

Adding Family Voice:

Tips and Tricks to Developing and Sustaining a Family Advisory Board



Presenters:

Marcela Hayes, FAB Facilitator

Jean Wnuk, FAB Facilitator

Irene Grzybowski, FAB Member

January 21, 2021

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/>.

Participants are automatically muted when they join.

Enter unique audio pin if calling in via phone.



Housekeeping (2 of 2)

Audio problems? Check settings in the GoToWebinar “Audio” tab.

We will have a Q&A session after the presentation is complete.

Please type your question into “questions” box to participate.

Technical difficulties? Email the organizer at deirdre.logan@umassmed.edu or use “Questions” tab.



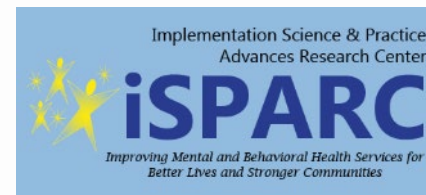
Acknowledgements



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

The contents of this presentation were developed with funding from the National Institute on Disability, Independent Living, and Rehabilitation Research, (NIDILRR), United States Departments of Health and Human Services (NIDILRR grant number 90RTEM0005). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The content of this presentation does not necessarily represent the policy of NIDILRR, ACL, and/or HHS and you should not assume endorsement by the Federal Government.



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



Photo by [Markus Winkler](#) from [Pexels](#)



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



iStock.com/BrianAJackson



Our Family Advisory Board



Transitions ACR
Vol 17, Issue 10
Family Advisory Board
June 2020



In 2019, the Transitions to Adulthood Center for Research's (Transitions ACR) Family Advisory Board created a tip sheet called *For Families or Caregivers: Self-Care is Putting on YOUR Oxygen Mask First* to remind caregivers about the importance of intentional self-care. In the wake of COVID-19, that tried and true saying of "putting on your mask first before helping others" takes on a whole new meaning and it applies even more. We asked our Family Advisory Board members to provide thoughts on how they adapted their self-care strategies and to share tips on supporting their loved ones with mental health conditions in the face of the COVID-19 pandemic. The United States' response to keeping the virus in check has completely changed our lives and we may not see a return to "pre-COVID normal" for over a year. In addition to acknowledging the extreme circumstances, it can be important to remember that we can reframe the situation and see hope as we come out the other side of the pandemic.

This is what our Family Advisory Board members had to say:



Mara's Advice
"Think about "value-based" goals for quarantine. It can help you feel like you are doing more than surviving and give you a sense of purpose."

Value-based refers to those behaviors that are important to your family, such as volunteering. In this time of social distance, how does a family do this? They could make, masks and donate them. They could paint, rocks and leave them out on walks they take to add brightness and color to the world.




They could let neighbors know when they are running errands and offer to add items needed to the list. Animal shelters may be impacted by social distancing, so you or your family could foster animals to help.

Margie's Advice

"I focus on gratitude and write down 3 things every day that I am grateful for before going to bed."

Practicing gratitude helps you notice the good things that are going on. Like trying to develop any new practice, it can take a while to see the benefits, so try to keep going. In positive psychology research, gratitude is strongly and consistently associated with greater happiness.



Sara's Advice

"Focus on breathing at times when you need to take a moment to relax."

I use the candle breath method, which helps me calm down when things are feeling tough. When I am out in public and other people are near me, I use ideas in the "Loving Kindness Meditation" to help me cope. I grant myself love and kindness and send out that same message, silently to them.



Marcela's Advice

"When you're having a rough day and struggling, remember to treat yourself like your best friend and be kind."

Would you talk down to a friend or would you help to bring them up and support them when they're down? Building your resilience will help you during this difficult situation. We are all together in this challenging situation and we need to be kind to ourselves. Also, be authentic about how you are feeling with others

Irene's Advice

"Sometimes we have to just embrace the funny and share it with friends."

It's important to find the humor wherever you can and try and keep lighthearted when you can.

- ✓ 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.



Photo by [fauxels](#) from [Pexels](#)



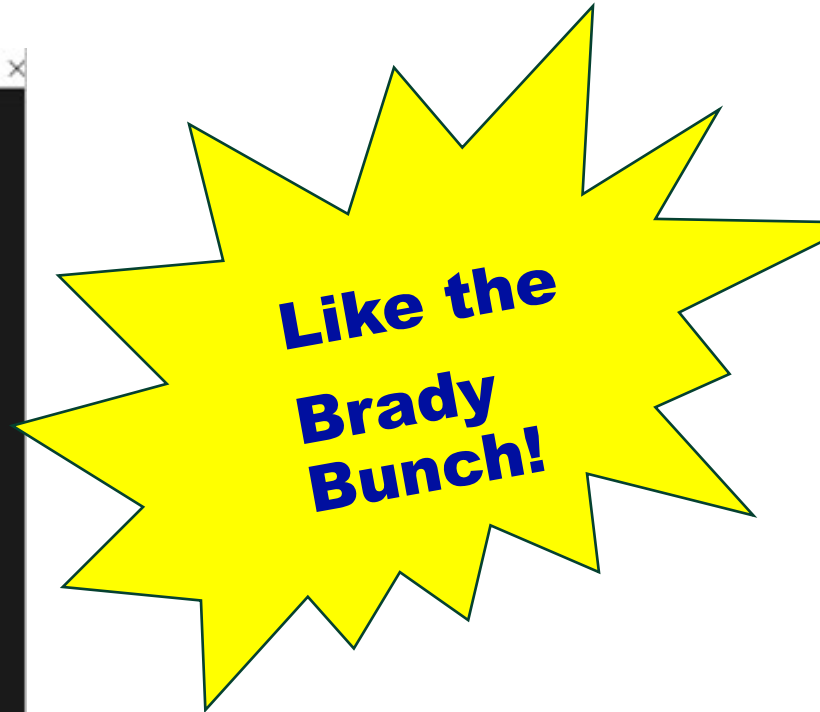
What does our FAB look like?



- 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?



We've Learned a Lot since March 2020! “How to Run a Virtual Advisory Board”



iSPARC Implementation Science & Practice
Advance Research Center
Vol 17 Issue 22 | Psychiatry Information in Brief | December 2020

Top tips for running 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!



SET UP FOR SUCCESS

Videoconferencing Programs: Purchase a program that allows you to set up group video meetings. Many programs include additional features that might be useful, including screen sharing, text chat, recording, and breakout groups.

Equipment Check: Check in with board members before the first meeting to make sure that they have a computer, tablet, or smartphone; a webcam; and a microphone. Budget for equipment costs so that advisory board members are not excluded if they cannot afford the needed technologies.

Scheduling: Book your meeting dates at least a month in advance and send invitations (Outlook, Google, etc.) that include the meeting link along with detailed instructions on how to access the meeting (and a password, if applicable). Send a reminder email 1-2 days before the meeting with the link to join.

Tech Lead: Identify a technical lead person who will do check-ins with new members to test their technology before the first meeting, as well as manage any technical issues that pop up during the meeting.

Information Sharing: Circulate the agenda and materials ahead of time. Consider preparing a PowerPoint to guide the session.

Group Size: Think carefully about how many participants to include in your meeting. The ideal size is 5-7 persons, but if your group is already larger, consider planning breakout sessions.

Using a virtual approach can help your advisory board to:

- Save travel time and money
- Provide access for board members w/ 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



Photo from Terovesalainen from Pixabay

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

We want you to join our Family Advisory Board (FAB)

Hosted by the UMass Medical School and the goals of the FAB are to...

1. Gather feedback from family members to improve products, research, and knowledge sharing
2. Discuss important issues related to supporting loved ones with serious mental health conditions

Do you have experience supporting a loved one with a serious mental health condition?

Becoming a member of the FAB means...willingness to:






- o **Share your experiences** with supporting loved ones
- o **Provide feedback** on relevant topics concerning family issues that are important to you and your family
- o **Brainstorm** additional products or research topics

• Compensation = \$45 stipend per meeting*

Meetings are held at the UMass Shrewsbury campus

*payment includes participation in 1.5 hour meeting including travel expenses

Interested in learning more?
Contact:
Marcela Hayes: marcela.hayes@umassmed.edu
OR
Jean Whuk: jean.whuk@umassmed.edu



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

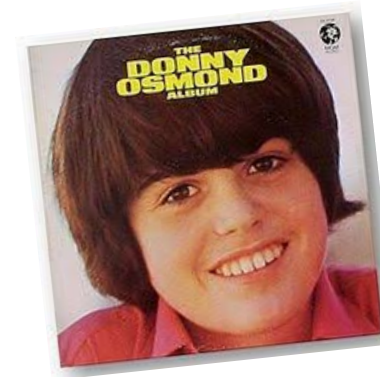


Photo from Lisa Fotios / Pexels.com

- **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



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

Zoom: provide link and password here

6:30	Check-in Question. Who was your first celebrity crush?
6:45	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.)
7:15	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.)
7:45	Updates on our FAB created Tip Sheet: Before a Mental Health Crisis Hits: Creating a Family Safety Plan

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

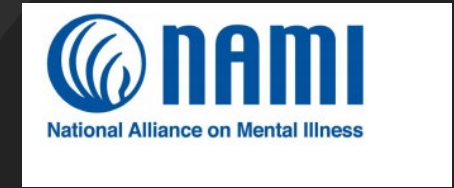


Provide Leadership Opportunities

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



Volume 17, Issue 14 Transitions to Adulthood Center for Research July 2020



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.

Parents Chime In:
Our Self-Care Strategies While Supporting Loved Ones with Mental Health Conditions During a Pandemic

Transitions ACR
Family Advisory Board
June 2020

In 2019, the Transitions to Adulthood Center for Research's (Transitions ACR) Family Advisory Board created a tip sheet called *For Families or Caregivers: Self-Care is Putting on YOUR Oxygen Mask First* to remind caregivers about the importance of intentional self-care. In the wake of COVID-19, that tried and true saying of "putting on your mask first before helping others" takes on a whole new meaning and it applies even more. We asked our Family Advisory Board members to provide thoughts on how they adapted their self-care strategies and to share tips on supporting their loved ones with mental health conditions in the face of the COVID-19 pandemic. The United States' response to keeping the virus in check has completely changed our lives and we may not see a return to "pre-COVID normal" for over a year. In addition to acknowledging the extreme circumstances, it can be important to remember that we can reframe the situation and see hope as we come out the other side of the pandemic.

Before a Mental Health Crisis Hits:
Creating a Family Safety Plan

Transitions ACR
August 2020

What Is a Family Safety Plan?

A Family Safety Plan is a tool created collaboratively with your loved one with a history of mental health condition(s), family members, medical staff and other professionals. It's your "playbook" of the best ways to minimize or divert a mental health crisis. The plan is prepared when your loved one is stable and can fully contribute. The goal of the plan is to identify possible triggers for a mental health issue and understand different scenarios, to minimize or prevent a crisis and ensure the safety of your loved one and other family members. The Family Safety Plan is prepared in conjunction with the **Family Emergency or Crisis Plan**.

Wearing and practicing a Family Safety Plan is preventative, just like wearing a seat belt. When, despite best efforts, a situation turns into an emergency, having a Family Safety Plan is essential and is the last piece of your family's safety planning. **Keep your Family Safety Plan and Family Crisis Plan in a visible location, in a binder with all the backup materials you need readily available to all family members. Most importantly, practice it with all family members and keep it up to date!**

Tips for Creating a Family Safety Plan

- Engage as many of your family members as possible in the process. Reach out to important friends and medical professionals for advice and input as well as a local mental health crisis team.
- Each family member should agree that it is in everyone's best interests to calm episodes before they become out of control.
- Explore strategies that have worked in the past to calm or diffuse a situation and consider new strategies that may be helpful. Discuss "what to do, if this were to happen."
- Approach each other with an attitude of curiosity and respect; ask permission to offer opinions.
- Use clear and succinct language. Keep it simple.
- Review options, scenarios and strategies together and document their level of helpfulness.
- Agree on what symptoms may look like from each of your perspectives without judgment or criticism. If your loved one perceives your observations as an attack, refrain from sharing them. However, document them in some form so that YOU remember when you observe these actions.

For Families or Caregivers:
Self-Care is Putting on YOUR Oxygen Mask First

Family Advisory Board Tip Sheet
August 2019

HAVE YOU EVER THOUGHT?

- "I don't have time to put myself first"
- "I feel guilty taking care of myself before others"
- "It's all my fault"
- "I feel like there's no light at the end of the tunnel"
- "I feel selfish putting myself first"
- "I always feel so alone and isolated"
- "I don't have anyone I can count on or ask for help"
- "I'm exhausted and tired of all the drama"
- "I am ashamed that I can't get it together"

Why Should I Put My Oxygen Mask on First?

Self Care is Important

During pre-flight instructions, flight attendants tell passengers that in the case of an emergency they should put their own oxygen mask on first even before helping children because otherwise the passenger will run out of oxygen and be unable to help anyone else. This is true when it comes to self-care because putting oneself first is an unselfish act and a priority. If you do not take care of yourself, you cannot help others. Being the caregiver for someone with a mental health challenge can be very difficult, but you must take a little time for yourself. *Self-care can start with just 5 minutes a day!*

Family Advisory Board members had to say:

Margie's Advice
"I focus on gratitude and write down 3 things every day that I am grateful for before going to bed."
Practicing gratitude helps you notice the good things that are going on. Like trying to develop any new practice, it can take a while to see the benefits, so try to keep going. In positive psychology research, gratitude is strongly and consistently associated with greater happiness.

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Irene's Advice
"Sometimes we have to just embrace the funny and share it with friends."
It's important to find the humor wherever you can and try and keep lighthearted when you can.



More Accomplishments

We have created and disseminated 2 videos in a series:

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



#TransitionsACR #youngadults

When a Mental Health Crisis Hit My Family: Mara's Story of How Setting Boundaries Helped Her Cope



UNIVERSITY OF MASSACHUSETTS MEDICAL SCHOOL

When a Mental Health Crisis Hit My Family: Irene's Story of Hoping and Coping



Our Voice is Heard

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

Top tips for running a virtual advisory board

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- Group Size:** Think carefully about how many participants to include in your meeting. The ideal size is 5-7 persons, but if your group is already larger, consider planning breakout sessions.

Translating Evidence for Successful Transitions (TEST)

SUPPORTING STUDENT-LED TRANSITION PLANNING FOR STUDENTS WITH EMOTIONAL BEHAVIORAL DISTURBANCE

Kathleen Biebel
Laura Golden
Sloan Huckabee
Marsha Langer Ellison

December 2018
Pre-publication Edition

Should I Attend College in the Fall?
Questions for Students with Mental Health Conditions to Consider

Volume 17, Issue 14
Transitions to Adulthood Center for Research
July 2020

The following questions are intended to help students with mental health conditions, their supporters, and loved ones make decisions about whether to return to college this fall. Your school has probably answered many of the basic questions for you regarding physical safety, finances, schedules, etc. But these are questions schools may not have addressed that may be helpful to think about when making the right decision for yourself. These questions may lead you to contacting your school for more information.

Things to consider if you are a college student with a mental health condition

- How was my experience in the Spring semester when we transitioned online? Did online learning work for me? If not, why?
- How do the symptoms I have or medications I take for my mental health condition impact the way I learn? How do I best learn? What types of support/resources do I need to do the best that I can?
- Can I navigate and organize my virtual classes? Can I organize and maintain my online class schedule/todos on my own, with virtual learning?
- Do I have the equipment I need to be successful in my upcoming online classes?
- Are the classes I registered for in the Fall particularly challenging for me in an online format?
- Do I need the resources, including health insurance, that my college offers to maintain my wellness? And if so, can I get them virtually or do I need in-person support? How could I make this work?
- Think about what happens for you when things get hard. How would I handle these times if I'm not on campus? Or if I'm on campus with new distancing rules in place?
- Can I do a good job advocating for myself with roommates or dorm mates if I have concerns about safety protocols?

TEST
Translating Evidence to Support Transitions

YOU GOT THIS:
Taking a Leadership Role in Your IEP Meeting



What is an IEP and who is it for?



An IEP is an individualized education program for students like you (ages of 3 to 21) who receive special education services in public schools. An IEP is a legal document that describes the help that you and other students with disabilities will receive at school.

What is an IEP meeting?

ADULTING SHORTS: AN INTERVIEW TALE, PART 1

HEY GIRL! YOU LOOK UPSET.

MY LAST JOB INTERVIEW WAS SO WEIRD. AND, I HAVE ANOTHER ONE TODAY.

WHAT HAPPENED?

THE GUY I INTERVIEWED WITH ASKED ME A WHOLE BUNCH OF QUESTIONS I DIDN'T KNOW HOW TO ANSWER.

LIKE WHAT?

LIKE HOW MANY DAYS I WAS SICK. WHAT MEDS I'M ON. HE EVEN ASKED ME IF I HAVE ANY PHYSICAL OR MENTAL HEALTH ISSUES!



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?!?



Photo from Robin Higgins from Pixabay



Let's hear from our members...

What is the value of a Stakeholder Engagement Group?





Photo from Tim Mossholder from Pexels.com

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.”





Photo from Tim Mossholder from Pexels.com

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.**





Photo from Tim Mossholder from Pexels.com

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 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*.





Photo from Tim Mossholder from Pexels.com

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





Photo from Tim Mossholder from Pexels.com

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!

Contact us at transitionsacr@umassmed.edu



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