Collaborate

SHARED RESPONSIBILITIES

Tools for Improving Quality of Care for Children with Special Health Care Needs

Statement on Family Participation

New England SERVE, September 2002

The Shared Responsibilities model encourages health plans to create meaningful ways for consumers to join in quality improvement efforts. Plans are urged to consider establishing advisory groups that bring family members, providers, health plan staff and state agencies together to advise on identification strategies, data collection, and setting priorities for improvement.

Why would parents of children with special health care needs be willing to join in such collaborative efforts? This statement was developed by a group of family members who served as part of a joint advisory council for over two years. It attempts to spell out the motivations, expectations and hopes of one group of family advisors.

New England SERVE

The following statement was developed by family members who participated on a health plan advisory council from 1999-2001. It summarizes the motivations and expectations of parents of children with special health care needs in choosing to participate in a quality improvement project using the *Shared Responsibilities* Project.

Why are we here?

- **To build a collaboration with mutual respect.** We do not want to look at our providers and health insurers as adversaries or enemies. We do not want to fight for what our children need. We want to feel that we are working together, with our health plan, in the best interests of our children.
- **To speak the truth.** We want people to know the Atruth@ about what it means to be the parent of a child (or children) with special needs and to understand how policies impact our families.
- **To share our view of the system.** We want to share the experience of how it is to deal with a system that you must use, but don=t understand.
- **To help other families.** We want to talk about our experiences, listen to others and reach out to other members of this group.
- **To improve services for other children and families.** We believe that health plans cannot improve services without our help. When parents and consumers come to the table, we believe health plans can build better systems of care, and we want to be part of creating those solutions.

What do families expect in order to participate?

- **To be heard.** Families need to believe that people are listening to what we have to say.
- **Respect.** To be sure that others will respect our participation.
- **Dialogue.** We want feedback and an exchange of ideas. We do not expect total agreement.
- **Family centered.** We want the conversations to have a perspective on the whole family, not just the child with special needs.
- **Avoid labels.** Children are individuals. Do not talk about Athese children@ as a group, or label an individual child as their diagnosis or disability.
- **Allow challenges.** Involve parents who challenge the system and may be difficult to listen to, not just those who are satisfied with their services.
- **Commitment to implement changes.** We want to hear that health plans are willing to make meaningful changes as a result of our efforts in working together.

What do families hope to accomplish through their participation?

- **Build partnerships.** We want to help the health plan build a system that expects parents will be accepted as equal partners in decision-making in medical matters about their child. Parents should not be seen as less expert or uninformed. Their expertise is different than medical providers, but equally important to successful treatment for our children.
- **Increase family supports.** We hope that the health plan will make a commitment to create systems that can support families caring for children with special health care needs even if they can=t advocate for themselves.
- **Identify family strengths.** We hope that the health plan will create a service system that identifies and builds upon family strengths.