes:
  - Programs and services to support youth provided by BOTH adults and youth (e.g. youth talking to other youth about mental health in schools or serving as peer support when a youth needs another youth to talk to);
  - Youth providing advocacy to and for other youth (e.g. a youth participating in another’s treatment team meeting to advocate for services and supports); and
  - An infrastructure for a Youth/Peer Support Movement that mirrors the Family Support Movement.
- Utilize youth as outreach workers on home visits to engage youth in services.
- Include youth advocates at team meetings to support and assist youth in the process. These must be youth/peer advocates rather than adults. Their roles can include meeting with the youth prior and helping prepare them for the team meeting.

### *Youth Involvement*

- Increase research to show youth involvement works.
- Create stable funding mechanisms to support youth involvement as advocates or advisors. These include part-time and full-time jobs for youth and attendance at

team meetings, advisory groups, panel presentations, planning and policy development meetings, leadership trainings, etc.

- Develop and provide training for youth to be or do advocacy work and for adults to work with and partner with youth.
- Create Youth Advisory Councils in all child-serving systems, including schools, youth bureaus, social services, etc. Youth can help to develop programming and serve as leaders for other youth.
- Utilize youth as trainers or presenters to teach students/workers what is important and how they feel.

### **Improving Workforce Education and Training**

- Create innovative educational programs for future workers who will serve youth with mental health challenges, so that they can experience and empathize with the youth's experiences. This can include having future social workers or direct care staff spend a night in a psychiatric hospital as a recipient of services to understand the setting and experience from a patient perspective.
- Training students in college on recovery, the CASSP principles, cultural competency, and current evidence-based practices. Teach them how to focus on what youth can do and what accommodations they may need to be successful.
- Train on good verbal skills— Being genuine and speaking at the youth's level, talking to youth as persons and not talking "down" to them. There should be respect.
- Educate providers how to be sensitive to the youth culture and ensure rules are developmentally appropriate. Providers should work with youth as partners, not in a rigid, authoritarian way, but rather by having conversations and setting guidelines.
- Teach sensitivity to workers, such as how to be empathic, respectful and gentle, even when setting rules or boundaries.
- Train workers on how to handle disruptive and acting-out behaviors in a constructive manner to reduce restraints. This includes, improving verbal skills, communication, and de-escalation skills. Create and train on alternatives to restraint and traditional de-escalation methods—these include creating calming, relaxation or rage rooms.
- Include a strong trauma focus in training to acclimate workers to the effects of violence and how viewing or experiencing violence can trigger responses in youth.

- Help to teach parents about trauma and triggers and how to recognize symptoms when challenges first arise
- Inform teachers and other individuals working with youth about triggers, trauma issues, and how to recognize symptoms.
  - This can be done by helping parents to create an early intervention/prevention plan for all caregivers, including babysitters.
- Train individuals working with youth on warning signs of crisis situations and how to handle them.

### **Coordinating and Integrating Systems and Services**

- Share information by having all case workers involved with the youth share case notes and progress reports.
- Reduce multiple intakes and/or assessments by:
  - Coordinating information across-systems (e.g., one case file for all systems)
  - Pooling questions into one multi-system form.
- Develop coordinated multi-system case management. When youth are involved in multiple systems and assigned more than one case worker, they must work together and communicate regularly to ensure they are consistent and that there is no duplication of services. It would be preferable if they:
  - Developed a single and agreed-upon treatment plan
  - Defined what each of their roles would be in working with the youth and family
  - Work from the same set of goals to be accomplished
  - Have joint meetings with the youth and family
- Ensure services are provided collaboratively and consistently to both a parent with a psychiatric disability **and** their child who has mental health challenges. One example of why this is important is when the parent and youth have different case workers and each provides different information or rules about what can and cannot be done.

### **Enhancing Individualized Care and Promoting Youth Development**

#### *Individualized Care*

- Ensure team meetings are value-driven and child-centered. The team meeting process has worked in accessing necessary services; however, the experience for youth itself has not been empowering or respectful. Suggested enhancements and changes to culture and tone of meetings include:
  - Ensure that the meeting is not solely focused on past mistakes or behaviors, and acknowledge the changes and progress that youth have made recently (a laundry list of wrongdoings is not helpful).
  - Adults should include youth as equal and active members of the team and the input of youth should be valued, and they should be given the opportunity to speak and make suggestions for services and supports.
  - Ensure youth are talked with and not just talked about; discussions must include youth. (e.g., conditions and guidelines can be agreed upon rather than lectures and rules given)
  - Have youth run the meetings or have youth advocate or family led meetings; this requires that materials and information are shared beforehand to allow them to prepare to lead.

### *Youth Development*

- Ask youth questions about how they are feeling before there are problems.
- Allow youth to talk about and explain how they feel rather than just being given a quick diagnosis.
- Educate youth on their diagnosis—what the diagnosis means, what the symptoms are, how to control symptoms, what helps, etc. Teach youth about the physical side effects of their medications.
- Teach youth how to be positive role models for themselves and for others in regards to their diagnosis and mental health challenges. Youth should not be told they cannot do things due to their illness—this can lead to depression, removal from activities and possible school dropout.
- Empower youth to know that having a mental health challenge is not bad and that good things can come of it. Educate youth that mental health issues are common.
- Encourage youth to exercise and eat healthy for own physical wellness and teach how it can impact upon mood, etc. Stress the positive (e.g., don't push the point with youth that they are fat due to medication side effect)
- Youth with mental health challenges should **not** be taught or learn self-helplessness. Rather, they should be taught independence, self-care, resilience, youth development, etc.

## **Enriching School Environments and Opportunities for Learning**

### *School Environments*

- Administrators should visit the schools on a more regular basis, get to know the students, and be able to see that staff knows students are happy and staff are good.
- Allow youth to rate and evaluate teachers on a regular basis.
- Offer driver's education for students not in mainstream education schools and classes.
- Make sure teachers are using creative ways to engage students—hands-on teaching, activities, discussion, etc.
- Reach out to students in need through more phone calls home, teacher-parent conferences, tutoring, etc.
- Help to make schools safe and secure; make them more of a controlled environment, especially in the lower grades by increasing supervision, such as increasing the number of security guards, school resource officers, and hall monitors.
- Help students transition easier (from placement or other non-mainstream setting) by providing more tutors and one-on-one help; with supports youth can be successful.
- Institute a “pass system,” and have available a designated place youth can go to, allowing them to take breaks when needed, talk to someone or go to a safe space when they need to.
- Increase after-school activities and programs—drawing, crafts, hobbies, bowling, etc.
- Utilize in-school suspensions rather than out-of-school suspensions.
- Make sure kids with MH challenges achieve all of their educational requirements so that they can receive a Regents diploma. This can be done by ensuring that teachers in hospitals and placements are qualified/certified to teach Regents courses OR make sure that these placements can make accommodations for youth who are able to complete Regents-level work. There should not be an assumption that youth with MH challenges cannot be academically successful.
- Teachers should get to know youth before they get into the class so that the teachers can know the stressors or triggers that affect youth. This can be done by including teachers in wraparound meetings the summer before school starts.
- Reduce the segregation of special education students from mainstream classes— integrate them into the school community, including programs, clubs, and recreation.

- Inform youth about their IEP earlier, when they are in elementary school, so they are familiar with their plan.
- Encourage kindness and team building between students early so that schools can reduce bullying.
- Institute homeroom each morning for both middle school and high school as a way to start the day for all school programs.
- Expand curriculum to address feeling, emotions, and health in addition to the core courses—youth should be involved in the development of this social/emotional curriculum so that it can include a youth voice and perspective.
- Teachers and counselors should encourage all youth to graduate, go on to higher education, specialized training or vocational education; they should have reasonable and high expectations for all youth—challenging them and encouraging them at the same time.
- Utilize assistive technologies to support and enhance youth skills and abilities.

#### *Opportunities for Learning*

- Provide general mental health and wellness education—who to talk to, how to recognize signs, and where to go for help. This also can include anti-stigma and anti-bullying education.
- Teach youth positive skills like understanding emotions, how to cope with stress, promoting healthy behaviors, as well as reducing risky behaviors like drug use with education about co-occurring disorders.
- Include independent living skills in school education, for example, how to pay bills, manage money, etc.
- Include education on social skills, including etiquette and interpersonal skills.