We work collaboratively with the family, health care providers, funding resources and other community providers for the positive development and well-being of children who are medically fragile and technology dependent. Each participant has important responsibilities and expectations to fulfill once the child is transferred home.

Expectations of the Participants

Home services for medically fragile and technology dependent children are complex. It requires multiple providers working together with the family. Open communication and collaboration is vital to the success of the program and delivery of services. We protect the family’s privacy by only sharing the information providers need to deliver services.

Parent/Guardian is the responsible party for the child and participates in the care of the child to the extent possible. The parent/guardian is expected to:

- Provide and maintain the physical integrity and safety of the home. This includes a working phone, utilities, and secure storage of equipment and supplies. Parent should contact their Specialized Care for Children care coordinator if having difficulty paying for phone and utilities;
- Follow the Medical Plan of Care (MPC) and consult with the physician (or health care provider) when the plan needs revision;
- Maximize all available insurance benefits as first payer and notifying their care coordinator of any change in benefits;
- Provide the nursing needs for the child when a nurse is not in the home;
- Establish the rules of conduct at home for all family members including the medically fragile child, visitors, and service providers;
- Treat nurses and service providers with respect. Dress appropriately when nurses and service providers are in the home;
- Observe service providers in the home. Notify the provider and the Specialized Care for Children care coordinator when unsatisfied with services;
- Create opportunities for the child to be involved in the community, peer-group activities, and enrolled in school as appropriate;
- Comply with both Medicaid and Specialized Care for Children policy and procedure, as applicable;
- Verify nursing services provided prior to signing the time sheet;
- Cooperate with nursing agency supervisor for required home visit every 60 days or more often as needed;
- Respond to monthly outreach by care coordinator to monitor progress and address any issues. Inform the care coordinator of any changes in the residence, guardianship, or insurance status; and

Contact us at (800) 322-3722 for questions or to obtain more information!
• Acknowledge that nurses, care coordinators, and other service providers are mandated reporters who must report any suspected abuse or neglect to the Department of Children and Family Services (DCFS) or Adult Protective Services (APS).

Specialized Care for Children Care Coordinator
• Acknowledge the family as the primary caregiver and decision maker for their child;
• Ensure the managing physician is kept informed of all events or issues affecting the well-being of the child;
• Inform family and service providers of any actions by Specialized Care for Children or HFS that affect benefits or services provided to the child/family;
• Monitor, coordinate, facilitate and update the service plan through collaboration with the family, physician, service providers and funding sources;
• Help the family with referral for Supplemental Security Income benefits, educational services, or non-medical services. May attend educational staffing at parents’ request;
• Assist the family in resolving issues with service providers as they occur. When necessary, provide information on new service providers to the family;
• Comply with state and federal regulations on documentation required to secure and maintain funding for the Home Care Program. Meet HFS deadlines for renewal of the medical plan of care; and
• Comply with the Abused and Neglected Child Reporting Act.

Department of Healthcare and Family Services (HFS)/Medicaid
• Approve or deny request for services in a timely manner. Apply criteria that ensures the medical plan is safe, cost effective, and in compliance with state and federal regulations;
• Provide the family a process for appeal when the reapplication for continued services has been denied or benefits reduced;
• Provide Specialized Care for Children timely notification of continuing approval to facilitate nursing and related services specified in the medical plan;
• Receive and pay bills from service providers and vendors for services, equipment and supplies required by the approved medical plan; and
• Provide the federal authorities the required documentation to assure compliance with and effective monitoring of the community based care plan.

Nursing Agency
Responsibilities to the Child
• Enroll with Medicaid as a provider;
• Comply with the Requirements for Participants in the Home Care Program;
• Create/Maintain a patient care plan that includes physician’s treatment and nursing interventions considering the child’s medical needs and level of growth and development;
• Provide competent Illinois licensed nurses to deliver high quality, medically prescribed care;
• Provide a RN to perform on-site supervision of nursing personnel at least every 60 days and more often if necessary;
• Submit timely supervisory reports to Specialized Care for Children that reflect child’s overall status, treatments and goal achievement;
• Review need for nursing hours with the physician, the family, and the Specialized Care for Children care coordinator periodically;
• Request/attend multi-agency staffing to review goals and outcomes. Identify present and potential issues that require a mutually agreed upon resolution;
• Provide the family with a notice of intent to discontinue services that allows sufficient time to obtain another provider; and
• Comply with the Abused and Neglected Child Reporting Act.

Responsibilities to the Family
• Acknowledge the family as the primary caregiver and respect their knowledge of the child’s physical, emotional and medical needs;
• Comply with the family’s rules of conduct regarding general use of the home. Ensure new nurses are oriented to the family’s rules prior to providing care in the home;
• If requested, assist the family in ordering and maintaining the inventory of supplies. Ensure required maintenance of equipment is performed and recorded; and
• When needed, clarify the nursing supervisor’s role in handling issues between the family and agency personnel.

Physicians
Perform a tertiary care function which defines and manages specialized medical care. They also perform a community care function that provides primary health care and supervision of the community based medical plan. When these two functions are performed by separate individuals, it should be clearly defined who is responsible for each of the following activities:
• Serve as managing physician of record. Provide medical reports, recommendations and prescriptions required for continued approval of the Home Care Program application and Medical Plan of Care (MPC);
• Provide or arrange for provision of needed tertiary medical care, preventive and primary medical care;
• Provide consultation, reports and recommendations to school authorities and other community service providers as appropriate;
• Monitor reports from the nursing agency and the family to assure compliance with and effectiveness of prescribed MPC;
• Cooperate with the family, Specialized Care for Children care coordinator, and other care providers to monitor and modify the community based care plan, as needed;
• Establish a method of communicating information about the child’s medical status and needs among the involved health care providers and family members;
• Notify the Specialized Care for children care coordinator when circumstances present that may affect the well-being of the child in the home and community;
• Determine when nursing and other Home Care services are no longer needed. When that occurs, provide a written prescription to discontinue services to the Specialized Care for Children care coordinator; and
• Identify the appropriate alternative to home care should it be necessary to discontinue the home and community based care plan.