

Deciding to have a child is a life-changing decision.

*The STRONG Partnership
A Family Support 360 Grantee
Administration for Developmental Disabilities*

Supporting a child's growth and development and successful transition to adulthood starts early. In fact, it starts from the time the parent decides to have a child. It begins with the family and extends to the community.

The knowledge, attitudes, and skills that support self-esteem, personal competence and self-determination are the foundation of successful transition.

During this presentation, consider how these competencies (which may be related to the knowledge, attitudes, or behaviors of parents and families, the community at-large, and most importantly, the child) promote resiliency and support successful transition across the lifespan.

The Family Prepares for Pregnancy

The mother takes charge of her health as she:

- Consults with your doctor and optimizes control of diabetes, hypertension and other health conditions
- Appropriately uses prescribed medications
- Gets treatment for alcoholism and drug misuse
- Takes steps to change lifestyle and gets plenty of rest, controls stress, and exercises
- Takes folic acid and eats a healthy diet
- Knows her family medical history (may prompt genetic counseling)
- Seeks assistance for domestic violence or other situations which could result in harm to self or child
- Takes steps to alleviate environmental factors such as second-hand smoke, lead paint, exposure to toxic agents at work
- Seeks early prenatal care

The family takes steps to:

- Understand the Family Medical Leave Act (when applicable)
- Assure that there is private insurance or another payor source (such as Medicaid) to cover prenatal care and child birth
- Learn what to expect during pregnancy and child birth
- Research and decide upon a pediatrician
- Plan for the baby's arrival home, prepare siblings & make arrangements for their care
- Identify supports and services (such as WIC)
- Obtain a car seat, assure that crib, mattress and other items meet child safety requirements
- Identify child care needs and preferences and select a provider

Following the birth of a child with a disability, the family:

- Faces grief and loss issues
- Seeks support
- Asks question
- Talks to other parents who have children with similar conditions
- Communicates with their baby in positive ways – for instance: touching, talking, reading
- Learns to communicate the baby's needs to caretakers and others

Hospital to Home...Getting a Grip

The family:

- Develops a routine
- Develops new dreams for the baby and maintains a positive vision of the future
- Becomes aware of baby's preferences and needs
- Helps family members to understand and explain the nature of the baby's disabilities and how to communicate her special needs to others
- Asks for help when needed
- Talks to other parents
- Develops a records keeping system
- Encourages siblings and shows them ways to interact with the baby
- Monitors personal physical and emotional health and that of other family members
- Recognizes burn-out and plans/seeks respite care

Takes an Active Role in Baby's Diagnosis/Evaluation and Treatment Planning and Systems of Care

- Identifies resources
- Establishes relationships with health and development professionals and other caregivers
- Accesses accurate information
- Asks questions, seeks second opinions
- Makes informed choices
- Seeks/gets support as needed
- Communicates child's preferences and needs and those of the family

Maintains the Physical and Emotional Health of Self & Other Family Members

- Finds time to relax, reads to the baby and siblings
- Talks to siblings and encourages them to share their feelings
- Helps siblings to develop a positive vision of the baby's future
- Talks about feelings with partner and other family members and friends
- Nurtures relationship with partner
- Knows that while its okay to feel grief and loss, unmitigated depression requires immediate professional attention
- Makes it a point to get out of the house and into the community on a regular basis (church, shopping, recreation, etc)

Plans for immediate needs and the future

- Identifies supportive relationships among family, friends, and caregivers
- Considers the unique strengths of the child and family and how these can be applied to immediate needs and future needs
- Identifies health needs, including: insurance/payor sources, home-care waivers, primary and specialty medical care, medications, augmentative devices, durable medical equipment and supplies, etc.
- Addresses accessibility issues, such as housing and transportation
- Considers financial needs and identifies how these needs will be met, such as SSI, etc.
- Plans for unexpected events to include the development of wills, estates, trusts, guardianship, etc.

As the child grows, the family:

- Knows where and how to access health and developmental services
- Develops coping skills, addresses grief and loss issues, and maintains realistic expectations appropriate to their child's developmental level
- Takes an active role in supporting the child's development
- Encourages self-help with simple activities of daily living, seldom doing for the child what she can do for herself
- Helps the child to understand her disability and to communicate her needs to others
- Provides opportunities for the child to interact with other children and adults, including those with and without special needs
- Gets and gives support to other families
- Plans for the future

Supports their child's development and prepares for success in school

- Establishes clear rules and consequences
- Teaches acceptable ways to deal with challenging and frustrating situations
- Encourages decision and problem-solving skills by offering simple choices, simple problems, and simple plans
- Creates ways for preschoolers to help out and gives them age-appropriate tasks
- Encourages the child to learn self-care skills; normal skills & those related to her special needs
- Reads to the child and encourages her to be curious and explore the world around her
- Supports the child in developing her vision of the future by asking "what do you want to do when you grow up"

IDEA

Individuals with Disabilities Education Act

- Part C: Infants and toddlers, birth to three, who have or are at risk of having developmental delays
- Part B: Children and youth, ages 3 to 21, who have a developmental delay or disability that has an “adverse effect on the child’s educational performance”

Part C: Kentucky Early Intervention System (KEIS) or First Steps

- Point of Entry in Jefferson County is Seven Counties Services, Inc.
- Each child is assigned a Primary Service Coordinator
- Philosophy supports the belief that the parents and family are a child's best teachers
- Focus is on the child and family with most services delivered in the child's home or other "natural environments"
- The Individualized Family Service Plan (IFSP) specifies the family's goals and priorities and the services that will be provided (including how, who and when the services will be provided)
- The family and providers develop the IFSP as a team

Plans for Transition to School

Preparing for transition starts early since it represents a major change to the child and family

- As early as the child's second birthday (but no later than 2 ½ years) the family starts planning for transition from home to preschool
- The JCPS Admissions and Release Committee (ARC) determines the child's eligibility for publicly funded preschool and related services
- The family is a member of the ARC "team" and exercises their rights to make decisions
- The family and other ARC members develops the child's Individual Education Plan (IEP) and determines where services will be provided.
- Children are served in the "least restrictive environment" – this means that the child is, to the extent possible, with other children her age who do not have disabilities

THE IEP Tells the Following:

- The IEP is a snapshot of the child, focusing on her strengths, likes and dislikes, and her level of performance
- Annual goals and short-term objectives
- What special supports and services the child needs to function in a regular preschool program
- What services will be provided (ie, specially designed instruction and related services)
- When services will start and how long they will last and who will provide them
- How and when the child's progress will be measured and how and when this information will be shared with the parents
- Who is responsible for implementing the short-term and long-term objectives

Creates a vision for the future...

- Children acquire the knowledge, attitudes, and behaviors that will support self-determination throughout their lives
- Children are included in age-appropriate family tasks and decisions and are given useful roles in the home and school and community
- Children develop self-esteem, begin to plan ahead, and take personal responsibility for normal self-care as well as skills related to their special needs
- Children make decisions and begin to understand that their choices carry positive or negative consequences
- Children are motivated to learn, accept challenges, and strive for achievement
- Children enjoy learning and care about their school and friends and their community

Prepares for Adolescence

- Children have a personal vision for their futures and feel that their lives have purpose
- Children begin to feel that they have control over the things that happen to them and learn to positively manage frustrations and challenges
- Children develop competencies and confidence and function well in social interactions with peers and adults
- Children develop the skills to resist negative peer pressure and dangerous situations
- Children understand that their bodies are changing and that they will have feelings and desires and learn how to manage these appropriately
- Children are encouraged to help others and to contribute their talents to the community

Prepares for Transition from Middle to High School

- Considers future career options and what's required
- Understands the options that are available in high school, including the difference between diploma and certificate bound
- Researches the choices in schools, including curriculum and focus, and decides what's most appropriate to their future plans
- Takes more responsibility for self-care and other activities of daily living and takes a greater role in their health care
- Prepares for a more active role in the development of their IEP by identifying goals and objectives, strengths and skills that they'd like to improve, educational preferences, required accommodations and supports, and other resources in the community that they would like to access.
- Receives services and supports, including augmentative devices, to facilitate independence and full participation in the community