

ELEMENT II. INVOLVING FAMILIES

An Overview and Rationale

For a program to be successful, it must meet patients' and families' needs in ways that they find welcoming and supportive. Many clinics and agencies already actively partner with families on a case-by-case basis, and some have family and patient representatives on advisory boards. Going a step further, involving patients and families in the planning, execution, and evaluation of programs speeds the development process and ensures that what the programs, practices, and/or clinics do meets the needs of those that it is intended to serve. Moreover, this type of engagement demonstrates that provider-family partnership is a true value and is honored and supported at all levels of the practice. Authentic partnership between providers and families can also be essential to helping sustain what is implemented as families often are the best champions and advocates at the practice, policy, and funding levels.

Goals and Strategies for Creating Family-Informed Services and Support/Resources

Goal 1: Develop systems and policies that support family involvement.

Goal 2: Involve families in service delivery planning, implementation, and evaluation



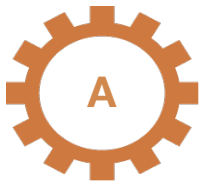
DEVELOP SYSTEMS AND POLICIES TO SUPPORT FAMILY INVOLVEMENT

Goal 1. Develop Systems and Policies to Support Family Involvement

Why Is This Goal Important for Trauma-Informed Integrated Care?

Several structural components should be in place to foster and sustain successful family involvement in your organization. Institutionalizing systems and policies ensures readiness, implementation, fidelity, and sustainability.

This goal includes two change concepts: 1) developing formal / informal documents to support family involvement; and 2) providing orientation for staff and caregivers.



DEVELOP POLICIES AND PRACTICES TO SUPPORT FAMILY INVOLVEMENT

Change Concept A: Develop Policies and Practices to Support Family Involvement

There are a number of documents that can be developed to support family involvement at the organizational level. These documents not only guide the operations, but they confirm the office's goal to involve families. Other structural pieces that can facilitate family involvement include statements (written or verbal) of commitment and support from leadership and staff. Training for staff on the importance of family involvement is useful when attitudes need to be shifted.

Below, you will see examples of how this change concept could be tested as concrete strategies. Each of these possible strategies is detailed further – making them even more practical and specific –in the sample PDSAs that follow.



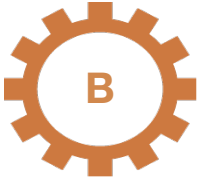
Implementing Change Strategy through Small Tests of Change (PDSAs)

We encourage you to use the strategies and small tests of change included in this toolkit as starting points: taking and adapting what might work for you, and adding to this list so that our collective work continues to grow. Below are more specifics about how you might consider testing and ultimately implementing these strategies in your own daily work.

Families from different races and cultures may respond to engagement strategies in different ways. Talk with your family advocate, or a sample of caregivers from your community to get a sense of what strategies they find most engaging, supportive, and respectful.

Change Concept A. Develop Policies and Practices to Support Family Involvement

Possible Strategies	Specific Ideas to Test
State your commitment to support caregiver involvement	<ul style="list-style-type: none"> → Include language about the office commitment to family involvement in office goals, value statement, or missions. → Make these commitment statements visible, e.g., on all practice documents, as posters in the office, etc. → Ensure that all staff know about this language and caregiver involvement as a value. → Include family partners in the development of these commitment statements.
Include in staff job descriptions	<ul style="list-style-type: none"> → Include mention of staff roles in helping family team members (e.g., buddy role, reminder calls, confirmation of child care needs, transportation, preparing caregivers before meetings, etc.) in staff job descriptions. → Include families and providers in helping craft the language for these staff roles. → Make sure these roles aren't simply added to a long list of other responsibilities without shifting or removing tasks. Staff will not appreciate the roles if they are perceived as "just another thing to do." → Ensure that staff are clear about these roles and connect them to the values of family involvement.
Develop clear reimbursement policies for families	<ul style="list-style-type: none"> → Allocate or dedicate funds to support family involvement. → Include specific guidelines on reimbursement for caregiver/family volunteer expenses (e.g., gas, tolls, transportation, meals, stipends, and child care). → Ensure that the reimbursement methods are simple for families to use (see Appendix B.2; Caregiver Compensation).
Ensure active leadership support for parental involvement	<ul style="list-style-type: none"> → Involve leaders to ensure that staff have dedicated time to support families. → Make sure that families are included at the leadership level in meetings, on teams, and in decision-making. → Ensure that the involvement of families is validated and celebrated in visible ways.



Provide Orientation for Staff and Caregivers

Change Concept B: Provide Orientation for Staff and Caregivers

Orientation for both staff and the family advocates themselves is important for ensuring the family advocates' role is a positive and productive experience for everyone. Orientation needs to include how to handle personal information – both the family advocate's and that of other clients or patients. It can be particularly delicate if a family advocate is actively receiving care at the site at the same time as serving as a member of the team. In that case, the potential family advocate and her or his primary provider may want to talk about the implications and what is in the family's (or child's) best interests. Staff members also may need to be reminded that their general privileges to access medical records do not extend to viewing the records of patients (in this case, those of the family team member) for whom they do not provide direct care.

It is also critical that certain assurances are made to families up front:

- No family member is required to volunteer, and volunteering will not influence future treatment in any way.
- Being involved does not require constant retelling of families' personal trauma history.
- Scheduling is flexible.
- Expenses will be reimbursed.

Moving from Change Concept to Concrete Strategy

Below, you will see examples of how this change concept could be tested as concrete strategies. Each of these possible strategies is detailed further – making them even more practical and specific –in the sample PDSAs that follow.



Orient Caregivers to the Organization

Orient Caregivers about Their Role at the Agency/System Level

Orient Staff about the Role of Family Advocates at the Agency/System Level

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Change Concept B. Provide Orientation for Staff and Caregivers	
Possible Strategies	Specific Ideas to Test
Orient caregivers to the organization	<ul style="list-style-type: none"> → Give family advocates an orientation to the organization itself. Include a tour and introductions to key individuals they may not have already met. → Make the family advocate feel like a true part of the organization by giving them their own identification badges, so they can come and go freely. → Try to give the family advocate an organization email so they can keep up on the organization’s internal communications and issues in real time.
Orient caregivers about their role at the agency/system level	<ul style="list-style-type: none"> → Reinforce the importance and value of family voice, perspective, and expertise. Use language like “lived experience” to validate what family advocates bring to the table. → Help family advocates understand how to handle personal information – both the family advocate’s and that of other clients or patients. → Remind caregiver advocates that they do not need to share their story or experience unless they truly want to – and this decision may change with the group and the situation. → Provide clear descriptions to family advocates about their role (see goal below for more details).
Orient staff about the role of family advocates at the agency/system level	<ul style="list-style-type: none"> → Organize a “reverse” orientation in which family advocates or community representatives set up visits to key community sites or organizations. → Invite clinic/agency team members to sit in as guests at meetings of other community groups to help the clinic team members gain a better feel for how issues are raised when community members are in the majority at a meeting. → Invite family advocates to talk directly to staff about their roles in their own words.

Assessing Your Progress

As you begin testing concrete strategies, you want to ensure that your changes are resulting in improvements. Below are some key questions to help you assess and reflect on how you are doing in each of the change concepts in this goal.

1	2	3	4	5
Serious Concerns/ Challenges				Very Strong, Positive

Change Concept A. Develop Formal/Informal Documents to Support Family Involvement

- How does the agency demonstrate support for family involvement?
- What structures are in place to facilitate and support family involvement (e.g., time, staff, budget, guidelines)
- How does leadership demonstrate support for family involvement?

Change Concept B. Provide Orientation for Staff and Caregivers

- How are family partners oriented to the agency, including staff and policies?
- How are family partners trained on their roles?
- How is staff trained on the value of family involvement?
- How is staff trained and supported on how to best work with family partners?



INVOLVE FAMILIES IN SERVICE PLANNING, IMPLEMENTATION, AND EVALUATION

Goal 2. Involve Families in Service Planning, Implementation, and Evaluation

Why Is This Goal Important for Trauma-Informed Integrated Care

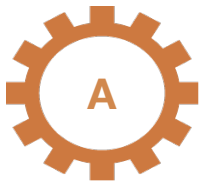
Patients and their families are a clinic or agency's primary stakeholders, and their experiences and opinions ultimately determine the success of proposed services and programs. Thus, they should be involved with planning, implementation, and evaluation, providing important suggestions on a range of issues, including office design, scheduling, staff knowledge, attitudes, communication styles, cultural responsiveness, and care.

Family participation helps assure that services are responsive to family needs, culturally sensitive, feasible for patients, appealing and acceptable, and thus promote long-term engagement in care and better outcomes. The family members involved can gain new skills, which can open doors for them in the community. Many come with or develop skills and knowledge that make them valuable potential staff members of the agency/clinic. Finally, patient and family opinions can be powerful forces for system change – their involvement can legitimize key choices in program design and help prioritize the changes the program seeks to make. And as advocates, they can be essential for the sustainability of improved systems.

Benefits of Involving Families

- Assure that services are responsive to families' needs
- Improve quality of care
- Increase patient satisfaction
- Strengthen cultural competence
- Empower parents to create change
- Develop advocates for your programs

This goal includes four change concepts: A) clarify caregivers' role within the organization; B) recruit families who are ready and interested; C) prepare family advocates; and D) encourage ongoing recruitment and provide support for continued involvement.



Clarify Caregivers' Role within Organization

Change Concept A: Clarify Caregivers' Role within Organization

There are different ways to get input from families on existing and/or proposed organizational practices. Families can help with planning, implementation, and evaluation, and they can serve as advocates.

Moving from Change Concept to Change Strategy

Below, you will see examples of change strategies that could be carried out to engage families at the start of a visit. Each of these possible strategies is detailed further – making them even more practical and specific –in the sample PDSAs that follow.

- I  Assist with Staff Trainings
-  Engage as Team Member for Specific Project
-  Test and Assess PDSAs
-  Participate as Board Member
-  Advocate for Programs with Funders/Policy Makers

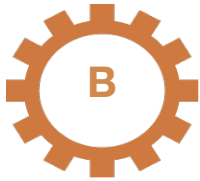
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Families from different races and cultures may respond to engagement strategies in different ways. Talk with your family advocate, or a sample of caregivers from your

community to get a sense of what strategies they find most engaging, supportive, and respectful.

Change Concept A. Clarify Caregivers' Role within Organization	
Possible Strategies	Specific Ideas to Test
Assist with staff training	<ul style="list-style-type: none"> → Invite families to provide their input on what should be incorporated into staff training. → Have them help deliver content to staff directly -- personal narratives from families can demonstrate the need/effect of protocols and interventions on patients.
Engage as team member for specific project	<ul style="list-style-type: none"> → Invite family members to be part of teams for specific projects, such as a Learning Collaborative or community outreach campaign. Remember that this may require flexibility about the timing and location of meetings.
Test and Assess PDSAs	<ul style="list-style-type: none"> → Encourage family team members to help select, design, and test tools, resources, materials, process, and practices (e.g., script for talking with caregivers about resilience, poster in the waiting room, screening tool, caregiver satisfaction survey). → Ask families for impressions and observations as part of the "Study" of the PDSA when the small changes are tested.
Participate as Board Member	<ul style="list-style-type: none"> → Serve formal standing groups, such as advisory board, planning committees, or task forces. By having family boards or family representation on your standing boards, you can obtain regular input on programs and develop a relationship with the family members over time (see Appendix B.1; Caregiver Advisory Board).
Advocate for programs with funders/policy makers	<ul style="list-style-type: none"> → Engage parent advocates to advocate for your program with organizational leadership, funders, and policy makers. → Help family advocates tell their personal stories and testimony in ways that augment the data, facts, and figures you may already have. → Encourage family advocates to take a lead role in identifying individuals and organizations that may be important to support and sustain your work.



Recruit Families Who Are Ready and Interested

Change Concept B: Recruit Families Who Are Ready and Interested

Not all families will be interested in getting involved, nor are all families ready to do so. Family members who are likely to do well as team members are those who have shown some initiative and understanding of larger needs of all families. However, many people who may be wonderful team members may not step forward or be those who have been the most vocal. Consider strategies to assess readiness and interest and actively recruit them.

Moving from Change Concept to Change Strategy

Below, you will see examples of change strategies that could be carried out to recruit families who are interested and ready. Each of these possible strategies is detailed further – making them even more practical and specific – in the sample PDSAs that follow.



Think Broadly in Your Outreach Efforts



Seek Out Family Members Who Express Interest

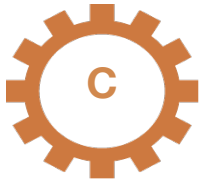
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community to get a sense of what strategies they find most engaging, supportive, and respectful.

Change Concept B. Recruit Families Who Are Ready and Interested	
Possible Strategies	Specific Ideas to Test
Think broadly in your outreach efforts	<ul style="list-style-type: none"> → Consider those in your clinic or agency who have different kinds of contacts with families – nurses, front desk staff, outreach workers or home visitors. → Invite staff to consider family members who have seemed particularly thoughtful or dedicated, or who have a skill set (sometimes from a prior stage in life or in another country) that could be helpful. → Encourage staff to consider not only those who have been positive about their experiences – bringing in families who have had differing experiences (both positive and negative) can offer invaluable feedback to system change efforts. → Make sure to explain to prospective family advocates how valuable their personal experiences are and can be to inform this work and validate how crucial their role is to the organization, especially if they seem hesitant to step into the role. → Reach out to families of graduates of your programs. They have more time, fewer conflicts, and more objectivity. → Recruit from peer community groups made up of family members like NAMI, Coalition, etc...
Seek out family members who express interest	<ul style="list-style-type: none"> → Look for family members who ask questions about the organization’s operations and policies, who offer to take on various responsibilities, who are interested in other families’ concerns, and who have ideas for activities and services (NCTSN). → Develop a brief checklist or “readiness assessment” based on the NCTSN characteristics in the box above. → Raise awareness among staff at all levels about the characteristics they should be looking for in their interactions with families.



Prepare Family Advocates

Change Concept C: Prepare Family Advocates

Preparing the family member(s) you have recruited as family advocates can take many forms, ranging from formal orientations to informal conversations and follow-up. Many family representatives may not know the clinic staff or facility, therefore it is important to build the family advocates rapport with the staff and comfort in the clinic setting. Being clear about expectations, providing an orientation, and a staff buddy are the foundation to make family advocates more comfortable.

Moving from Change Concept to Change Strategy

Below, you will see examples of change strategies that could be carried out to prepare family advocates. Each of these possible strategies is detailed further – making them even more practical and specific –in the sample PDSAs that follow.



Set Clear Expectations



Provide Orientation



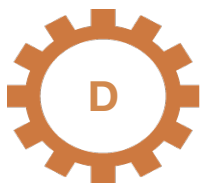
Use a Buddy System

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Change Concept C. Prepare Family Advocates	
Possible Strategies	Specific Ideas to Test
Set clear expectations	<ul style="list-style-type: none"> → Be clear and honest in what you expect from families and what they can expect from you. → Create these mutual expectations in partnership with families, using language that is meaningful to them.
Provide orientation	<ul style="list-style-type: none"> → Provide an orientation to family representatives about the clinic’s mission, values, as well as a tour of the facilities (see strategy A). → Ensure the staff feels welcomed by the staff by using first names at meetings (try not to use titles for some people, but first names for others), being informal, and taking the time to get to know one another and appreciate the different perspectives at the table.



Encourage Ongoing Recruitment and Provide Support for Continued Family Involvement

Change Concept D: Encourage Ongoing Recruitment and Provide Support for Continued Involvement

Being a family advocate is a huge commitment. On the other hand, empowered family advocates can be impassioned members of your team and they often report satisfaction and personal growth with the role. To ensure sustained family involvement, it is important to recruit potential family advocates on an ongoing basis and provide continued support.

Moving from Change Concept to Change Strategy

Below, you will see examples of change strategies that could be carried out to prepare family advocates. Each of these possible strategies is detailed further – making them even more practical and specific –in the sample PDSAs that follow.



Look for New Family Advocates



Provide Support to Sustain Involvement

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Change Concept D. Encourage Ongoing Recruitment and Provide Support for Continued Involvement

Possible Strategies	Specific Ideas to Test
<p>Look for potential new family advocates</p>	<ul style="list-style-type: none"> → Ensure that you have multiple positions allocated and that the position(s) are filled. → Ensure that there is more than one caregiver engaged with the team at any given time -- having multiple family advocates spreads out the responsibilities, provides the advocate with a support network of other families, ensures that multiple voices, perspectives, and experiences are represented, and guarantees substitutes when people move on.
<p>Provide support for existing family advocates to sustain their involvement</p>	<ul style="list-style-type: none"> → Review The FRIENDS National Resource Center for Community-Based Child Abuse Prevention’s guide entitled “Meaningful Parent Leadership: A Guide for Success” (Appendix B.1), which outlines strategies to sustain family advocate involvement. Ideas include: <ul style="list-style-type: none"> • Hold meetings at times that are convenient for families. • Ask how best to stay in contact (text, calls, or email). • Ensure that families’ input is being heard with verbal acknowledgement and documentation in meeting notes. • Define acronyms that only clinic staff understand. • Continually check-in with the caregiver advocate to see if the workload is manageable, troubleshoot when necessary. • Provide training on topics related to the program or on leadership skills. • Recognize and celebrate family representative’s for their role and contributions. • Where possible, consider providing concrete support for families’ involvement in the form of childcare when necessary as well as stipends for their time.

Assessing Your Progress

As you begin testing concrete strategies, you want to ensure that your changes are resulting in improvements. Below are some key questions to help you assess and reflect on how you are doing in each of the change concepts in this goal.

1	2	3	4	5
Serious Concerns/ Challenges				Very Strong, Positive

Change Concept A. Clarify Caregivers' Role within Organization

- How does the organization get input from families on existing and/or proposed practices and policies?
- How are families engaged in planning, implementation, and/or evaluation efforts?
- How are families engaged as advocates for the work of the organization?

Change Concept B. Recruit Families Who Are Ready and Interested

- What criteria are used to recruit families to serve in family partner roles?
- What type of outreach efforts do you use to identify and recruit potential family partners?
-

Change Concept C. Prepare Families Who Have Volunteered

- What type of formal preparation do you provide to family partners?
- What type of informal preparation do you provide?

Change Concept D. Encourage Ongoing Recruitment and Provide Support for Continued Involvement

- How are you engaging in ongoing recruitment of family partners?
- If you already have caregiver partners, how do you support them in using their experiences and expertise to enhance your work?

Element II. For More Information

Goal 1. Develop Systems and Policies that Support Family Involvement

The resources listed below can be found in **Appendix B.1**

Caregiver Compensation

1. FAQs on Compensation for Family, Youth, and Consumer Involvement

Caregiver Feedback Forms

1. [The NHS Friends and Family Test- Implementation Guide: www.nhs.uk](http://www.nhs.uk)

Toolkits

1. Strategies to Increase Birth Parent Engagement – *Foster Care*
2. Family Engagement Resources – *Foster Care*
3. Meaningful Parent Leadership- A Guide for Success
4. Pathways to Partnerships with Youth and Families
5. *This document addresses youth and family involvement at both the clinical and organizational levels. A self-assessment tool for each level is included, with specific goals and activities organizations can use to increase engagement.*
6. Growing and Sustaining Parent Engagement
7. *This toolkit is a quick guide to implementing three strategies for supporting sustained parental engagement in the care and services provided to their children. The strategies include a roadmap for agencies and communities to define their goals and approaches, a checklist to assess the effectiveness of engagement efforts, and a network of different groups dedicated to supporting parent engagement. Available at:*

<http://www.cssp.org/publications/growingandsustainingparentengagementtoolkit.pdf>

8. NAMI Family Guide- Integrating Mental Health and Pediatric Primary Care

Goal 2. Involve Families in Service Planning, Implementation, and Evaluation

The resources listed below can be found in **Appendix B.2**

Caregiver Advisory Board

1. Parent Advisory Groups in Pediatric Practices: Parents' and Professionals' Perceptions (Young, McMenemy, & Perrin, 2001)

This article reports the results of a survey asking parents and providers about their experiences with parent advisory groups. Overall, both describe the groups as beneficial, with each group emphasizing specific aspects of the experience.

2. Tips for Developing an Effective Advisory Board

A quick two-page summary of the role of an advisory board, recruitment of members and planning meetings. Includes a case example. Available at: http://www.nctsn.org/sites/default/files/assets/pdfs/Pathways_AdvisoryBdTipsheet.pdf