

When a Parent Learns Their Child has Exceptional Challenges, Special Health Care Needs or Disabling Conditions



Emotions have to be recognized and validated in order to best advocate for and support our children with exceptional challenges

Common Reactions:

Shock – It doesn't make sense, it wasn't supposed to happen to **me**. I took care of myself.

Fear – What will happen to my child? What about our dreams for our child and our dreams for ourselves? What about my job? Will I be able to work?

Denial – Acceptance of this situation and lifestyle come ever so gradually. Denial is a period of searching for answers, searching for treatments, searching for cures. Denial prevents the bad news from hitting all at once.

Anxiety – What do I do to reduce my feelings of powerlessness? What do I do to help my child? Anxiety mobilizes the energy required to face these new challenges.

Financial Impact:

- One parent often becomes unemployed or with limited employment
- Takes a huge toll over the years on the finances of a household
- Medical expenses require difficult decisions over what to pay for – clothes, groceries, medical bills. Forget vacations.

Stigma of disability – history

Medical model – a person with disability is sick or “disabled”... excused from typical obligations of society like going to school, getting a job, taking on family responsibilities, etc.

Rehabilitation model – having a disability is a deficiency that must be fixed by rehabilitation professionals or other helping professionals.

What is your frame of reference about disability?

Preconceived Notions – The messages we hear from the larger world:

- Focus on the glass half empty – the disability, the “can't do”, the burden
- The words we hear: suffer, burden, courageous, victim, special, crippled, stricken
- Negative and false stereotypes: People with disabilities don't work, criminalized, perverts, victimized, exploited, failures, can't learn
- Disability is viewed with fear, discomfort and loss. It is stigmatized and the emphasis is on correcting and curing disability.
- Stereotypes about people with disabilities often come from the fact that American culture emphasizes what and how much a person can produce or how athletic or academically gifted people are.
- People with disabilities are laughed at and teased.

The challenge for families:

- We love our child, but because of perceptions and attitudinal barriers in everyday life, we feel isolated.
- We struggle with grasping that we are now part of the world of disability that has been perceived so negatively.
- We know our child can learn if given the right supports, but not everyone shares the same belief.

How does a family reconcile?

- Be honest with your feelings.
- Take one day at a time.
- Never underestimate your child's potential.
- Encourage your child to develop to the best of their ability.
- Find positive mentors, other parents and professionals who recognize your child's special gifts.
- Recognize your role as expert on your child and be involved with their educational program and medical care.
- Focus your attention on the positive contributions your child with special needs has made on the family.
- Believe your child will learn.
- Let a child be a child first. Therapies and interventions may be necessary but remember you have a child who wants to play.



With the assistance of families throughout NY, Parent to Parent has developed a network of parents (Support Parents) throughout the state who have made the offer to speak to another family who may be facing similar challenges. Would you like to speak with another parent? Would you like to join our network of parents helping parents and become a Support Parent?

Do you questions or need information about your child's disability or health care needs? Contact Parent to Parent at 800-305-8817 or refer to our website for more information about our regional offices. www.parenttoparentnys.org