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Section 9:
Beyond
Meeting
Participation

Beyond Meeting Participation

There are huge benefits to engaging your service population in policy and program decisions. However, while your board may recognize the need to increase family and youth involvement in policy decisions but may not be at a readiness level to begin that immediately. There are other steps your board and agency can take now to recruit actively, acknowledge, and utilize the perspective of consumers on your services.

It is important to remember that bringing on a family or youth board member before your board is ready can be more challenging than it needs to be. Therefore, properly identifying steps based on your board's readiness is a prudent choice in moving this effort forward.

1. Understanding alternative ways to engage families and youth
2. Focus groups and key informant interviews with families and youth
3. Surveys
4. Ad Hoc Committees
5. Advisory Council or Committee
6. Going to the families and youth
7. Using existing infrastructure to access family and youth input
8. Using technology to access family and youth input
9. Example Materials

These strategies can supplement the family and youth members on your board. You may find that a combination of options will be best for your board. *These strategies are also important for boards with active involvement already underway, as they expand the diversity of family and youth voices included in a decision-making process.*

Barriers to boards receiving family input:

- Feedback provided at the grass-roots practice level does not make it to the board level;
- There is no structure in place for the board to receive service level consumer suggestions;
- There is no designated person or resources associated with cultivating this perspective; and
- Fear of retribution if not positive feedback

- This is not a board priority.

Suggestions for board level engagement from service level consumers:

- Dedicate funds to support time and materials for a board designee (see below);
- Provide for two individuals versus only one will provide a consistent voice and a more secure support system
- Establish a board designee (not a service provider or manager), who is tasked with bringing input to the board level and developing a communication pipeline between consumers and the board; and
- Create a regularly scheduled time on the board's agenda to address feedback and response.

Strategies to bring the family and youth perspective to your board include:

- Focus groups;
- Key informant interviews;
- Surveys;
- Ad hoc committees;
- Advisory groups;
- *Hosting casual lunches to dialogue about activities and services*
- Drawing from existing family and youth engagement venues; and
- Using technology to access family and youth input.

Focus Groups and Interviews³

Focus groups and key informant interviews are commonly used research strategies for gathering information from families and youth beyond the boardroom. Which strategy you use depends on your goal in gathering information from families and youth, so it is important to have a clear understanding of what you wish to accomplish before setting out. In many instances, you may find it helpful to conduct both kinds of interaction with families and youth, since what you learn from each strategy may inform different aspect of your decision-making. The more richly informed your decisions, the more effective they will be!

Focus Groups. A focus group is a controlled group interview of a target audience. The facilitator leading the interview covers a set series of questions or topics. A focus

³ Health DATA Program – Data, Advocacy and Technical Assistance. The UCLA Center for Health Policy Research, http://www.healthpolicy.ucla.edu/HealthData/pdf/hd_factsheet.pdf

group might provide the opportunity for participants to address any ideas they have for improvements and needed changes. Because the purpose is to learn without bias what the focus group participants think about the topic issue or issues, the facilitator keeps his or her own opinions and experiences private, engages in no analysis, and in general confines his or her role to merely eliciting a discussion amongst the participants. We recommend that translation services be provided when necessary to minimize language barriers.

Focus groups should not be conducted unless resources are also available to compile and analyze the information from the focus groups. Analysis includes reviewing all of the information with an open mind, identifying themes and key examples such as quotes, and reporting the results in a format that is accessible not only to your board, but also to the participants of the focus groups. Finally, it is also important to disseminate the results of the groups to all the participants, so that they can see how the information they provided is being used.

Benefits of focus group sessions include improved perceptions by board members on the issue or issues, better informed decision-making, and a decrease in the kind of misconceptions that can lead to ineffective decisions or slow down your decision-making.

Youth may facilitate a youth focus group – on-line, through a social marketing venue or in person. Youth may be in the best position to gain accurate and telling feedback from other youth.

Primary reasons to use focus groups include:

- The need to collect data, evaluate services, or test new ideas;
- Capture valuable information on perspective of the consumer
- To understand better opinions, beliefs, and attitudes;
- To review and test the assumptions of target audiences;
- To identify gaps between the perceptions of different stakeholder groups;
- To encourage discussion about a particular topic;
- To learn more about a specific topic or business issue; and
- To build rapport with consumers.

Key Informant Interviews. A key informant interview is a qualitative, in-depth, one-on-one interview with someone who knows what is going on in the community on a particular issue. Key informant interviews are useful when you are seeking detailed

information on a specific topic or when your board wants information that may not be disclosed easily in a group setting.

When conducting key informant interviews, it is important to interview someone from each major stakeholder perspective, so that your results are not skewed by the omission of a major perspective. For example, key informant interviews might be conducted with family members, youth, local service providers, and a family advocate all involved with the same systems. Key informant interviews can be conducted on the phone or face-to-face.

Just like focus groups, key informant interviews should not be conducted unless resources are also available to compile and analyze the information. Analysis includes pulling themes from across interviews and identifying the areas of disagreement or conflicting views. Reports generated from key informant interviews often include quotes from the participants, with the names and identifying information kept confidential.

Primary reasons to use key informant interviews include:

- To understand the motivation and beliefs of community residents on a particular issue;
- To get information from people with diverse backgrounds and opinions and be able to ask in-depth and probing questions;
- To discuss sensitive topics, get respondents' candid discussion of the topic;
- To get the depth of information you need from individual or small group discussions (two to three people maximum);
- To create a comfortable environment where the interviewee engage with you in a frank and open discussion;
- To get more candid, in-depth answers about an issue; and
- To explore ideas about changes needed and strategies to accomplish such changes.

Focus Group, Key Informant Interview, or both? In the ideal situation, both are generally best, but ultimately it depends on your goal in gathering information from families and youth. The focus group dynamic may prohibit you from candidly discussing sensitive topics or getting the depth of information you need. Sometimes the group dynamic can prevent some participants from voicing their opinions about sensitive topics. On the other hand, a one-on-one key informant interview engages just one person's perspective at a time, so you may miss the kind of insight that comes from the group discussion dynamic.

Ensuring confidentiality / anonymity. Depending on the nature of the topic, you may need to let key informants and focus group participants know that you will not use their names or any other potentially identifying information in the resulting final report or recommendations. You will want to assure families and youth that their responses will be kept confidential, and that the results will focus on the content of the discussion rather than identifying who said what. Confidentiality whenever possible may encourage participation, open dialogue, and the expression of true opinions more freely.

Surveys⁴

Traditional methods of determining mental health consumer needs tend to be based on professional input only, which can inhibit good policy development. While progress on addressing mental health consumer needs has been achieved when shared goals have been identified, it has also been hindered by the lack of known areas of consensus between stakeholder groups. Establishing *both* shared goals *and* areas of consensus between stakeholder groups greatly increases the chance that a group of diverse stakeholders will be able to move forward effectively.

Surveys can be a cost-effective method of discovering and documenting shared views from those stakeholders with the greatest stake in the size and direction of the mental health service system. Identifying shared views is necessary to coordinating stakeholder efforts—it allows you to create a solid, agreed-upon set of assumptions on which to base discussions of new efforts or policies.

Surveys can be created and conducted online using sites like Survey Monkey, or in person or by mail using paper surveys, or through a combination of both. Soliciting survey-takers can be shared amongst board members so as to maximize their contacts. Surveys also provide a method for collecting information and opinions from people you might otherwise not have ready access to, like rural residents and consumers.

Survey questions can be leading or misleading; an important step in any surveying process is to review the questions with a few individuals who have not been involved in its development. Ask them how they interpret the question to ensure

⁴ Hammaker, 1996.

you haven't narrowed the answer to the one thing you want to hear, or led the respondent to an entirely different type of information than you hoped to capture. Once survey data is collected, analyzing the information is an important step to be conducted by someone who understands how to compare data to develop findings. Final survey reports can include the basic counts (how many people said what), but ideally also include analysis (percent of families members who agree, compared to percent of youth).

Benefits of surveys include:

- Finding areas of consensus;
- Identifying areas of divergent opinion;
- Providing anonymous input;
- Helping to prioritize services;
- Detecting training needs; and
- Enhancing and coordinating advocacy efforts.

***Ad Hoc* Committees**

Ad hoc committees are generally formed to address a specific problem or task. Usually these committees are established for a set period of time for the purpose of temporary oversight of an issue or a review of the standing rules or policies of an organization, program, or system. An ad hoc committee may have, in some cases, a long term or indefinite duration of existence. In these cases, an initial workgroup, committee, or forum may transition to a more permanent committee.

An ad hoc committee could be used to vet your board's proposals related to family and youth concerns prior to finalizing them. You could also establish an ad hoc committee to take an existing set of proposals and adapt them to fulfill better the needs of families and youth. If your board plans to conduct focus groups, key informant interviews, or surveys with families and youth, an ad hoc committee that has family and youth participation might help in designing a successful process.

Benefits of an Ad Hoc Committee include:

- Flexibility in duration: time limited or a longer-term extension;
- It may be easier to get a meaningful commitment to something that is time-limited;
- Issue or program focused;
- Provide oversight over a particular and well-defined set of proposals or processes; and

- Targeted input.

Advisory Councils or Committees

An advisory council is a group of people who have been appointed by a board of directors or other governing body to provide general and specific advice, perspective, and direction on current and future issues. This is a more formalized, permanent structure than an ad hoc committee and has the capacity to offer input on a broad array of topics, issues, programs, and policies. Just as with boards, Advisory Council members may serve on a permanent basis or for a set term, to be replaced by someone else who can represent their area of interest when their term expires. Changes in membership can provide a regular source of new perspectives and devotion to the work. In addition, because membership generally turns over on a rolling basis, continuity of effort and results can be maintained and improved over time.

An advisory council specifically composed of all families, all youth, or some mix, may create a safer and more accessible environment for families and youth to have in-depth discussions of policy issues. The use of an advisory council, rather than one time focus groups, allows for increasing knowledge among participants of the policies they are asked to inform. This capacity is important when complex and interconnected policy issues are being addressed by the board.

Benefits of an Advisory Council include:

- Works to find consensus on policies and programming to bring to the Board of Directors or governing body;
- Functions under specific policies and procedures;
- Ability to provide input on numerous issues;
- Capacity to be long-term; and
- Can help to align multiple board projects and policies.

Going to the Families and Youth

To increase your likelihood of getting substantial family and youth involvement in your surveys, focus groups, and key informant interviews, approach families and youth where they already congregate. For example, you can solicit youth to participate in your surveys, focus groups, or key informant interviews at:

- Schools and after school programs;

- Skate parks and other youth activities; and
- Stores and restaurants that youth frequent.
- Clubs such as 4H or Junior achievement

Solicit adult participation through:

- School meetings and events;
- Grocery stores and other service settings;
- Child care centers;
- Support groups;
- Health, mental health, oral health, and wellness service organizations;
- Cultural brokers and contacting folks well thought of in the community
- Contact churches and other faith based organizations
- Soliciting to other similar non-profit organizations for participants

Engaging providers and staff in each of these settings to make personal invites can be a very effective way of increasing participation in your survey, focus groups, or key informant interviews.

Using Existing Infrastructure

Colorado has benefitted from multiple federal, state, and local initiatives that have brought together diverse stakeholders and expanded advocacy efforts. Through grants and the will of communities, the infrastructure of Colorado's behavioral health advocacy network and its attention to the input of families and youth is expanding statewide. Using the existing network of resources of youth, family and consumer advocacy organizations and forums can greatly increase the input and feedback you get from families and youth.

This network includes such things as:

- Policy boards and other committees that already have family and youth participation;
- Family run organizations with trained advocates;
- Community organizations or committees driven by family and youth leaders;
- Support groups for and run by families and youth;
- Public health and preventative/wellness healthcare sites; and
- Leadership academes for families and youth that have emerging leaders eager to participate in policymaking settings.
- The Colorado Youth Advisory Council (COYAC), primary purpose is to "examine, evaluate, and discuss the issues, interests, and needs affecting

Colorado youth now and in the future and to formally advise and make recommendations to elected officials regarding those issues." (HB 08-1157) Youth from anywhere in the state are eligible, although there is a preference for youth from rural areas for those positions. To view a map of the Colorado Senate districts visit: <http://comaps.org/cosenate.html>

Approaching groups like this for feedback and input will:

- Eliminate barriers to participation;
- Provide valuable perspective to ensure activity success
- Engage consumers in a comfortable and familiar environment;
- Prove your interest in their work;
- Acknowledge that you value their time and recognize their effort;
- Maximize the likelihood of a high response rate; and
- Capitalize on already-invested stakeholders.

The Federation of Families keeps a list of advocates, contacts, organizations, and support groups, organized by county, on their website. To access it, go to: <http://www.coloradofederation.org/sup.html>

Also find resources through EMPOWER Colorado and Family Voices Colorado: www.familyvoicesco.org

Using Technology

The web and other multimedia methods are an important, emerging tool for building healthy, supportive communities. They may also be useful for engaging youth and family input. The World Wide Web has one tremendous advantage over other methods for youth in that youth are already fluent in the language and culture of the internet—it is an enormous “market” just crying out to be tapped effectively. And adults are not far behind!

On-Line Social Networking. On-line social networking is a tool that can build youth and adult coalitions and address issues affecting people today – from health care to employment to education. In the age of YouTube, Twitter, My Space, and Facebook, young people and even adults are increasingly aware of and responsive to web content and digital story telling. Policy boards that want to increase youth and adult participation and involvement will benefit from embracing the internet as a coalition-building tool.

Benefits of computer-mediated communication and issue forums include:

- Building community awareness;
- Encouraging local decision-making;
- Fostering dialogue between groups, especially far-flung ones;
- Increasing and supporting community participation by youth and adults;
- Increasing issue and resource awareness; and
- Providing youth with multimedia creation and editing skills.
- Outreach for other activities is easy and readily accessible.

The internet provides an excellent resource for fostering creativity as a way of engaging youth. In addition, the digital medium crosses more boundaries and can bring together diverse parties in a way that more traditional approaches to coalition-building and community engagement simply cannot hope to better.

Full Disclosure and the Internet. The benefits of online and computer-based forums are many, but users do need to be warned about a few things:

- There is a potential lack of confidentiality inherent in online communication;
- References, sources, and authorship can be difficult information to maintain; and
- Abuses of identity that stem from the lack of face-to-face interaction can occur.

Examples of Internet Tools. There are numerous many online health and wellness resources, discussion forums, chat rooms, blogs, and networks. You can host your own through GoToMeetings. Here are just a few Colorado, National, and youth-specific examples.

Colorado Forum Example:

- National Network of Libraries of Medicine: Colorado:
www.nnlm.gov/mcr/states/colorado.html

National Forum examples:

- Mental Health Forum: www.mentalhealthforum.net/forum/index.php
- Mental Health Support Community: www.psychforums.com

- Med Help – Finding Cures Together: Mental Health: www.medhelp.org/forums/MentalHealth/wwwboard.html
- Depression Forums: www.depressionforums.org/forums/forums.html
- Psychology Self-Help and Mental Health Forum: www.forum.psychlinks.ca/

Youth-Focused Examples. Canada has some excellent examples of innovative information technology programming that provide a voice for disenfranchised youth:

- Project YouthTube is a coalition of youth, youth-led organizations, and agencies serving youth from across Toronto who have come together to wield the political clout of Toronto's youth. Recognizing the systemic nature of the exclusion of youth from electoral politics, YouthTube aims to challenge the structural barriers facing youth in Toronto's underserved neighborhoods, from feeling welcome in and/ or accessing Canada's political system (with emphasis on those marginalized on the basis of race, gender, immigration/ citizenship status, sexuality, etc). <http://projectyouthtube.ca/>
- Regent Park Focus Youth Media Arts Center, a Toronto-based, youth driven, not-for-profit organization, is motivated by the belief that community-based media can play a vital role in building and sustaining healthy communities and seeks to increase civic engagement and effect positive change through youth-led media productions. The Center's programs are aimed at culturally marginalized diverse youth living in and around the community. With free access to media technology, participants work collectively to explore issues and develop resources that contribute to the health of their community and address systemic barriers to equitable social participation. <http://www.catchdaflava.com/>

Other Resources for Your Board

- Parent-Professional Partnership Training, Training oriented to improve the relationship between families and agency staff. Contact the Federation of Families

for Children's Mental Health ~ Colorado Chapter at
<http://www.coloradofederation.org/> or 303-572-0302.

Materials and Examples

- ✓ Best Practices and Steps for Focus Groups
- ✓ Discussion Guide for Using Input from Outside the Room

Please note: The resources provided in this workbook are in no way exhaustive.