



Chapter One

Dealing With The Diagnosis

Learning that your child has a disability can cause a variety of emotions. You may fear the unknown as it relates to your child's disability. You may feel powerless because you do not have control over your child being born with a disability. You may also feel scared and doubt your ability to raise a child with a disability. You may feel confused about what is happening and you may not have much information about your child's disability. The initial shock may cause feelings such as disappointment and grief. You may need time to process and come to terms with the unexpected.

What you go through as a family may depend on your individual circumstances, prior knowledge about people with disabilities, and the information and help that you may or may not receive. The adjustment period may take more time for some, but parents usually find that a sense of stability does return to their lives. Over time, families have found the strength within themselves (and with the support of others) to support their family member and manage situations related to their disability.

1.1 Getting The Diagnosis

Doctors or other health professionals may not have a lot of knowledge about your child's disability. In the past, many doctors would minimize the expectations and hopes that parents should have for children with disabilities. Fortunately, this is happening less and less. There are now many doctors and health care professionals who rightfully take a more positive view of people with disabilities. If a health professional tells you not to expect too much from your child, know that these opinions may well be inaccurate or untrue for your child. People with disabilities can and do live enriching lives full of opportunity when they have access to the right supports.

Sometimes, children with disabilities have medical issues that may need to be addressed. For example, young children with Down syndrome may have a heart condition that requires surgery. Make sure you ask questions and request information on any potential medical problems that may arise or may already be occurring.

Tip: If you learn that your child has a disability soon after birth, ask for a private hospital room. This may be a helpful way to give you some privacy to address your feelings and to spend some quiet time with your child or with other loved ones.

1.2 Delayed Diagnosis

Sometimes, finding out that your child has a disability can take time – even months or years. This is particularly true with some types of disabilities such as Autism Spectrum Disorder, certain intellectual disabilities, muscular dystrophy or learning disabilities. Depending on the circumstances, the diagnosis of your child's disability may happen quickly. At other times however, parents may face a longer journey to receive a diagnosis. In these circumstances, parents may encounter medical professionals or others who discount your child's experience. It may take a lot of persistence before you receive an accurate diagnosis for your child. When this happens, people often feel a sense of validation because they finally have answers and can seek out the necessary information, services and supports.



1.3 Dealing With People's Reactions

While some people may react positively when they learn that your child has a disability, others may not know what to say and some may even react with a sense of pity. It is important to keep in mind that other people's reactions often stem from a lack of understanding. Remember that as people with disabilities become more involved in our communities, other people's reactions will become more positive.

1.4 Talking With Your Other Children

Having a child with a disability will affect everyone in the family. This includes other children that you may have. It will be important for you to talk to your other children about their sibling and their disability. For many children, having a sibling with a disability can be a positive experience. It can teach them to accept people for who they are. Children can also learn about family responsibility by helping around the house or by helping their sibling in various ways. Be aware that sometimes other children may react negatively. This may be the case if they feel that their sibling with a disability is receiving all of your energy and attention. You may need to find ways to ensure that your other children are feeling appreciated and loved.