

— by Nicole Forgione



Blum Family: Lorraine, Douglas and Ryan

PERSONAL CONNECTION Makes A Difference For Parents Of Kids With Special Needs

With today's technology, health related information is readily available through Internet searches, social networking sites and hotline phone numbers. But sometimes you need that personal connection. It is helpful to have someone to speak with who has gone through similar experiences of fears, uncertainty and hopes. This is the case for many parents who have a child with special needs.

From One Parent To Another

Amy Adler found this to be true when her son Benjamin, now 6, was born with Down syndrome. She did not have a prenatal diagnosis, but researched online after her baby was born. "When things began to fall apart, I needed people to touch base with," she shared. Adler reached out to the Down Syndrome Parent Group of WNY, Inc., which she is now co-vice president of. She shared that there were negative experiences in the beginning and it was good to talk with people who had gone through the same initial shock. Adler commented that regardless of a diagnosis like Down syndrome, you still had a baby and it feels good to have people congratulate you.

Parents with a newborn with Down syndrome can get connected to the Down Syndrome Parent Group of WNY right away in the hospital. Information packets are provided with an initial message of "Congratulations on the birth of your

baby," along with a variety of helpful resources and a phone number to call once parents are ready to connect with the group.

A resident of Amherst, Adler says, "Talking to other parents is the best resource there is — the support for me was the most important." Adler shares that you do not have to re-invent the wheel each time and offers the advice of not to be afraid — there is a community in our area with Down syndrome of all ages. She also emphasizes that you can always seek help, but it is okay to refuse help, as the outreach experience may seem overwhelming and intrusive. It is important to feel comfortable and move at your own pace. "Sometimes you just want normalcy. Since there is a large community of help available there are options — if you need a lot, it is available; if you need a little, you can pick and choose," says Adler.

Education & Linking To Services

According to the National Down Syndrome Society, there are more than 400,000 people living with Down syndrome in the United States and the chromosomal condition occurs in people of all races and economic levels. If you are like many first-time parents or have more than one child, there may be a desire for a "how-to book." Keep in mind there is no "right" way to raise a child no matter what their abilities are.

As Western New York Lead Coordinator for Parent To Parent of New York (716-

517-3448 or 800-305-8813, www.parentto-parentnys.org, p2pwny@verizon.net) for 16 years, Lorraine Blum of Yorkshire, knows from personal experience that the process to obtain assistance can be challenging. As a mother to Ryan, 21, with Down syndrome, Blum offers some helpful tips for parents who have a child with a developmental disability or other healthcare issues.

"Learn about the disability or special healthcare issue," Blum advises. "People may not always be ready right away, but it is good to know the available resources." An initial important task is to get linked to a Medicaid service coordinator who can help you through the process of education and referrals to services, such as Early Intervention or to agencies having programs focused on serving people with special needs or developmental disabilities. She added that it is important to find out about financial resources available and eligibility requirements for programs such as Supplemental Security Income (SSI).

Denial is not unusual among parents. Blum shares that "it is normal to go through a grieving process or to ignore issues," but encourages parents to talk with others. She points out, "There is a need to get services and the sooner the better for the benefit of the child." For parents who have an older child with a disability, Blum added that it is important to learn about inclusion programs in schools, transition to work services and residential opportunities.

Taking One Day At A Time... and having some fun along the way

One bit of advice that may not be utilized as often as it should be, says Blum, is to "maintain your sense of humor." She also notes that parents need to take care of themselves too and try not to feel guilty about it. "It is important to do something fun and enjoyable."

Gathering and utilizing the resources which are best suited to you and your child's individual needs is essential. The main mission of Parent to Parent of NYS, a statewide not-for-profit organization, is to provide support and connect families of individuals with special needs. Additionally, the organization provides trainings and workshops to families, community groups and hospital staff upon request.

Parents can get connected to the Down Syndrome Parent Group of WNY, Inc. by a

phone call, meeting or fun family activity (716-832-9334, www.dspgwny.org, dspgwny@hotmail.com). Regular support group meetings are held with guest speakers such as pediatricians, nutritionists, speech therapists, and movie nights. The organization also plans fun activities for the whole family to enjoy, including holiday dances, spaghetti dinners and awareness walks.

There are many programs in Western New York that provide a fun and interactive atmosphere for people with special needs. One of those is Danceability Inc. (716-651-0094, www.danceabilityinc.com), a program for children and adults with special needs utilizing dance and movement to promote physical, social, and mental wellness in a family environment.

Cathy Wilde of Clarence has a daughter, Mary, 9, who is currently in her fourth year in Danceability Inc. Wilde shared that she got Mary involved in the class not only because she loves music and dancing

around the house but thought it would help Mary with physical challenges.

"I love the Danceability class because not only does Mary find it fun, but it also reinforces her socialization skills, helps her in following directions and keeps her physically active," Wilde said. "The class has helped my daughter grow in other ways, too. Mary has Down syndrome and has limited verbal skills. She's only recently begun speaking in full sentences and asking questions. But about a year ago, we were coming back to dance class after having a few weeks off. In the car, Mary began bouncing up and down, saying, 'Mom! Mom! Sidah! Sidah! Sidah!'"

Wilde asked her daughter if she was excited about dance class and her daughter said, 'Yeah! Dancing! I excida! I excida!' Wilde explained further that this was not only a cute story, but an important one. "Because up until this time, Mary had never told us her feelings. She had never once told us that she was happy or sad or scared.

However, on this day, because she was so filled with joy about going back to dance class, she was compelled to tell me that she was excited."

Sharing Milestones

Regardless of your child's accomplishment, it is important to make sure it's treated as milestone in their life — whether it is being able to finally stand on their own at age 2, getting potty trained at a later age than the average child, adding more new words to their vocabulary than you thought you'd ever hear, or simply being able to express feelings. Each achievement counts — it's important to use your bragging rights as a parent. Parents of special kids deserve to feel especially proud of every bit of progress their child makes. Adopt a positive attitude and your child, as well as those around him, will benefit greatly.

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Nicole Forgione (formerly Nicole Passantino) is the public affairs manager for People Inc., a not-for-profit health and human services agency providing programs and services to more than 10,000 people with special needs, their families, and seniors throughout Western New York. Since 1971, People Inc. has assisted individuals to achieve greater degrees of independence and productivity.



Mary Wilde with Robin Bishop, LMSW, co-founder and senior instructor of Danceability, Inc.



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