



FACT SHEET #19 - PARENTING A CHILD WITH SPECIAL NEEDS

What about children with special needs?

Every parent wants and expects to have a "normal" child. Like everything else in life things don't always turn out the way we had envisioned. Between 5 and 20% of children will have a special need, which may range from a physical disability through a specific medical condition or illness, to developmental delay or mental disorder. The disability may be visible or invisible. It may be apparent at birth or emerge as the child grows older. Or it may come later as a result of an injury or illness. Its cause may be known (e.g. genetic) or as is the case with many children with developmental problems, its cause may be speculative (e.g. environmental) or unclear.

Finding Out

Finding out that your child has a special need can evoke a range of reactions from parents, from shock and disbelief to grief, guilt, anger, confusion and depression. For some parents the situation is made more difficult by the lack of a clear diagnosis or prognosis. Often the child must be subjected to a series of tests that can go on for sometime and can be quite traumatic for the parents and the child. Most parents need time and support from family and friends in order to adjust to their new situation.

The joy and the challenges

Parenting a child with special needs can enrich your life and bring inestimable joy. It can also pose challenges, depending on the kind of disability:

- Dealing with day to day physical care and disability related issues (e.g.

eating, sleeping, behaviors)

- Accessing , advocating , & co-ordinating services, attending appointments
- Juggling care of child with special needs with other life demands (e.g. work, siblings, extended family)
- Finding inclusive childcare
- Dealing with extended family, friends and professionals who may be unsupportive or insensitive
- Taking on multiple roles (e.g. therapist, playmate, teacher, advocate etc.)
- Dealing with medical emergencies
- Getting the necessary support in the education system
- Dealing with related stress (e.g. financial, marital, physical fatigue, loss of job etc.)

What parents can do

- Give yourself time to adjust. It may feel like an emotional roller coaster for a while.
- Accept that other people (e.g. spouse, other children) need time too and may react differently
- Get as much information as you can about the disability (E.g. library, conferences, internet, etc.).
- Get in touch with organizations that specialize in your child's disability
- Remember you are not alone. Talk to other parents. Join a support group
- Ask for help from professionals, extended family and friends
- Take care of yourself. Take time off, go out for the evening, spend time with spouse, siblings, and friends, exercise, eat well.
- Find out what financial assistance is available (e.g. parent relief.)
- Take time to enjoy your child.

Dealing with professionals

- Prepare questions ahead of time.
- Take notes.
- Don't accept everything you are told. Professionals are not always right. Remember you are the expert on your child.
- Learn how to be an advocate. Learn to work with professionals to solve problems and ensure your child's needs are met
- Make sure professionals know what others have asked you to do with the child so that you or the child does not become overwhelmed with treatment activities.
- Keep track of whom you talked to and when.
- Keep a notebook of possible resources.

Your child

- Don't prejudge what your child can or can't do. Children with special needs can overcome incredible obstacles
- Stay positive about your child. Love them for who they are and the gifts they bring
- Take your child with you as much as possible. Include them in family and community activities

To Think about:

"As I recall the hours of early intervention our daughter received, the most valuable lessons were based on recognizing her worth as an individual, taking into account our abilities, as her parents, to seek out ways to encourage her growth and development and, finally, reaching out to other families with children, with or without disabilities, to participate in mutually supportive relationships that meet the needs of each individual in the family as well as the community." Parent's testimony (Behr, 1991)

"He's made our lives better in a way. It makes you realize what's important in life....it's not how many things you have or where you live...what's important is caring for people or being sensitive to others." * Parent

"It gave us more strength and we'd go and say, 'way to go Caroline...Look at what you have made of us. You made us door openers.' And we're getting really good at it." * Parent

"I don't believe things always happen for a reason, but I believe meaning can be found in what ever happens. Having Amelia has brought incredible joy and enrichment into my life as well as other people's lives. At the same time I have been forced to meet challenges I could never have imagined and to grow in ways I would never have thought possible." * Parent

"The tragedy is not the child with the disability, but how we as a society respond." * Parent

Stainton, Besser (1998)



Posted by Voices 4 Children.