

Meaningful

CSHN program directors must establish a rationale and defined role for their YAC. However, youth leaders need to help create the vision of the work to be accomplished. The role that youth play as advisors must be meaningful, clear, and connected to outcomes that they see as important.

A lot of thought and planning went into preparing for the initial meetings of Maine's Youth Advisory Committee back in 1999 and 2000. We realized that, while youth needed to have a context to the work, the work needed to be kept open-ended enough to allow them to make their own meaning of the work as well, and shape the direction of the YAC within a framework of advising the CSHN program and addressing the program needs. We drew a great deal on our experience working with the Family Advisory Council (FAC).

During the initial meetings youth engaged in trust and community-building activities. They came from all parts of the state and did not know one another. Then, through a variety of processes (differentiated to address learning styles and needs) they discussed ideas and challenges they faced in school, their transition, health and health care. Collaboratively they helped define their roles and expectations, and the outcomes of their work. In addition to supporting their community-building, this helped considerably to understand the issues youth were facing and to define and refine the role of the YAC to influence the policy direction and practice of the CSHN program. Together they developed working conditions to ensure they could complete their best work in a safe and supportive environment. All of the sessions were designed to build on the youths' previous knowledge, and helped them to recognize that they were a learning community, and could learn from and with one another. Quickly the participants came to appreciate the diversity of experiences and knowledge that each member of the group brought to the work, and came to understand that their success required both group and individual accountability.

It was clear that the youth needed specific tasks to keep their focus and momentum! But, having such focus greatly contributed to the youth taking ownership of the work and their role as advisors. For one of our first activities the youth designed, organized and delivered two statewide conferences for youth on youth leadership, advocacy and transition. The youth leaders designed and delivered a wide variety of workshops and facilitated discussion groups. Most importantly, they took the lead in designing and preparing workshops, and designed conference materials! Topics covered during these events included health, college, independent living, and employment.

YAC member: "It was great to see our hard work come together in the end. We had a great turnout and it was so exciting to see the faces of all the youth who attended and realized the possibilities of what they could achieve or become involved in!"

Maine involves youth in...Policy! Evaluation! Professional development! Materials development and dissemination!

Informative

The work of Youth Advisory Committee members can (and should!) inform both the CSHN program and the youth themselves. By working collaboratively with their peers, and other experts and leaders, in ways that effectively engage learning, all benefit from new knowledge and information that is timely, useful, relevant, and valuable for the CSHN Program, the youth with special healthcare needs, and those who support them.

A number of factors influenced our work in this area. Our participatory needs assessment found that youth wanted (and needed) to learn to speak up for themselves, and others wanted to hear directly from them about what they wanted in order to inform policy and practice. And, maybe even more importantly, our initial work with the YAC demonstrated for us the incredible knowledge and insight the youth themselves had to share. The youth (and their families) shared the challenges they were facing, the issues and frustrations that characterized their daily lives. We charged the youth with changing the scene—what would you tell folks if you had the chance?

The YAC designed and delivered a series of presentations that they titled YOUTHSPEAK. The presentations were designed to share information about the needs and desires of youth, and were directed to a number of different audiences: policy makers, educators, parents, employers, healthcare providers, and peers.

Youth leadership sessions were conducted in collaboration with partners across the state to support youth learning to personalize and conduct YOUTHSPEAK presentations to a wide variety of audiences. Teachers, school nurses, medical students, legislators, parents, and peers were provided interactive learning sessions, led by youth, which were (and are) positively received across the state.

One young man became a believer in the power of speaking his truth when an audience member told him she would teach differently due to what she learned from him, that “a teacher’s attitude can disable a student more than a physical handicap.”

Health Care Provider: “Including all youth as active participants in their care is key.”

Peer: “Today I learned how to treat a person who has a disability with respect, just like anyone else.”

Parent: “The presentation reinforced for me that kids with disabilities want the same things in life that everyone else wants.”

Maine involves youth in...Policy! Evaluation! Professional development! Materials development and dissemination!

Purposeful

Youth advisory activities must be purpose-driven. For what reason do you want and need youth engaged? Youth need to clearly see the connection between their contributions and the relevance and timeliness of the work and issues to which they are "assigned." Our experience has shown that youth can be committed to improving services provided through CSHN and other programs!

Following receipt of Maine's Integrated Services initiative, our YAC met in a two-day retreat to learn about and discuss the project designed, and the roles and responsibilities in which we hoped to involve them. Our D-70 grant is designed, in part, to collect information from youth and family members with special healthcare needs across the state of Maine, related to the extent to which Maine's community-based system of care is consistent with MCHB's six national performance measures. In our grant application we had proposed using a "Report Card" based on the M & M Indicators our Utah colleagues had designed.

The meeting started with an overview of the purpose and goals of the upcoming project. Participants engaged in a variety of activities to promote discussion and understanding of the project. They then discussed the importance of collecting timely data to inform policy and practices within the state from those most impacted. The draft report cards were then introduced to the team. YAC members broke into small groups to review, refine, and revise the report cards. The small groups came together and reported recommendations to the large group, the large group discussed and accepted recommendations to improve the report card and, in particular, to make it "youth-friendly." The YAC then developed a collaborative action plan followed up by on-going meetings to disseminate the report cards to youth with special healthcare needs and their families.

Our Regional Youth and Family Facilitators are currently disseminating the "report cards" to youth and young adults across the state to evaluate the extent to which the Maine CSHN program is achieving a community-based system of care consistent with MCHB's six national performance measures. The analysis will be used to inform the Block Grant application, and state priorities.

Maine involves youth in... Policy! Evaluation! Professional development! Materials development and dissemination!

Valuing Voices ≠ Support

Authentic engagement of youth requires a significant commitment of time and resources. However, our experience has demonstrated that it is critical and necessary (and well worth it in the end). Like all of us, youth must feel valued in order to do their best work. Meetings, materials, and "assignments" must be relevant, occur at times that make sense for them (Saturdays!) and accessible. But, just as importantly, fun, energy, and opportunity should characterize the ultimate outcomes.

We've done a great deal over the last eight years that demonstrate how we value the voices of youth and are committed to providing "whatever it takes" to support their active engagement. We have provided compensation for their contributions (both annual stipends and hourly, or per diem, honoraria), and reimbursed mileage and out-of-pocket expenses, including meals and personal assistance. We've provided opportunities for youth to share their knowledge, and experience as youth leaders, as presenters across the state of Maine and the United States. Our retreats are held at fun places that have pools, hot tubs, and good food!

To ensure that all participants are able to actively participate in meetings we have utilized many strategies. For instance, we have provided youth email accounts when necessary. We have utilized teleconferences when necessary. We have long provided support and logistics related to transportation to meetings and YAC activities, including presentations and other assignments (committee representation, for example).

Another way in which we have supported the participation of all youth is by partnering members to work together. Jesse was very nervous and had never spoken publicly, but wanted to share his story at a youth conference. So Elijah and Jesse worked together to create the presentation, and Elijah served as narrator while Jesse advanced the slides. A few months later Jesse felt comfortable enough to share his own story and proudly presented at a New England Regional conference.

All of the YAC meetings infuse the elements of Celebratory Learning to promote a fun and engaging environment conducive to learning and active participation. We use a variety of structures and differentiated strategies throughout the day to allow for small and large group work, as well as individual reflection and processing time. It is important to remember to involve the youth in determining next steps and outcomes to maintain relevance. We regularly involve youth in designing the meetings and retreats, and make sure that time for fun is built into the day.

Youth: "We always include time for fun and activities to get to know each other at our meetings. Because of that I've become friends with the other members and look forward to future projects and meetings!"

Maine involves youth in...Policy! Evaluation! Professional development! Materials development and dissemination!