



The Family Connector

Information and Resources for Families of Young Children with Disabilities in Connecticut

Fall 2014

Welcome to the second edition of *The Family Connector*. Family Connections is a statewide program that provides support, information and resources to parents who have infants or toddlers involved in Connecticut's Birth to Three System. Our quarterly newsletter is one way we hope to address any questions you have about raising a young child with a disability. Do you have a question that you'd like answered in our next newsletter? Let us know! Our goal is to provide you with a helpful and informative newsletter, so if you have feedback or suggestions, contact us today.



One Family's Story

Lauren Morley - Family Connections Mentor

My son was born at the end of 2005 and diagnosed with Down syndrome within a week of his birth. Once we got past the NICU phase, we started researching Down syndrome on line; everything from the medical community was negative, lists of things my son would never do. It broke our hearts. But then we came across a web site that opened our eyes to a

whole new world of Down syndrome, it was a site full of encouraging letters written by parents who were on various paths in their journey with Down syndrome.

Probably the most defining thing about that particular site was the pictures, seeing children, teens, and adults with Down syndrome; all doing things that any other person their age would be doing. It made all the difference in the world; it gave us hope for our son's future. Through that site I found several blogs, and eventually found Facebook, where I now have a tremendous network of friends and advisors.

One thing I learned was, that I was not alone, sentenced to a life of nevers. I cannot imagine what parents did 30 years ago when they were handed their child with a pamphlet and told "Good luck!" The Internet, especially networking groups like Facebook, Twitter, or MySpace, and technology have brought together some of my now closest friends, many of whom I may never meet but will always be a part of my life.

"One thing I learned was, that I was not alone, sentenced to a life of nevers."

Originally published in *Birth Through 5 News*, Fall 2012, Vol. 13, No. 1

Do you have a story to share?
Email us for possible inclusion in our next newsletter.

A Note About Being A Family Connections Parent Mentor

"The most rewarding aspect of connecting with another family through the program is helping them feel that they are not alone. Everyone's journey is different which can feel so isolating, but having a mentor to talk to can help answer questions and alleviate some fears. The program creates a comfortable environment where people can talk freely and without judgement. Some days can be harder than others, but always remember as long as 'your train keeps moving' then you will eventually get to your destination."
- Naomi Willard, Parent Mentor

Tips from a Parent Mentor

"You do so much for your kid and you're giving and giving and giving and you get to the point where you're completely burnt out. So it's important that you as the caregiver take care of yourself as well."
- Santina Ragonese, Parent Mentor

Connecticut Parent Advocacy Center
338 Main Street, Niantic, CT 06357
1-800-445-2722
www.cpacinc.org • cpac@cpacinc.org

FamilyConnections
A Program of Connecticut Parent Advocacy Center

Funding for this newsletter is provided by a grant from the CT Birth to Three System.





For Parents When They Learn That Their Child Has a Disability

by Patricia McGill Smith

If you have recently learned that your child has a developmental delay or a disability (which may or may not be completely defined), this message may be for you. It is written from the personal perspective of a parent who has shared this experience and all that goes with it.

When parents learn about any difficulty or problem in their child's development, this information comes as a tremendous blow. The day my child was diagnosed as having a disability, I was devastated—and so confused that I recall little else about those first days other than the heartbreak. Another parent described this event as a “black sack” being pulled down over her head, blocking her ability to hear, see, and think in normal ways. Another parent described the trauma as “having a knife stuck” in her heart. Perhaps these descriptions seem a bit dramatic, yet it has been my experience that they may not sufficiently describe the many emotions that flood parents' minds and hearts when they receive any bad news about their child.

During this period of time when so many different feelings can flood the mind and heart, there is no way to measure how intensely a parent may experience this constellation of emotions. Not all parents go through these stages, but it is important for parents to identify with all of the potentially troublesome feelings that can arise, so that they will know that they are not alone. There are many constructive actions that you can take immediately, and there are many sources of help, communication, and reassurance.

Seek the Assistance of Another Parent

My first recommendation is to try to find another parent of a child with a disability, preferably one who has chosen to be a parent helper, and seek his or her assistance.

Talk with Your Mate, Family, and Significant Others

Over the years, I have discovered that many parents don't communicate their feelings regarding the problems their children have. One spouse is often concerned about not being a source of strength for the other mate. The more couples can communicate at difficult times like these, the greater their collective strength.

Rely on Positive Sources in Your Life

One positive source of strength and wisdom might be your minister, priest, or rabbi. Another may be a good friend or a counselor. Go to those who have been a strength before in your life. Find the new sources that you need now.

Take One Day at a Time

Fears of the future can immobilize one. Living with the reality of the day which is at hand is made more manageable if we throw out the “what if's” and “what then's” of the future. Even though it may not seem possible, good things will continue to happen each day. Worrying about the future will only deplete your limited resources.

Read the full article on the Center for Parent Information and Resources website:
www.parentcenterhub.org/repository/notalone or contact us for a copy.

The article is also available in Spanish.

Helpful Family Resources

Funding Resources for Families <http://ow.ly/B9BAg>

This is an extensive list of financial resources for families with children with special needs developed by the Bureau of Education and Services for the Blind (BESB).

“Just in Time” Hearing Resources www.infantheating.org/familysupport/just-in-time-color.pdf

“Just in Time” Hearing Resources was compiled by the National Center for Hearing Assessment and Management and offer information about organizations that provide assistance to families when they have a concern about their child's hearing.

Small Steps in Speech www.smallstepsinspeech.org

Small Steps in Speech is a non-profit foundation created in memory and in honor of Staff Sgt. Marc J. Small. The organization helps children with speech and language disorders by funding supplemental therapies and treatments for individuals as well as grants to charitable organizations who serve children with communicative disorders.

CPAC Lending Library www.cpacinc.org/helpful-resources/lending-library

Did you know that CPAC has a lending library? Check out the newest addition to our library, *Andrew Can Ski: Even with C.P.* by Sheryl Haraghey. The book tells the story of Andrew and his journey from struggling to walk due to his Cerebral Palsy to trying out for the U.S. Adaptive Alpine Race Team.

Contact us at 1-800-445-2722 or cpac@cpacinc.org to borrow this book or