

# CCFH Ministries Supplemental Topics

## An Open Letter to Parents of Children with Disabilities

**Dear Parents,**

*Working with families with child with disabilities for more than 40 years has been a wonderful experience. It has also been a great in-service training experience. Observing the families' attitudes toward the child, how they relate to the child, how they relate to people who work with him, how they relate to the rest of the family—has led me to a strong belief that if the family creates a positive climate for the child with a disability to develop, he will be a better adjusted human being. So, how can a family create that environment?*

- 1. Love and nurture your child.** Hugs, a warm smile, a kind word—make for an attitude I am loved and belong. You will log a lot of time going to therapy, doctor's appointments, evaluations, and the like. Use those times to affirm your child. The child will grow and develop surrounded by a real sense of loving and being a part of the family.
- 2. Talk to your child about his disability.** Down syndrome, cerebral palsy, and autism happen to real people. To be told that you are just like your peers is not fair. The child may wonder: "Why do they not have to go for speech therapy?" "Why are they not in special education?" "Why doesn't he wear braces?" If a child knows his diagnosis is a part of him but does not define who he is, he will be a healthier person.
- 3. Stress the positive traits in your child personality.** Tell him what a beautiful smile he has. Note his politeness. Encourage your friends who see your child often to express his positive traits. Such an approach will assist your child in leading a happier life and will influence people in his world. If he is in a safe, comfortable world, with nice things to do, you are creating a wonderful world for him to live in.
- 4. Allow your child to do as much for himself as he can.** Let him try. If he can not, then assist by helping with an alternative to accomplish the task. Don't do for him what he can do for himself. A wonderful lady who raised a very self sufficient son with cerebral palsy, jokes about the way she taught him to swim. She put a life jacket on him and put him in the lake. He is still a swimmer. He lives by himself and has adapted to his environment.
- 5. Advocate a spot for him in the community.** Take advantage of what is available for him. Enroll him in the city's recreation department's summer program, go to Special Olympics, go to camp, and take him to church. The beauty of inclusion is that we are rewarded by being a part of a group and the more ways we are included the better.

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*The foregoing suggestions will help create a positive environment for the child to reach the peak of his God-given capacity. The following ideas will enrich that environment.*

**6. You will need some extra help from time to time.** So, take advantage of respite care. Whether it is informal through family and friends or formal through agencies, use it.

**7. Surround yourself, your family, and your child with a lot of friends.** Be open about your needs. Let them help and trust them to do the right thing. Do not pull away. Be open about your child's needs and yours as well.

**8. Find a person or persons who will walk with you in your journey of raising a child with a disability.** Having such a resource will add to your confidence, a sense of peace, and a feeling of not being alone.

**9. Your family is a group.** Your child with the disability is not the only member. Give each member attention. In the beginning, it might not be equal by time constraints, but it is a worthy goal. Spend special time with the child who does not have special needs.

**10. Befriend the people who work with your child.** I am not suggesting being intimate friends. The teachers, therapists, physicians, and caregivers who work with your child deserve your appreciation. Some of my most meaningful keepsakes are notes and gifts from families whose children I have served.

*As much as you can, adhere to these suggestions. I believe they will make for a healthier environment for your child to grow up. Furthermore, if my final suggestion is handled early, it will likely add greatly to this positive atmosphere.*

**11. Prepare for the future.** There are two parts to this suggestion: (1) where the money will come from for his future care and needs; and (2) where will he live.

First, what will be the source of the funding? In reference to this, my purpose is not to tell you what to do. There are banks and lawyers to help you. Find out what government money is available. Detail your plans in some legal document-- a will, a trust fund. My best advice is to start early with a plan for future funding for your child.

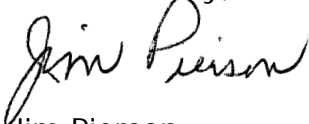
Second, who will provide care when you are gone? "What will happen to my child, if something happens to me?" - is a question that starts almost from the moment of diagnosis. Instead of the operative word "if," "when" would be a better choice. In all likelihood, someone else will be responsible for the care. A few suggestions to help with the process follow:

- Learn the residential options available to people with disabilities.
- Deal with the cultural belief—you are putting the child away. Many parents are haunted by the idea and feel guilty even to think about placement.

- Consider: It might be in your child's best interest to be in a place of his own when it comes his turn to leave the nest. It is a normal cycle of life for child to go to college, get married, get a job or just move out of the nest. When a child with a disability faces that time, it might be good for him to have a place of his own in the community or region. No matter where it is, you can still be a part of his life.
- Allow your child to develop his own community and circle of friends. Many adults with cognitive disabilities have the same set of friends as their parents. They deserve their own world. A mother told me that she could not watch another Charlie Brown movie with her daughter. When the daughter went to a place of her own, she relished making cookies for her house mates and having the highest reading skills. Her new found friends loved to watch Charlie Brown movies.
- Reflect: If you wait until "something happens," your child will have to deal with two major upheavals without you: death and adjusting to a new living situation.
- Important: Communicate clearly to your child the reason you are seeking residential placement. You want them to grow. You are not getting rid of him. Affirm your love. Say how much he means to you. You want him to be all he can be.
- Think typically: You can remain a part of your child's life. You can be a part of the ups and downs of his life. It is the same as when a child without a disability goes to college or gets married. As parents you can continue to be an important, valuable part of his life.
- Be proactive. State the way you want your child to be cared for in a legal document. Write a letter stating what you expect and attach it to the document. It will clarify and enhance your wishes for your child's care. You are still in charge.

*Working with families with children with disabilities for more than four decades has indeed been a blessing. I hope these ideas gleaned from my involvement with them will enrich the lives of families with children with disabilities.*

Most sincerely,



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