



Massachusetts Consortium for Children with Special Health Care Needs



Family Partners Initiative: Guiding Principles

- Family members have unique contributions to make to health-care policy makers and organizations that shape how health care services to children with special health care needs (CSHCN) are financed and delivered.
- Family members can offer policy-makers and organizations insight and perspective on:
 - Experiences navigating the health care system
 - Health care system demands on consumers and their families
 - Creative solutions to problems
 - Barriers to care
 - Potential ways to save costs
 - Resources available outside the organization and unmet resource needs
 - Effective strategies for improving communications and collaborations with consumers
- When family members partner with public agencies, health plans, hospitals and other providers, programs and services become more responsive, more comprehensive and easier to use.
- Successful partnerships are based in mutual respect, open and honest communication, a genuine desire to work together to improve systems of care and the belief that collaboration, not confrontation, will produce the most effective results.
- Family partners are working to improve systems of care for CSHCN rather than addressing personal or individual family challenges.
- Family partners represent and speak for many families, not only their own. When representing their own personal situation or an organization they may represent, they make the distinction clear.
- Family partners strive to share the perspective and experiences of families of children with a variety of special health care needs.
- Family partners respect the privacy of families whom they represent and are careful when telling stories about other consumers that neither the details nor the context of the story identifies that person.
- Family partners respect the confidentiality of conversations and communications within the health care organization

- Family partners are clear with their partnering organization about any difficulties that might accompany their role --- about what information can and cannot be disclosed; about what level of advocacy they can engage in without fear of repercussions and what kinds of accommodations can and cannot be made for their special circumstances (e.g. health care and other needs).
- Family partners stay connected with other families in similar positions for purposes of support and information sharing.
- Family partners are truthful about their own skills and abilities and take responsibility for informing others when they need additional support or training.
- Family partners agree to share the lessons learned from their participation in the MA Consortium for CSHCN's Family Partners Initiative, in order to contribute to future Consortium efforts to improve systems of care for children and families in Massachusetts.