



INSTITUTE FOR FAMILY-CENTERED CARE

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Patient and Family Leaders in Paid Positions: Common Challenges — Effective Solutions

Increasingly, patients and families are becoming involved as advisors and leaders in health care organizations to assist in advancing patient- and family-centered care and enhancing the quality and safety of health care. Typically, however, these roles are on a volunteer basis. As paid staff, patients and families can contribute greatly to the mission and work of health care organizations. There are a variety of positions in which patients and families can serve including coordinator of peer-to-peer support programs, coordinator of patient- and family-centered care initiatives, patient and family representatives, patient and family liaisons, and staffing patient and family resource centers. Clearly there are challenges for health care organizations to consider when hiring patients and families. This resource discusses several challenges and offers some solutions.

Challenge: Patients and family members are experts on the experience of care, but some may lack the professional skills needed to work in an organization. They may be asked to do things for which they have not had complete training.

- Articulate role expectations clearly.
- Develop clear job descriptions.
- Create opportunities for patients and families to learn new skills.
- Ensure access to supervision.
- Establish a mentoring program for patients and families serving in these roles.

Challenge: A patient and family member may be hired because of outstanding interpersonal skills, but lack administrative skills needed for the job.

- Create a range of patient and family advisory and leadership positions.
- Hire those with patient and family experiences and skills as well as traditional professional skills to do administrative work.
- Create opportunities for patients and families without formal education to do community outreach and public speaking.
- Provide orientation and ongoing training to patients and families serving in paid positions.

Challenge: Patients and families may have illness and/or extraordinary caregiving needs. How can those needs be met with the needs of a job that must get done?

- Develop part-time positions.
- Offer job sharing.

- Reimburse for phone calls made from home.
- Develop flexible hours and flexible work places.
- Develop a sabbatical or leave policy for patients and families serving in paid positions.
- Assist patients and families in establishing and maintaining boundaries between work and home commitments.

Challenge: Professionals may resist or be unsure how to begin working with patients and families who are also employees of the organization.

- Demonstrate strong administrative support.
- Provide inservice opportunities for professionals – present both theoretical and practical aspects of patient and family involvement and effective collaboration.
- Develop training opportunities for patients, families, and providers together.
- Provide opportunities for providers to discuss issues openly and receive feedback.
- Help providers see the advantages and benefits for themselves and for the program.
- Keep providers informed of the work that patients and families are doing.
- Keep sending the message that patients and families have important insights and expertise to share with the organization.
- Offer rewards and incentives for providers who help advance patient- and family-centered care and the collaboration with patients and families at all levels of the organization.

Adapted from: Jeppson, E. S. & Thomas, J. (1995). *Essential Allies*. Bethesda, MD: Institute for Family-Centered Care.