



Family & Youth Involvement

A Workbook for Policy & Governance Boards and Planning Groups

Tips and Tools for:

- Preparing for family and youth involvement on a policymaking or governance board
- Recruiting and retaining families and youth on a board
- Gathering family and youth input outside of board meetings

Prepared by the [Center for Systems Integration](#) for Colorado LINKS for Mental Health, 2009

Linking Interagency Networks for Kids Services

Colorado LINKS for Mental Health is a statewide initiative that has, from 2005 - 2009, focused on promoting partnerships among state agencies and key stakeholder groups by weaving together existing efforts to create a more coordinated continuum of behavioral health services for Colorado children, youth, and families.

For more information about the Initiative, please contact José Esquibel at j.esquibel@state.co.us or 303-692-2421 or visit the Initiative's website at <http://www.csi-policy.org/links>

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Primary authors of the workbook include:

Natalie Portman Marsh

Rebecca Kahn

Jewlya Lynn

Also available at: <http://www.csi-policy.org/links>



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Introduction

Introduction

Congratulations! By reading this workbook you are taking an important first step towards increasing the engagement of families and youth. Your policymaking and governance will benefit from this critical work.

Welcome to a self-assessment and user friendly workbook prepared by the Colorado LINKS for Mental Health's Leadership Team on Family Youth Involvement in Policymaking and the Grant Implementation Group. The workbook is a response both to boards and to families sharing their need for training and information not only for family and youth participants on boards, but also for boards who wish to expand their knowledge of how to engage new members of their boards.

The goal of the workbook is to help boards involved in policymaking, governance of behavioral health and related systems to embrace family and consumer representatives on your board. The workbook is designed to be succinct and practical, with overviews, discussion guides and checklists, with sample bylaws, reimbursement forms, and other materials.

This workbook includes sections on a broad array of topics, including:

- Section 1: Structuring Meetings to be Family and Youth Friendly
- Section 2: Compensation and Reimbursement
- Section 3: Marketing and Recruitment
- Section 4: Youth Participation
- Section 5: Leadership Development for Youth and Families
- Section 6: Culturally Competent Boards
- Section 7: Privacy and Confidentiality
- Section 8: Evaluation Strategies for Family and Youth Involvement
- Section 9: Beyond Meeting Participation

Your board decides where to start based on your level of readiness and need. Ready, set...Go!

Why Family and Youth Participation is Important

There are many different kinds of boards. While some boards may have fiduciary responsibilities (non-profits, for example), other boards may focus on policy. Policymaking boards are largely composed of professionals, many who have

leadership roles in state and local government. They have a rich breadth of knowledge on policy issues and a commitment to improving systems. Their recognition comes from their agencies as well as the array of partners who work with them on a daily basis.

It is important to clarify the scope of responsibility of your board with any new member, particularly for youth and family members. To be clear, it is not typical for boards to address day-to-day operations, but they do provide oversight. This clarity for any new board member may help to avoid potential frustration in role and scope of their input and participation.

"The system building process that fails to develop meaningful partnership with the constituency that will depend upon the system is inherently suspect and limited in its capacity to build an effective system. Meaningful partnerships with families and youth require concerted attention, dedicated resources, and capacity building across all parties"
Sheila Pires, 2002

Families and youth bring another perspective that other board members do not have: their lived experiences as beneficiaries of services and systems. As consumers of services, they will know the barriers and benefits first hand. Since policy-focused boards are more likely to inspire conversations that are relevant to experiential knowledge, consumers will be better able to participate (Newberry, 2004).

Colorado is joining many other states that have consumers, family members, and youth on policy boards; state planning entities, local governance boards, and agency boards. This very exciting movement brings great opportunity for change.

The valuable contribution of new representation will naturally generate more family friendly and culturally responsive policies and practices. Policies will inevitably be more aligned to meet the needs of the service population and the community and board structure may be more flexible to accommodate new local partners.

Is it Time to Develop Family and Youth Leadership on Your Board?

Now is the time to engage in a discussion with your board! An attachment accompanying this introduction, called "Board Self-Assessment" has questions for your board to ask about their readiness to engage families and youth and the steps they need to take first, including:

- How does your board value the contributions of families and youth at meetings?

- Is your board ready to be flexible and change the status quo of how it has always held meetings, prepared and disseminated information, and made decisions?
- How will you know whether your board is ready to open the doors and accept uncomfortable, but enlightening conversations that can change how business is done?
- Who among you are the emerging leaders with the passion to lead your board's next development phase?

Family and youth involvement in policymaking, governance, and agency oversight will make a difference. Like other issues, it will take enthusiasm and leadership to see the work through. But your board will only sustain this important participation if the board is ready to make a commitment!

Family and Youth Involvement in Colorado

Cross system committees, task forces, and councils in Colorado vary widely in their engagement of consumer, family, and youth voices.

At the policy level, many of Colorado's systems do involve family and youth representation, but state and local boards vary greatly in their level of involvement, creating the potential for state policy to be made without sufficient consumer input. Without a state or federal statutory mandate, few systems voluntarily engage the consumer, family, or youth voice. (Behavioral Health Task Force Report, 2008).

Yet, the complex problems we have in our communities require many perspectives and people who are willing and able to lend an active hand and work together to solve them. Families understand and have experienced the barriers and can help identify potential solutions to complex problems (Community Toolbox, 2007). Not only are families important partners in Colorado, they are also ready to be partners!

Continuous quality improvement efforts over the past decade in Colorado:

- Family members, consumers, and youth in our state have been exposed to leadership and advocacy training that has been made available through grants and efforts from system of care, wrap-around, and family to family projects (among others). Specific examples include the Leadership Training Institute through Project Bloom and the Parent-Professional Partnership from the Federation of Families for Children's Mental Health.

- Best practice and evidenced based approaches have trained family partners as ‘parent-partners’ (wraparound), as ‘family support partner’ (family to family).
- Colorado was chosen in a competitive bid to send a delegation of leaders to the first ever policy academy on family-driven services; a clear recognition of Colorado’s leading steps on engaging the family voice in all levels of government.
- An increased number of policy boards and state and local government committees with family, youth and / or consumer involvement.
- An increased number of families in advocacy roles in local systems.
- Legislation recognizing the benefit of family, youth and / or consumer involvement. Do we have specific legislation identified?

Many of the family members and youth who will have an interest in your board may have participated on previous boards or advocacy activities. Expect and plan for great variability in their experiences, everything from no experience at all to observing to participating as a decision-maker, testifying at the legislature, or advocating directly for another family or youth.

Despite being a common principle across sectors, adding this constituent group to a board has at times been met with resistance and challenge in Colorado. Change is hard at all levels. A mere seat at the table is long way from meaningful involvement (Valentine & Capponi, 1989). Families and consumers taking an active part of developing policies and principles of an agency where they were once consumers primarily require relationship building.

In addition, once a family or consumer representative is on the board, they may feel like a token, isolated and not truly included in the board process. To overcome these and many other barriers, this workbook has clear, concise steps for your board to take to ensure authentic family and youth involvement is achieved!

Understanding Family and Youth Involvement for Your Board

When discussing the importance of family and youth participation, it can be easy to argue for why it is not important or appropriate. Below are a list of the common justifications for why family and youth participation is not appropriate and explanations of why these justifications are problematic.

Common Misconceptions about Family and Youth Involvement

Justification 1: The topics addressed by the board are too complex or require too much specialized knowledge for a family member or youth to participate.

Even the most complex topic is ultimately intended to have a direct or indirect affect on how families and youth experience the system and services. For example, a board exploring privacy laws as they develop a consent form would benefit from family and youth input on how to explain privacy in an accessible, accurate way to families. A board developing continuing education requirements for staff would benefit from family and youth input on their experiences with staff having out of date or irrelevant information, instead of current and helpful information from recently completed trainings.

Justification 2: The board members are also consumers (e.g. of general healthcare services), and thus can represent both their agency and the consumer perspective

While the board members may have some experiences with the system, their perspective is still limited to that of someone with extensive knowledge of the system. The perspective that a family or youth brings who is not informed about the system by working in it will be very different. Also, it hard to balance bringing a professional and a consumer perspective to the table at the same time.

Justification 3: The board members work directly with consumers, and thus can bring the consumer perspective to the table based on their experiences with consumers or the system.

3. Board members may learn a lot about the consumer experience from what their own clients tell them. However, there is a significant advantage to having direct experience at the board meeting instead of only second hand stories. For example, an issue may arise that never occurred to a board member to ask clients about, but a family or youth participant can draw on their own experience to contribute to the conversation.

Justification 4: Boards must ask family members to excuse themselves so they do not hear confidential discussions during the meeting.

Privacy standards are addressed here to put to rest any legal fears related to confidentiality concerns at board meetings. Policy and governance boards will not typically focus on specific cases but may globally discuss case related issues. Either way, privacy and confidentiality can be maintained while family members on your board remain in the room for the discussion.

Justification 5: Boards are not able to find, train and sustain investment from family members on their committees.

This workbook will offer worksheets, tips, tools and additional training references to help identify locations for possible recruits to your board, tips for recruitment, enhanced board flexibility suggestions and leadership development techniques including specific ways in which to better engage and cultivate family leaders.

Justification 6: Boards are resistant to bringing families on at this time. There just isn't anything we can do.

Alternative ways to bring the family and youth voice to your table are discussed in the workbook. Since there are numerous ways in which to include this essential perspective in system building and policy discussions, there is no excuse to leave consumers out of the dialogue. Self-assessments and discussion questions might help you identify the resistance.

Typical Challenges and Strategies to Overcome

Typical barriers that families have expressed when discussing their experiences on boards include (Valentine & Capponi, 1989):

- ‘Tokenism’ - being the lone family voice on a board or committee;
- Consumer / family members not given time to state their concerns or issues;
- Lack of financial reimbursement for their time;
- Reimbursement that negatively impacts public assistance benefits;
- Childcare considerations and unwillingness for a board to recognize the difficulty to access care providers for special needs children
- Inflexibility on part of the board to accommodate time or meeting location to the schedules of family and youth participants;
- Joining an established group with norms and acronyms that make it very difficult to feel included as a partner; and
- Stigma related to sharing their ‘stories’ when no one else does.

All of these issues are relevant as we move forward as a state to identify an infrastructure for family involvement at the policy level. The following chapters will suggest tactics and tools to minimize or avoid these barriers.

Tokenism: Families involved in the creation of this workbook, as part of the Family and Youth Involvement Committee of the LINKS Initiative, as well as many other sources have shared the following to eliminate the barrier of tokenism:

- Recruit in partners – they can attend together or tag-team, but they will have each other to process and use for support. This is establishing an internal buddy system;
- Reach beyond the board for feedback and input. The family members can take information presented at the board to family groups to vet and offer additional insight;
- Make sure the input is acknowledged - arrange for full participation on the board/committee, inclusive of voting privileges. (Ensure that their input is accurately reflected and recorded in the meeting minutes.)
- Advocate for 50% consumer/family participation, or another mix that would offer significant family and youth input;
- Deal honestly with the issues of stigma; and
- No “Alphabet Soup”. Eliminate jargon. People get lost quickly if you use acronym short cuts. If you must use a familiar letter abbreviation, take time

each time there is a new person at the meeting, to ask if everyone understands what the letters mean. (Stevens and Ibañez, 2004)

Planning Your Next Steps

Your board members bring different capacities for participation with respect to information, knowledge, skills and experience. While training is important for new board members, this workbook promotes board self-evaluation and training for both new and long-time board members. The goal is to better prepare your board for family, youth, and/or consumer engagement through practices and strategies, to maximize family involvement and role satisfaction.

The worksheets and prompts in this workbook have been taken from multiple resources with an eye toward specific use for Colorado policy boards and committees. We share a rich culture in Colorado of innovation and drive. Our families are strong and want boards to walk the talk and look to build your internal capacity to make some changes to really let families in. Making the commitment to change your board's climate and practices and successfully engage families and youth involves planning with your board.

Other Resources for Your Board

- *Mental Health Consumer Participation on Boards and Committees: Barriers and Strategies*. 1989. Developed by M.B. Valentine and P. Capponi with the Human Interaction Research Institute in collaboration with The GAINS Center
- *Partnering with People with Diverse Abilities On Consumer Advisory Boards, Best Practice Guide*. Developed by Judith Stevens, M.Ed. and Barbara Ibañez, M.A., with the Center for Development and Disability Partnership Initiative Project at the University of New Mexico in 2004
- Pires, Sheila A. (2002). *Building Systems of Care, A Primer, Spring 2002*. Human Service Collaborative, Washington, DC
- Kahn, R., Lynn, J., Braga, A., Hoxworth, T. & Donovan, K. (2008). *Youth Partnership for Health: Engage Youth! Colorado's Guide to Building Effective Youth-Adult Relationships*. Denver, Colorado: Colorado's Youth Partnership for health, Colorado Department of Public Health and Environment

Materials and Examples

- ✓ Board Self Assessment on Family and Youth Involvement. *This assessment includes questions for your board to discuss as you develop a plan for increasing the family and youth leadership on your board. The worksheet will help to identify first steps, create a plan, and define the outcomes your board wishes to achieve.*

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