



INSTITUTE FOR FAMILY-CENTERED CARE

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PRESENTATIONS BY PATIENTS AND FAMILIES: STAFF LIAISON COORDINATION AND PREPARATION ROLES

- ▼ Receive requests for patients/families to present to health care professionals or trainees. Clarify what the requesting instructor, department, group, or agency actually wants and needs.
 - Who will the actual audience be?
 - What does the audience want to learn about?
 - Are the patients/families being asked to limit themselves to a specific topic or speak in general about their experiences?
 - How many patients/families are they looking for?
 - Do they want the audience to hear about positive as well as negative experiences? (Staff, students, and trainees often benefit from hearing examples of what works and what doesn't work so well. So, it is sometimes helpful to suggest that patient or family presenters share information about good experiences, demonstrating positive aspects of patient- and family-centered care, and negative experiences that could be used as opportunities for learning and improvement.)
 - Will travel and child care costs be reimbursed? Can they also compensate patients/families for their time (e.g. an honorarium or stipend)?

- ▼ Select patients/families to make the presentations.
 - Try to identify patients/families with relevant experiences/expertise/perspectives.
 - Select people who have an ability to share personal experiences in a way that others may learn from them.
 - Plan for diversity when possible.
 - Respect patient/family scheduling needs.
 - Avoid selecting individuals who are angry or focused only one issue or one aspect of their experience.

- ▼ Offer to meet with patients/families prior to their presentation to assist them in preparing. When meeting with patients/families, a number of key points can be emphasized.
 - Recognize the value of individual patient/family experiences in helping to train professionals.
 - Use notes or index cards to keep track of thoughts.
 - Stick to an agreed upon time limit.

- Prepare for unexpected emotions. (Suggest ways to handle emotions that may arise when speaking.)
- Avoid referring to specific providers or programs, especially when describing a negative situation.
- Focus on positive experiences and what they exemplify.
- Convey information about negative experiences constructively so that members of the audience can develop their understanding of, and ability to distinguish, beneficial practices as well as practices that are not helpful. (Suggest communication strategies that minimize the likelihood that they will be dismissed as “just an angry patient or parent.”)
- Handle questions from the audience. (Patients/families may not be comfortable answering personal questions, help them to plan possible responses to use.)

▼ Call patients/families soon after their presentations.

- Thank them for their presentation.
- Offer feedback and constructive criticism.
- Offer to discuss any emotions kindled or rekindled by sharing their experiences. (Patients/families who have never presented this way before may find themselves surprised at the range of emotions that are rekindled by speaking about their experiences.)

Adapted from Nancy Abernathy/Nancy DiVenere, *Parent to Parent of Vermont*, 1992.

For additional guidance available through the Institute for Family-Centered Care: Blaylock, B. L., Ahmann, E., & Johnson, B. H. (2002). *Creating Patient and Family Faculty Programs*.