Building an Effective Family Advisory Council
A Practical Guide

Developed by the Sala Institute for Child and Family-Centered Care to share best practices creating, growing and sustaining a Family Advisory Council
Background and History

In 2013, the Sala Institute for Child and Family Centered Care was established to create an enduring, broad, and flexible patient and family-centered culture at Hassenfeld Children’s Hospital at NYU Langone. The Sala Institute endeavors to inspire new national standards and models for patient and family-centered care that integrate a strengths-based model of resilience, patient safety, and quality, research and education. Through the Sala Institute’s unique programming and services, we strive to develop partnership between patients, families and the health care team.

At Hassenfeld Children’s Hospital, children and families are supported as partners with healthcare professionals in all aspects of care delivery. Their perspectives are essential in providing safe, effective, family-centered care. Through our Family Advisory Council and Youth Advisory Council, our 35 plus trained Patient, Youth and Family Advisors play an active role in providing recommendations that guide our programs and services. In addition to partnering with advisors on our Councils, we have a Family Consultant and Senior Family Advisors as part of our employed, professional team who receive advanced training and partner with leaders and teams on safety, quality, research and operational initiatives.

Why it Matters

At Hassenfeld Children’s Hospital, our Patient and Family Advisory Council (FAC) is a group of parents and young adult patients (who have received care here as youth), senior leadership, clinicians, and front-line staff. The Council meets regularly to provide input, ideas and perspectives on policies and programs with an aim to improve the quality, safety and experience of care.

Currently in its fifth year, the Family Advisory Council at Hassenfeld Children’s Hospital includes families of children that have received care at our hospital, mirroring the population we serve with regard to their child’s diagnosis and family demographics of race, ethnicity and socio-economic status. Our Family Advisory Council meets monthly for two hours to offer input and feedback on operational, safety, quality and research initiatives, as well as a variety of other policies and programs.

In addition to the monthly meetings, Family Advisors consult on ad hoc projects, host Family to Family Hours, advise virtually through email collaboration and serve on committees.

What is a Family Advisory Council?

At Hassenfeld Children’s Hospital, the Family Advisory Council has made a difference in care delivery, the experience of care and in the development of resources and programs.

When families who have children receiving care provide input on future delivery of care and programming, it can improve the overall experience for patients, families and staff. (Fondrick, Johnson, 2002)

A project is more likely to succeed when viewpoints and considerations from each key stakeholder are considered. For example, when our Central Line Associated Blood Stream Infection prevention team presented ideas to the Family Advisory Council about how to discuss potential infection risks with families, the families greatly influenced the team’s approach. A new educational resource was co-designed by family advisors and patient safety leaders that reflects true safety partnership, transparency and family engagement.
Building an Effective, Valued Family Advisory Council

While it may seem easy to bring a group of families and staff together, creating an effective Family Advisory Council (FAC) takes thoughtful planning and maintenance. Important initial steps are:

Engage leadership

Before you bring patients and families together to influence programs and designs for your hospital, meet with leaders to ensure leadership support and buy-in for your FAC. Support, engagement and interest by leaders will raise the profile and potential impact of your FAC. It can become buy-in from clinicians and staff, who are key to ensuring a variety of project topics and ongoing recruitment.

At Hassenfeld Children’s Hospital, our Senior Vice President of Children’s Services is a champion for the Council as well as an active member and participant. Additionally, our Director of Nursing and Director of Social Work are key members, who attend meetings regularly. Several leaders from the Sala Institute for Child and Family Centered Care regularly attend Council meetings and listen to and highly value family feedback.

If leadership interest is elusive, you can still move forward. Once you launch your FAC, consider inviting several leaders to attend a meeting where the topics are rich and meaningful and you can be sure of a lively discussion. Nothing ensures buy-in more than a meeting where the topics are rich and meaningful and you can be sure of a lively discussion. Nothing ensures buy-in more than a meeting where the topics are rich and meaningful and you can be sure of a lively discussion.

Identify Chair or Co-Chairs

One of the first steps to creating your Council is to identify a capable Chair or Co-Chair. There are many different variations of FAC leadership throughout the country; some Councils have one Chair – a staff person, clinician or family member. Other Councils select one clinician and one parent to co-chair the Council. Having Co-Chairs cultivates leadership skills in several members of the team and ensures that a Chair will always be present each month if one is unavailable. Since our leadership is active on the Council and can chair the meeting as needed, our Family Advisory Council currently has one Chair.

Essential qualities for a Chair include respect for families’ diverse perspectives and strong facilitation skills. The Chair wears many different hats in supporting and leading the Family Advisory Council. Two primary responsibilities of the Council Chairs include:

1. Preparing for, Managing and Leading Meetings:
   - Scheduling conference rooms and logistics
   - Identifying topics and speakers
   - Communicating with FAC members to invite and remind them of meetings
   - Creating and distributing agendas
   - Prepping speakers
   - Coordinating catering
   - Ensuring a staff or volunteer note taker for the meeting to capture valuable family input
   - Co-presenting/facilitating with speakers
   - Facilitating engagement, discussion and feedback from the Council
   - Distributing follow-up notes to speakers after the meeting
   - Inviting speakers to return to provide updates including how FAC influenced the work

2. Recruiting and managing Family Advisors:
   - Presenting to committees and clinical teams about the need for new Council referrals
   - Following up on and outreach to referrals
   - Interviewing, onboarding, and conducting orientation
   - Collaborating with volunteer services to onboard FAC members
   - Preparing, communicating with, and debriefing members
   - Managing and hosting annual Honoring Reception

Recruit Family Advisor Council members

Families are the most important part of your Family Advisory Council. Recruit diverse families who reflect the many diagnoses and backgrounds of children cared for in your hospital or area. Most referrals come through clinicians; however, referrals may also come from FAC members themselves who might know someone who may be a good fit. Recruit for and promote the Council during operational meetings, in emails, family welcome books, and in staff and family newsletters.

Effective qualities

Certain qualities make for a very effective FAC member. These qualities include:

- Respect for others’ perspectives, opinions and experiences
- Ability to share positive and negative feedback constructively
- Skill to share healthcare story in ways others can learn
- Ability to apply personal experience to a range of topics
- A strong listener, who knows when to share ideas, when to listen and when to give others time and space to speak

Interview and vetting

Once a family member has been referred by a clinician or another Council member, he or she should complete an application (see Family Advisory Council member application, appendix) and have an interview with the Chair and potentially others. This is an opportunity to determine if the family member is truly a good fit for the FAC. Not every referral is a match.

Interview questions should explore why the candidate is interested in joining the FAC, how the potential Council member might contribute to the FAC discussion and how he/she offers feedback constructively.

These are some interview questions and discussion points to consider including:

- Ask how the candidate learned about the Family Advisory Council (FAC).
- Share an overview of how the FAC functions and the value it brings to the hospital.
• Explore the candidate’s interest in the FAC.
• Ask if they have experience on committees and groups that seek perspectives from multiple members. If so, what successes or challenges have they seen?
• Ask the candidate to share their family’s experience at the hospital. Could it have been improved and if yes, how so?
• Share the commitment and expectations for participation on the FAC and ask the candidate if they anticipate any challenges that may make it difficult for them to participate.

Orientation
We welcome Council members to bring unique perspectives as patients or family members. In our orientation we emphasize that although each person brings a unique perspective and may have individual hopes and dreams for the hospital, the FAC patients and families share an important mission to improve care and practice for the entire Hassenfeld Children’s Hospital and all of our patients and families. We ask them to focus their attention on the shared agenda, not personal family goals and motivations. The Chair of the FAC leads our orientation and:
• Offers a background on our hospital and the philosophy of our FAC and the vision of child and family-centered care.
• Reviews expectations, ground rules and tips for serving on FAC
• Shares past agendas and highlights some of the topics and feedback, as well as the value the FAC has brought to projects and programs.

Some members also find it helpful to receive additional resources to learn more about family-centered care, such as a link to the Institute for Patient and Family Centered Care website (www.ipfcc.org).

Onboarding
At our hospital we work very closely with Volunteer Services when on-boarding our FAC members. Since our FAC members may need to participate in meetings within the hospital, each member is on-boarded with the same requirements as those volunteering in patient areas. Reach out to Volunteer Services to learn what your hospital’s requirements for Family Advisory Council members includes. Keep organized as you track new member status. You may want to create a grid to keep track of the on-boarding status of pending FAC members (see image below). Our Volunteer Services’ requirements include:
• Background Check
• Online e-learning modules regarding:
  - Fire Emergency Procedures and Fire Extinguisher Use
  - Infection Prevention and Control
  - HIPAA Privacy & Security
• Signed HIPAA Compliance Form
• Reference Letter
• Medical Clearance, including TB screening and flu shot during flu season

Setting expectations
We discuss expectations and ground rules for patients, families and staff partners on our Family Advisory Council and offer them verbally and in writing at orientation and prior to the first meeting. Below are our guidelines for patients and families:
• Attend at least 70% of the monthly meetings each year.
• Share your point of view and be prepared to listen and reflect on the diverse perspectives of others.
• Maintain confidentiality of personal and hospital information shared by Council members and guests at meetings.
• Reflect on your experience at Hassenfeld Children’s Hospital and bring ideas to Council meetings.
• When sharing stories about health care experiences, please refrain from using provider names – whether the experiences are positive or negative.
• If you are sent materials in advance, please read them before the meeting.

“As a Family Advisory Council member, you wear two hats. Family Advisory Council members collaborate with clinicians who may also provide care to their own children. It is important as a family to keep being a parent at the bedside separate from being a Council member.”

- Chair of Family Advisory Council
Hassenfeld Children’s Hospital

Engage staff partners
We welcome participation from Staff Partners on the FAC. Leaders and/or frontline staff from medical, nursing, and social work attend Council meetings and contribute to discussions when appropriate. We have found that it’s most helpful for staff partners to:
• Be respectful collaborators
• Have an understanding that family and patient feedback (rather than staff feedback and input) is the primary goal of the Council
• Be a strong listener
• Have ability to apply their own clinical experience to a range of topics

Role and responsibilities
Staff Partners have an important role, which they should feel comfortable with and prepared to fulfill prior to participation and may include:
• Providing more context and details during Council discussions
• Explaining current processes in the hospital when helpful
• If appropriate, sharing practicality of Council suggestions
• Bringing family feedback and input back to colleagues and teams to facilitate awareness and change
• Suggesting topics and speakers to the Chair for FAC meetings
• Ensuring awareness of the FAC among staff/clinicians, as they lead projects that could benefit from family input

Cultivate relationships
Patients, Families and Staff Partners often tell us it takes several meetings for them to feel comfortable participating in the meeting. Here are some ways to ease the transition:
• Host an orientation prior to the first meeting that they can attend.
Sustaining and Growing your Family Advisory Council

To successfully sustain and grow your Council, ensure that members and staff want to return the next month because each meeting is interesting and respectful. It should be an opportunity to engage on meaningful topics and an effective use of time. Families should feel the FAC ultimately leads to change in the hospital and that their contributions are valued.

Manage logistics

Running a successful Council involves many event planning details. Here are some of the elements:

• Catering: Meetings scheduled during meal times should include a light meal for families.
• Find out if families have any food sensitivities or allergies in advance of selecting your caterer. You may need to order several individual meals that follow specific dietary guidelines.
• Be cognizant of your budget when selecting a caterer.
• Shake it up. Try to diversify your caterer and selections each month.
• Check in with the FAC several times a year to find out which catering choices members favored.
• Stipends: A small stipend (an AMEX card for example) is a nice way to honor the time and expense it takes for families to get to meetings. Speak to your accounting department about any specific rules to follow.
• Timing: Use the same day/time each month for meetings. Look ahead to see if any of the meetings fall on holidays or typical school vacation weeks. Adjust the calendar accordingly and in advance. Send out a calendar of meetings for the year ahead.
• Location and space: It should be comfortable and spacious enough. There should be good acoustics and AV in the room. Make sure it is easily accessible by FAC members and that you have notified security in advance if necessary.
• Topic length: Estimate how long a topic needs (between 20-60 minutes) based on the complexity of the topic, the nature of the questions being posed to the Council, and how many topics you have for that meeting. Stick to your schedule as much as you can.
• Agendas: It is ideal to send out agendas in advance of the meeting so families can prepare appropriately. Sometimes presenters ask if families can look over documents in advance which can be attached to the agenda email.
• Format: While guests speaking at the front of the room and then engaging in group discussion works well, it can be enjoyable to change the format every now and then. Break up into small groups and have each small group address one of the guest’s questions. Include note takers for each group and add in time for a report back to the large group. Alternatively, invite the group to walk around the room to respond to images taped to the walls-welcome them to add feedback or comments with post-its or in small group discussions while standing. Changing the format adds to the energy and excitement of the discussions and helps engage more quiet members.
• Note takers: ensure you always have note takers that capture soundbites, ideas and concerns from families in writing. These notes should be shared later with guests and leaders, as appropriate, to help influence the work ahead. Don’t rely on memory!

Host the council’s first meeting

Your first meeting is an important way to engage your Council. First impressions are important. Things to consider for your first meeting:

Beginnings

When the Council is newly formed, it may take some time to have the meetings run smoothly. Be patient with members and with Council leaders.

Introductions

Provide a specific way for members to introduce themselves. To avoid members sharing too many personal details or taking too much time, the Chair and a member who has been prepared ahead of time should start the exercise and model for the group. Intros should be brief and succinct, no more than 1-2 sentences.

Warm-up exercises

“Getting to know you” exercises that are not too personal or emotional help break the ice. Consider breaking the group into smaller groups of 3 or 4.

Distribute coins and ask the families to talk about something that happened in their life the year the coin was created.

It takes time to coordinate with Guest Discussants and prepare them to bring topics to the Council. We meet with them in person at least once and once by phone to go over slides, make edits and help them formulate three main questions they have for the FAC. The Chairs should plan at least a month in advance of each meeting and be prepared for delays.

Manage challenges when they occur

There are a number of potential challenges with a Family Advisory Council.

A small group

Sometimes, despite your reminder emails and requests for RSVP’s, FAC members cancel last minute and your group is much smaller than anticipated. Small groups can be very engaged and open, however, and can go deep with topics and themes.

Difficulty engaging around a topic

Guest discussants may have challenges engaging the group on a particular topic or question. In advance of the Council meeting, it is important for the Chair to meet with Guest Discussants to plan their session and to clarify the 2-3 questions they have for families. Additionally, during the session, chair facilitation helps focus discussions that veer from the topic and key questions.

The Chair, who is also a family member, can speak from a family perspective and from a staff perspective, prompting initial and valuable responses to the questions. The Chair energizes the Council and sparks a meaningful conversation.

Select topics

To plan each monthly meeting, the Co-Chair coordinates with leaders and clinicians to discern operational priorities and determine which projects might benefit from FAC feedback. On our Family Advisory Council, topics typically focus on safety and quality, family experience, resilience, hospital design, research and technology. Buy-in from senior leadership helps ensure that staff and clinicians are motivated to include patient and family perspectives.

“At our monthly Safety and Quality meetings the Director often asks presenters, “have you brought this to the Family Advisory Council?” Endorsing the idea that patients and families should be included encourages clinicians and staff to bring projects to the Council and be open to receiving feedback.”

- Chair of Family Advisory Council
Hassenfeld Children’s Hospital

Running a successful Council requires a lot of planning in advance – below are some tips to help.

“The FAC meeting is over, I am starting to identify our topics and guest discussants for the next meeting!”

- Chair of Family Advisory Council
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Challenges participating in a group

Some of your Council members may have never participated in a formal meeting before, while other Council members may be inclined to monopolize discussions. No matter the challenge, a member might need additional coaching on how to participate in a group respectfully and effectively. In those situations, it is helpful if the Chair sits down with the Council Member and provides some respectful but direct guidance.

“Preparation and Participation”

We had one member that was dominating our Council conversations. It had become disruptive to a healthy group dynamic. After two meetings of politely moving the conversation to someone else, I asked the member if we could talk before the next meeting. It was difficult, but I let the member know that a vital part of continued participation was keeping input timely and brief and respecting the space for others to share their views."

- Chair of Family Advisory Council
Hassenfeld Children’s Hospital

Prepare guest discussants

The success of a meeting is dependent on the quality of the discussion for each agenda topic. For instance, if guest discussants are not prepared or if the discussion is confusing, members might become unfocused and it is unlikely the guest will get the feedback they seek. To ensure a thoughtful and meaningful discussion, it is helpful to prepare guest discussants. Some guests have never presented to families and will need additional coaching, but here are some general tips for how to successfully prepare speakers for the FAC. (also see Guest Discussant Guidance, Appendix)

- Meet with guest discussants in advance to support an effective presentation. Offer them a set of 3-4 template slides to help them structure their content, including: (1) Title slide (2) Background (3-5 bullets, including challenges and goals) (3) Questions (clear, concise and specific questions that will solicit feedback form families).
- Top 3 questions: Ask guests discussants “What are the three things you most want to know from families?”
- Guidance for Guests: Remind guests that the best sessions are where they speak for 3-4 minutes, offer background and then primarily listen to feedback from families for the rest of the time, while occasionally interjecting deeper questions. Also, prepare guests in advance that they may hear ideas they already had themselves, but that to just go with it. No need to tell families you already had that idea, which can quiet creative thinking and engagement. Instead, praise their ideas, encourage more, or ask a deeper question to have them think about things you may have not thought of yet.
- Co-present with the guest. The Chair knows the audience and can provide assistance in facilitation.
- Time Signals (10 minutes, 5 minute, and 1 minute): Discuss in advance how you will alert the guest about remaining time to speak.
- Updates from Presentations: Councils often express interest in hearing from past guests about the status of the project and how FAC influenced it. Tell the guest discussant in advance that they will be expected to provide a six month or yearly update to the FAC.
- Follow-Up:
  - Check in with and thank guest discussants after the meeting to learn their initial feedback and to provide an overall professional experience.
  - Send notes taken during the meeting to the respective guest; keep track of any next steps that the FAC or the Chair needs to do.

Be consistent

Each Council meeting should have a consistent format so Council members know what to expect. Sending agendas out in advance gives members advance notice about meeting topics. Sometimes guest discussants ask if families can look over documents in advance, which can be attached to the agenda email.

Start on time and end on time. Sometimes it helps to give families a fifteen minute buffer before meetings begin, but then try to start always after that fifteen minute buffer.(see sample agenda, appendix)

Communicate

Sending reminder emails to Council members and gathering RSVPs in advance are essential to ensuring a quorum as well as knowing how much food to order.

“I usually send three reminder emails (with request for RSVP) out in the month – a week in advance, 2 days in advance and then on the day of the meeting”

- Chair of Family Advisory Council
Hassenfeld Children’s Hospital

It’s important to continuously recruit new FAC members. Patient and families’ priorities change and you want to have new members joining faster than members leave. New members invigorate the group discussion and bring fresh ideas and recent experiences to the dialogue. Meetings occur monthly, but recruitment should be all year long.

Survey your council

Survey the FAC to evaluate how members feel about topics, presentation approaches, catering, logistics, and Council structure. By understanding the member’s experience of the Council, it will help you improve all aspects of it.

Show appreciation

Show the Council members how much you appreciate all of their time, effort, and sharing of experiences and perspectives. We show our respect and appreciation by providing:

- Meals at each meeting
- Start and end times to the meeting that are true and consistent.
- An Honoring Reception. Distinguishing the end of the year and the institution’s appreciation for all of the family advisors’ time and effort is a common element of many councils and a special part of ours. At this venue, it is common to highlight the projects and topics influenced throughout the year.

“\textbf{The particular venue is less important than the message … \textit{we appreciate you!}}”

- Chair of Family Advisory Council
Hassenfeld Children’s Hospital

Summary

Starting a Family Advisory Council at your hospital offers patients, families and clinicians an opportunity to collaborate to improve practice, care, safety and the overall patient and family experience. Your council supports relationships between patients, families and clinicians and enables each stakeholder to hear one another’s perspectives in a thoughtful and respectful forum. Setting up a successful FAC requires advance planning and attention to details. A Family Advisory Council is not just a monthly event; it is the cultivation of an ongoing and robust partnership between and among families and staff.

We hope that this guidebook is helpful to you as you develop your own Family Advisory Council. Please don’t hesitate to reach out to Beth Silber, Family Consultant, Chair, Family Advisory Council, with any questions you may have: beth.silber@nymc.org

References

Appendix

Table of Contents of Appendix:
1. Family Advisory Council Application
2. Family Advisor Interview Questions
3. Guest Discussant Guidance
4. Sample Meeting Agenda

Appendix 1 - Family Advisor Application
1. Contact Information
2. Briefly tell us about your experience in receiving care.
3. Briefly describe something that has gone well when receiving care.
4. Briefly describe something you wish had gone better and how your experience could have been improved.
5. If you have been an advisor for other programs or organizations, (including your child’s school, community or work) please tell us about this experience.
6. Are you available at the time/days of the monthly meetings?

Appendix 2 - Family Advisor Interview Questions
Interview questions should explore why the candidate is interested in joining the FAC, how the potential Council member might contribute to the FAC discussion and how he/she offers feedback constructively. These are some interview questions and discussion points to consider including:
• Ask how the candidate learned about the FAC.
• Share an overview of how the FAC functions and the value it brings to the hospital.
• Explore the candidate’s interest in the FAC.
• Ask if they have experience on committees and groups that seek perspectives from multiple members. If so, what successes or challenges have they seen?
• Ask the candidate to share their family’s experience at the hospital. Could it have been improved and if yes, how so?
• Share the commitment and expectations for participation on the FAC and ask the candidate if they anticipate any challenges that may make it difficult for them to participate.

Appendix 3 – Guest Discussant Guidance
Welcome to the Family Advisory Council
We are delighted you will be joining us as a guest discussant at the Family Advisory Council. This information will provide you with background on our Council and share some methods and strategies that work best in presenting to our group.

About the Family Advisory Council
• The Family Advisory Council was founded nearly five years ago and is comprised of over 20 families whose children have been treated at Hassenfeld Children’s Hospital at NYU Langone. The Family Advisory Council members are diverse culturally and with respect to the diagnoses of their children.
• Family Advisors are recruited, trained, and mentored to collaborate on strategic and operational initiatives, using their first-hand experience to influence programs and resources and advance a culture of child and family-centered care.
• Staff partners serving on the Family Advisory Council include: Senior Vice President of Children’s Services, Executive Director of the Sala Institute for Child and Family-Centered Care, Director Center for Child and Family Experience, Director of Nursing, Director of Social Work, Physicians and Chief Residents.

Recommendations for Guest Discussants
From experience leading the Council we have learned that the most effective sessions include the following characteristics:
• Keep it short. Speak for no more than 3-4 minutes, pose your questions and listen to the amazing perspectives. Use a PowerPoint that outlines the highlights of your initiative or program in less than 5 slides:
  - Project Background/rationale
  - Project Goals
  - Challenges
  - Three questions for families
• Use plain language. Avoid acronyms or abbreviations.
• Pose three straightforward discussion questions you would like the Council to answer.

Meeting Logistics
Location: XXXXXXXXXXXXXXXXXXXXXXX
When: 5-7pm - A light dinner is available during the meeting.
Contact: Please contact XXXXXXXX to plan your presentation.

Appendix 4 - Sample Meeting Agenda
Family Advisory Council Agenda
Meeting Date: Thursday, October 8th, 2018
Meeting Time: 5-7 PM
Location:
Meeting Sponsor: Chair’s Name

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<thead>
<tr>
<th>Topic</th>
<th>Goals</th>
<th>Speakers</th>
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<tbody>
<tr>
<td></td>
<td>Goal 1</td>
<td>• Sallie Johnson</td>
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<td></td>
<td>Goal 2</td>
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<td>Title</td>
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<td>• Jamie Kling</td>
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<tr>
<td>Update</td>
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<td>• Dave Jacobs</td>
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Next Monthly Meeting: November 12th from 5:00 to 7:00 PM