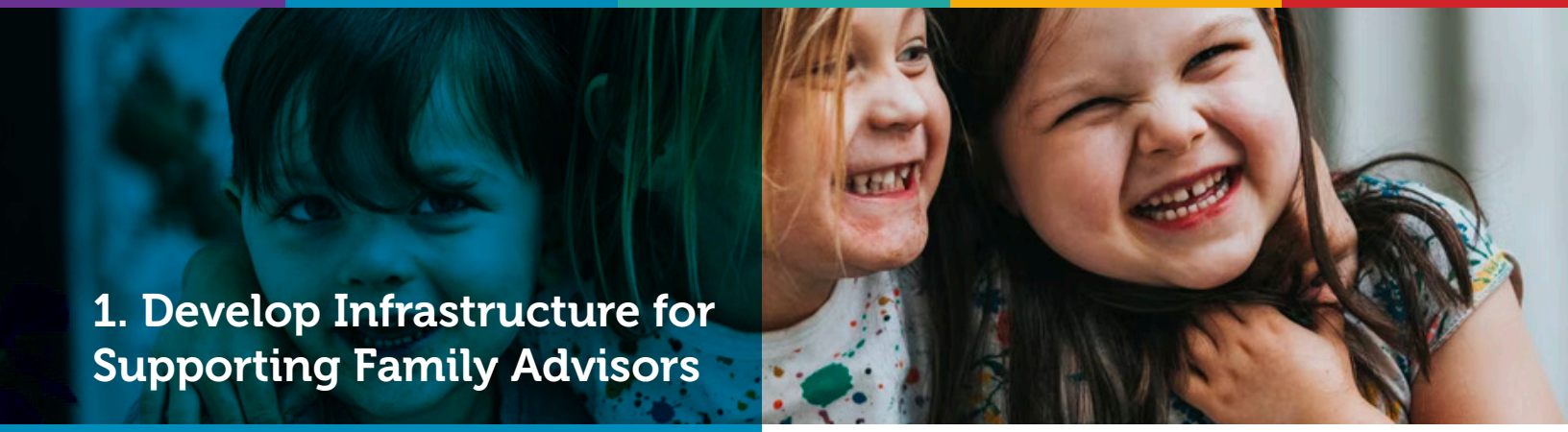

1. Develop Infrastructure for Supporting Family Advisors

Shifting the Culture Within the Practice Team

Prior to recruiting, practice staff need to ensure the culture of their practice is ready to engage family advisors. First, practices need to understand the role and purpose of family advisors and ensure there is buy-in from all staff to support them on the practice team. Explore the benefits and value family advisors can add to improve patient outcomes. Also, practices should determine their needs and the expectations of the role family advisors will play. To do this, determine what local changes the practice wants to see to better support their patients and how family advisors can help reach that goal. To the right are steps and questions to consider before recruitment begins. Keep in mind, every time new staff is hired, they should be made aware of the goals and expectations of family advisors.

- Assess the readiness of the practice[6] to take on Family Advisors
  - Do all practice staff understand their role and expectations?
  - Do all practice staff see the value of engaging a family advisor?
  - Answer the following questions around staff and practice readiness using this resource.[7]
- Identify a staff person to be a mentor for family advisors. This will be the main contact that family advisors know to reach out to with questions, concerns, and ideas.
- Address and educate about implicit and explicit biases in practice staff (See: Learning Topic 2: Race and Ethnic Equity)
- Be culturally respectful, responsive, and aware
- Change the relationship between provider and parent – facilitate a partnership
- Remove tokenism
  - Do not add family advisors to practice team solely to check a box; have clear roles and expectations for them
  - Identify more than one family advisor to gain broader perspectives and reduce the expectation that "one family advisor speaks for all families"
  - Identify mechanisms to regularly engage family advisors as part of the team

6. https://www.ipfcc.org/resources/Checklist_for_Attitudes.pdf
7. https://www.nichq.org/sites/default/files/resource-file/Assessing_readiness_for_practices_and_staff-English.pdf

Characteristics of Family Advisors

Identifying family advisors can be a struggle. In addition to shifting the culture, mentioned above, reviewing as a practice team what type of person and what specific roles you want family advisors to do can help establish guidelines for identifying family advisors. To the right are some common characteristics and responsibilities of a family advisor.

While there is no one ideal family advisor, the following characteristics can be beneficial.

- Lived experiences
- Ability to present problems and offer solutions tactfully
- Empathetic
- Ability to say "No" and "I don't know"
- Desire to learn
- Emotional intelligence
- Knowledge of local resources and organizations in the community
- Has time and ability to fully participate (consider childcare, transportation, time of meetings or work)
- Ability to separate advocating for their child and advocating for all children

Responsibilities of Family Advisors

This is not an extensive or required list of responsibilities for a family advisor. The specific role should be developed based on the needs, experiences, and goals of both the practice and the family advisor. Consider areas in the practice to be improved upon and how a family advisor could help the practice reach their goals. For more information, please see the Examples of Family Advisor Tasks. (Appendix B)

- **Be a Liaison:** Facilitate questions and concerns between the families and the practice team
- **Share Your Story:** Share your health care experiences with providers and other patients and families.
- **Provide Input on Services:** Serve as a partner in projects working to make improvements to specific provider and clinic services.
- **Review Practice Environment and Materials:** Ensure office resources, policies, and programs represent the patient population and are equitable.
- **Engage Community Partners:** Develop and maintain positive relationships with community stakeholders and identify gaps in programming efforts and/or partnerships.
- **Expand Your Knowledge:** Develop knowledge and professional skills through continuing education, professional development, current literature, and seminars, etc.
- **Represent the Practice:** Be available to represent the practice as a family advisor and answer questions.
- **Participate on Committees:** Bring the patient and family perspective to committee meetings.
- **Participate on Quality Improvement (QI) Team:** See box on next page that outlines methods for family advisor engagement in QI work.

The Institute for Patient and Family-Centered Care (IPFCC)'s Framework for Family Involvement in QI and Classification.

- **Level I** Families complete surveys or engage in other evaluative activities as respondents (e.g., focus groups).
- **Level II** Family advisory councils serve as a resource to the quality improvement team (e.g., review projects, documents).
- **Level III** Families participate as occasional reviewers and consultants during an improvement project.
- **Level IV** Families participate as active members of improvement teams and/or may serve on unit-based task forces and committees and faculty for staff and clinician education.
- **Level V** Families are co-leaders of improvement initiatives: They are fully integrated as critical members of the QI team at all levels. They co-design and lead tests of change for staff education.

Job Description

To ensure there are clear and agreed upon expectations between the practice team and the family advisors, a job description (See Appendix A) should be developed. Together, practice staff and family advisors should identify areas the family advisor has an interest, establish their goals, abilities, and time commitment, and answer any questions or concerns. Through this conversation, a plan with a timeline can be developed. Family advisors should also be provided with optional training opportunities to advance their work.

Compensation

Compensation needs to be provided to show family advisors their time and expertise are valued. It is necessary for practices to be flexible and communicate the best way to compensate family advisors. For example, some family advisors may not feel comfortable receiving an IRS Form 1099 (for reporting taxable income) so offering other incentives for participation should be considered. Compensation could include:

- Stipend
- Gift cards
- Reimbursement for items such as parking, meals, childcare, travel, etc.
- Seek alternate sources of funding from within the practice and through community partners such as, local and institutional foundations