Adding Family Voice:

Tips and Tricks to Developing and Sustaining a Family Advisory Board

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Housekeeping (1 of 2)

Webinar is being recorded and will be available on the Transitions to Adulthood Center for Research’s website https://www.umassmed.edu/TransitionsACR/.

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Housekeeping (2 of 2)

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The mission of the Transitions to Adulthood Center for Research is to promote the full participation in socially valued roles of transition-age youth and young adults (ages 14-30) with serious mental health conditions. We use the tools of research and knowledge translation in partnership with this at risk population to achieve this mission.

Visit us at umassmed.edu/TransitionsACR

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Presentation Goals:

1. Discuss the value of Stakeholder Engagement groups & Family Advisory Boards (FAB)

2. Share tools and strategies for successful recruitment and engagement of council members

3. Describe successes and challenges of our FAB

4. Show sample products from our FAB
What is the Transitions to Adulthood Center for Research (Transitions ACR)?

**National Center that aims to:**
Improve supports for the successful completion of schooling and movement into rewarding work lives among young people, ages 14-30, with serious mental health conditions (SMHC)

**How do we do that?**
- Conduct research that supports the employment and education goals of young adults
- Develop and translate knowledge to the public
- Infuse Participatory Action Research (PAR) into all activities
What is Participatory Action Research (PAR)?

PAR is the **critical end-user voice of our stakeholder members**, including those with lived mental health experience and those who support them. These voices are embedded into all aspects of our research and product dissemination.

**PAR:**
- Recognizes the unique needs, goals, and values of persons affected by serious mental health conditions
- Ensures services are friendly and culturally appropriate
Our Family Advisory Board

- Provide a valuable perspective and infuse a family voice into center research
- Develop relevant topics of interest surrounding important family issues as caregivers of young adults with lived experience
- Provide relevant end-user feedback on research activities, tools, protocols and initiatives
- Create products for family members in the community
- Identify ways to best share products and knowledge into the community
How could a Stakeholder Engagement Group help your organization?

• Ensure activities are conducted with critical end-user voice and direction.

• Maximize the relevance and usability of knowledge generated.

• Provide feedback through personal expertise and advise on processes, activities or end products.

• Provide input for consideration and assist in identifying priorities.
What does our FAB look like?

- 8-12 members (children ages 6-28)
- Today we have all moms (figures, right?) Diversity challenged (as Max doesn’t count)
- Representatives from national and local groups (FREDLA, NAMI and Grow a Strong Family)
- Broad spectrum of mental health “diagnosis”
- Monthly 1.5 hour meetings with stipend provided ($45)
- If in person, provide meal or snacks
What does our FAB look like today?

Like the Brady Bunch!
We’ve Learned a Lot since March 2020!  
“How to Run a Virtual Advisory Board”

Using a virtual approach can help your advisory board to:

- Save travel time and money
- Provide access for board members with childcare responsibilities, transportation barriers, or disabilities
- Reach diverse people from a variety of locations
- Increase attendance rate
“FAB members are experts on supporting loved ones with lived mental health experience and provide an authentic voice to the work we do.”

Marsha Ellison, PhD.
Associate Professor, Department of Psychiatry
Deputy Director, Transitions to Adulthood Center for Research
Communications Director, Implementation Science & Practice Advances Research Center (iSPARC)
How to Develop your Stakeholder Board

• Define FAB member roles and responsibilities
• Recruitment
• Develop your mission together
FAB Member Roles and Responsibilities

Create a Job Description, including:

**Time Commitment:**
- Participate in monthly in-person meetings lasting approx. 1.5 hours
- Ability to commit to the council for one full year from start point

**What will your role as a Family Advisory Board Member look like?**

During advisory board meetings, you will be asked to:
- **Share your perspective and ideas** by providing feedback on relevant topics concerning family issues and support loved ones with serious mental health conditions.
- **Give input and feedback** on current products that are being produced and research grants that are being written.
- **Speak about what is happening in your area/organization** to support family members with lived experience. What could improve? What’s been successful?
- **Share what you need to know more about** and what type of information would be useful for you and your family.
- **Work collaboratively to brainstorm additional topics of interest** for products or research topics that would be important for family members.
Recruitment of Members

1. Create an engaging and clear recruitment flyer
2. Spread the word!
   - social media
   - local organizations w/ shared mission (NAMI)
   - family support groups
   - conferences (FREDLA)
   - word of mouth
3. Determine whether it’s a good fit
   - Schedule
   - Appropriate family “profile”
   - Shared vision
   - Length of commitment
Create A Mission & Vision Collaboratively

Our goals: The FAB will

- Infuse family voice into iSPARC and Transitions ACR research and knowledge sharing activities
- Gather insight and feedback from family members of loved ones with mental illness on our work to improve the lives of people with lived mental health experience.

Your Goals:

Photo from Adobe Stock Graphic
Meeting Structure and Process

- Building rapport
- The value of an agenda
- Provide leadership opportunities
- Always provide feedback on the results of the advisory board’s work
Building Rapport

• **Establish a Safe Zone:** for sharing and build rapport to work collaboratively and hear all voices

• **Create a Comfort Clause:** Vegas rule! Confidentiality matters

• **Create Engagement Rules:** Everyone contributes but… you can say “pass”!

• Embrace and value **open honesty**! Share your experience and expertise (Judgment-free zone) while being respectful.
The Value of An Agenda

- Have a defined agenda with timeframes
- Start with an icebreaker
- Respect member’s time
- Take & share notes / record meetings

FAB Monthly Meeting Agenda  8/20/20  6:30-8:00pm

<table>
<thead>
<tr>
<th>Time</th>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>6:30</td>
<td>Check-in Question. Who was your first celebrity crush?</td>
</tr>
<tr>
<td>6:45</td>
<td>Celine will share info on a new grant to develop a platform to support the care/self-care of individuals presenting to an emergency dept. w/suicidal ideation and wants our feedback on platform ideas. (30 min.)</td>
</tr>
<tr>
<td>7:15</td>
<td>Dylan’s team is considering creating an “Adulting 101 course for YA w/ SMHC. They want our feedback on what we think should be included. (30 min.)</td>
</tr>
<tr>
<td>7:45</td>
<td>Updates on our FAB created Tip Sheet: Before a Mental Health Crisis Hits: Creating a Family Safety Plan</td>
</tr>
</tbody>
</table>
Provide Leadership Opportunities

Taking the lead on projects

• Developed content for tip sheets
• Created and starred in their own self-care video series
• Refreshed existing products
• Joined presentations & conferences (Hi, Irene!)
• Lead initiatives for members’ other organizations within the FAB.

Members have opportunities to disseminate our FAB work within their own network, as well as present their organization’s work to the FAB team. Some examples:
Provide feedback on the results of the Advisory Board’s work

Provide members with examples of how their feedback was used to improve research/services

• Acknowledge the stakeholder group on final products:
  “The Transitions ACR would like to send a very special thanks to our Family Advisory Board who helped in the development of this tip sheet.”

• Share results
  ✓ modified research tools or activities
  ✓ initiative developments
  ✓ grant proposals
Our Successes

• Our FAB has written and published 3 Tip Sheets which have been distributed to and by Family Support Groups across the country and shared across our dissemination channels.

• Additional Tip Sheets are planned for 2021.
More Accomplishments

We have created and disseminated 2 videos in a series:

“When a Mental Health Crisis Hit My Family - Stories of Coping Strategies”.

[Video excerpts of two individuals sharing their stories]
Our Voice is Heard

• We have provided “Family Voice” on multiple research products & center initiatives.

Acknowledgements:
The Transitions ACR would like to send a very special thanks to our Family Advisory Board who helped in the development of this tip sheet.
Our Challenges

• We are diversity challenged!

• Sometimes it’s a struggle to get our researchers to find time to visit us and utilize our expertise.

• Occasionally we have to work hard to make sure all voices are heard.

• Competing priorities can make attendance more difficult.

And the #1 Challenge: Should we budget for pizza for in person meetings in 2021?!!?
Let’s hear from our members…

What is the value of a Stakeholder Engagement Group?
Family Advisory Board Member Experiences

“... FAB exists as a place where family members can come to offer their insights in a meaningful way

……gives value to the experiences that family members face....

It is wonderful that we have a website and tip sheets which enable us to reach a broader audience possibly nationwide.”
Family Advisory Board Experiences

Bonnie’s Experience

• Meet with other parents with Lived Experience.

• Be with like-minded parents who get it.

• Take that anger and upset and feel empowered by having a voice.

• Have a say in creating resources for others.

• Do something good; it’s beautiful to make a difference for the next family.
What is the value of participating in a stakeholder engagement group such as the FAB?

- In my lived experience, I saw real systemic problems that I felt needed to be addressed.

- I experienced information gaps and service gaps that I felt shouldn’t exist.

- After the 2 year crisis period subsided, I wasn’t ready to simply throw those insights away.

Participating in FAB was the way to help improve the situation for others and pay it forward.
In what ways does a stakeholder engagement group bring value to an organization?

- Connects you to your constituents
- Allows you to tap into deep insights
- Enriches the skillset of your organization

Opportunity to validate that what you are doing is what makes sense for your constituents
What advice would you have for organizations who are looking to develop a stakeholder board?

• It must be part of overall strategy – know why you are doing it, what you want as outcomes and why that is important to your organization.

• Build a diverse board and be prepared that it will require active management and active communication.

• Recognize the potential of what you have created.

Foster a culture of mutual respect and open communication.
Main Take Aways

• Advisory councils are an excellent way of making research, policies and services more accessible and relevant to the target population by infusing the voice of your stakeholders.

• Follow best practices for recruitment and meeting structure to develop and sustain a Family Advisory Board, or any advisory board.

• Be clear in your mission and work collaboratively! Offer opportunities for leadership and confirm purpose by sharing tangible results of their efforts.

Can YOUR organization benefit from a stakeholder advisory board?
Content Credited to the FAB

1. **Before a Mental Health Crisis Hits: Creating a Family Safety Plan** – Sept 2020
2. **Should I Attend College in the Fall? Questions for Students with Mental Health Conditions to Consider** – Aug 2020
3. **Parents Chime In: Our Self-Care Strategies While Supporting Loved Ones with Mental Health Conditions During a Pandemic** – June 2020
4. **When a Mental Health Crisis Hit My Family: Mara's Story of How Setting Boundaries Helped Her Cope** – Feb 2020
5. **When a Mental Health Crisis Hit My Family: Irene's Story of Hoping and Coping** – Jan 2020
6. **For Families or Caregivers: Self-Care is Putting on YOUR Oxygen Mask First** – August 2019
More Resources on Advisory Boards

• The **Benefits of Stakeholder Engagement** to your work
• Learn more about our **Family Advisory Board**
• Webinar: **Tips and Tricks to Starting a Young Adult Council**
• New Tip Sheet: **Top tips for running a virtual advisory board**
Thank You!

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