



Parent to Parent Connection

7 Things You Don't Know About a Special Needs Parent

**This is an excerpt of the full article. Please go to the following site for the full (and powerful) version:
http://www.huffingtonpost.com/maria-lin/special-needs-parenting_b_1314348.html

1. I am tired. Parenting is already an exhausting endeavor. But parenting a special needs child takes things to another level of fatigue. Even if I've gotten a good night's sleep, or have had some time off, there is a level of emotional and physical tiredness that is always there, that simply comes from the weight of tending to those needs.
2. I am jealous. It's a hard one for me to come out and say, but it's true. When I see a 1-year-old baby do what my son can't at 4-years-old (like walk), I feel a pang of jealousy. It hurts when I see my son struggling so hard to learn to do something that comes naturally to a typical kid, like chewing or pointing.
3. I feel alone. It's lonely parenting a special needs child. I can feel like an outsider around moms of typical kids.
4. I am scared. I worry that I'm not doing enough. What if I missed a treatment or a diagnosis and that window of optimal time to treat has passed? I worry about Jacob's future, whether he will ever drive a car, or get married, or live independently.
5. I wish you would stop saying, "retarded," "short bus," "as long as it's healthy..." I know people usually don't mean to be rude by these comments, and I probably made them myself before Jacob. But now whenever I hear them, I feel a pang of hurt.
6. I am human. I have been challenged and pushed beyond my limits in raising my son. I've grown tremendously as a person, and developed a soft heart and empathy for others in a way I never would have without him.
7. I want to talk about my son/it's hard to talk about my son. My son is the most awe-inspiring thing to happen to my life. Some days I want to shout from the top of the Empire State Building how funny and cute he is, or how he accomplished something in school (he was recently voted class president!). Sometimes, when I'm having a rough day, or have been made aware of yet another health or developmental issue, I might not say much.

This experience has helped me understand that true love is meeting someone (child or adult, special needs or not) exactly where he or she is— no matter how they stack up against what "should be." Raising a special needs child shatters all the "should bes" that we idolize and build our lives around, and puts something else at the core: love and understanding. So maybe that leads me to the last thing you don't know about a special needs parent... I may have it tough, but in many ways I feel really blessed.



April prepares her green traffic light and the world thinks Go.
~Christopher Morley~

A note to our readers:

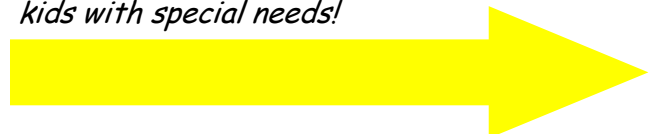
Last year, for the Spring edition of the Parent to Parent Connection newsletter, we had a special tribute to moms. Several mothers shared stories about their journey of raising a child with special needs. For this 2012 Spring edition, we are recognizing some of our amazing dads! Please enjoy the following stories shared by fathers raising kids with special needs!



The Parent to Parent Connection newsletter is provided by the Yakima County Parent to Parent program located at Children's Village.

Parent to Parent is dedicated to supporting families raising children with special needs. For more information about Parent to Parent, please see the last page of this newsletter.

Children's Village



About Amelia...

The other night my twelve year old daughter Emma mentioned to me how great life would be if every bite had frosting. She meant this tongue in cheek but as I pondered my past six years as a father of a special needs child, the phrase became much more meaningful to me. When Amelia, my six year old with Williams Syndrome, was born my wife and I went through all of the thoughts that come with such a major happening. We worried about her health. We searched for answers. We attempted to cope with an understanding that many of the 'normal' events in life would never happen for her. We pondered the relationships among our three other children and Amelia.

We honestly felt a bit sorry for ourselves.

As we came to grips with what was happening, we found that Amelia provided us that frosting in every bite. She has a pure spirit of love that changed our family dynamic and made us all closer. She is happy all of the time and can bring a smile to my face with every simple act. The things she may miss in life are not even a concern to her, as she will be happy with who she is (a lesson for me).

I cannot imagine my life as a parent without her and feel blessed every day I can give her a hug and share a happy moment.

Amelia's older sister provided me an insight into what being a special needs parent can bring into life. While much different than parenting my other children, the frosting Amelia provides is a unique and special opportunity that I would not trade for anything.

~Ryan Kloepfer~



Daaaaaaad!

Little did I know hearing that word each day would prove to be the most cherished of moments in my life, giving me so much pride and joy for all the accomplishments hearing that word encompasses. For it was fourteen years ago I found myself staring into the face of a beautiful baby girl, full of love, a daddy's pride, and overwhelmed with uncertainty and fear. Being thrust into a world of "Down Syndrome" was not even the remotest possibility in my mind. The pregnancy was as good as could be expected; all the tests came back with no concerns. Yet, those results failed to prepare me for the life-changing journey I was soon to engage. As I stared into the face of the reality of my daughter being less than "perfect," I soon came to realize she, too, is a person and had the same inane desires we all have—to love and be loved.

Don't let me fool you; yes, I cried over the things I wanted for my daughter. Let me say that again, ". . .things I wanted for my daughter." Replacing my bubble of expectations for a "normal" daughter with the realization that in her "nothing is impossible" was an incredibly humbling experience. Further, it was liberating for me in how I would see her and through her, and the world, from that point forward. I have since reflected many times on the doors this girl has opened and am amazed how blessed I have been to be on this journey. She, without even trying, has been the catalyst to creating life-long friendships throughout many worthwhile associations such as the Washington State Father's Network, Kindering Center, Bridge of Promise, Parent-to-Parent, ARC, Children's Village, Children's Hospital in Seattle, and others. I have no doubt these friendships and life support structures would not have occurred had I not been thrust into this journey.

As the years have passed, yes, I still see in her the Down Syndrome. Yet, it is not with the fear felt early in her life or with the expectations of a "normal" child. I see in her, and from her: hope, excitement, intrigue, faith, willingness, encouragement, and most of all, the desire to help others. It is this last one, I believe, will be her life's legacy. Even as a vulnerable, helpless infant with a "disability" she has been teaching the greatest lesson of life:

Immeasurable Joy Comes Through Giving.

Gentry Valley—father of Dorian, 14



Raising Morgan

Raising a child with special needs, I have to say as a father, is the most wonderful gift a parent could receive. My daughter is 3 years old and has had a number of problems since the age of 3 months. Morgan has had two operations and a number of tests done. She has been in the Early Intervention program at Children's Village and in the Washington State Elks Therapy Program for Children. I do have to say having a child with special needs takes a lot of effort and time. It can be stressful at times, especially when you are in a waiting room waiting for her to get out of surgery. At the same time it is the most rewarding thing in the world. I could not ask for more and I would never trade it for anything in the world. My daughter Morgan is now three and doing wonderfully. She is receptive, steady on her feet, and, as I type this on my laptop, she is sitting next to me with her pink Leaptop laptop on her lap as well. No matter what the case in raising any child with special needs, it does take a lot of work and effort, but, when she smiles, runs up and gives me a hug or an Eskimo kiss, it makes me feel like the luckiest father on earth. And I am. It is also the most rewarding thing ever. Like I said, I would never trade it for anything in the world. I also have to give a big thanks to the staff at Children's Village and the Elks Therapy Program for all their help and support through this journey.

Loving Father, Ray Edwards



Fatherhood is pretending the present you love most is soap-on-a-rope.

~Bill Cosby~



Helpful websites:

Division of Developmental Disabilities (DDD):

<http://www.dshs.wa.gov/ddd/>

Supplemental Security Income (SSI):

<http://www.ssa.gov/ssi/text-child-ussi.htm>

Office of the Education Ombudsman:

<http://www.governor.wa.gov/oeo/>

Free 24/7 Nurse Advice Line for all Community Health Plan (CHPW) members

Plan members can now call the free Nurse Advice Line to get health care information 24 hours a day, 7 days a week. To speak to a nurse, call toll free (866)418-1002.

****Please note- you do not have to be a CHPW member to utilize this resource*****

Information can also be found at: www.chpw.org

Support Services for Families Raising Children with Chronic Healthcare Needs

Yakima County Interagency Coordinating Council (YCICC) invites you to a panel presentation where you will learn about:

- ⇒ Healthcare services
- ⇒ Respite
- ⇒ Personal care
- ⇒ Palliative care
- ⇒ And more!



Join us on Thursday, May 24

12-1:30 pm (Panel presentation)

1:30-2:30 pm (YCICC business meeting)


Children's Village, 3801 Kern Rd., Yakima

Childcare available to families.

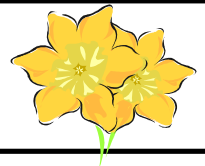
Please call Parent to Parent to reserve:

(800)745-1077 (509)574-3200

Local Meetings & Groups

 Activity	Date/Time/Place	Contact
Valley Parents-Yakima Support, information and education for parents and caregivers raising children with special needs.	1st Tuesday of every month 6:30-8:00 pm Children's Village Child care provided with notice	Parent to Parent (509)574-3200/(800)745-1077 traciehoppis@yvmh.org
Valley Parents- Sunnyside Support, information and education for parents and caregivers raising children with special needs.	4th Monday of every month 6:30-8:00 pm Family Engagement Center 1901 E. Lincoln Ave., Sunnyside	Parent to Parent (509)574-3200/(800)745-1077 traciehoppis@yvmh.org
Yakima Autism/Asperger Support Support, information and education for parents and caregivers raising children with Autism Spectrum Disorders.	3rd Thursday of every month 6:30-8:00 pm Children's Village Child care provided with notice	Parent to Parent (509)574-3200/(800)745-1077 traciehoppis@yvmh.org
Scrappin' at the Village Scrap-booking group for Village parents	3rd Friday of every month 9-11:00 am Child care provided with notice	Parent to Parent (509)574-3200/(800)745-1077 traciehoppis@yvmh.org
Yakima Chapter Fathers Network Support for dads raising kids with special needs.	4th Tuesday of every month September-May 7-8:30 pm	John Mahaney (509)248-0843
Type 1 Diabetes Support Group for parents and caregivers	Last Thursday of every month 6-7:30 pm Child care provided with notice	Rick and Abby Furguson (509)952-9725

*For information about Spanish language support groups for parents and caregivers, please see the Spanish Parent to Parent newsletter available at:
www.yakimachildreenvillage.org/espanol/parenttoparent.asp



Conferences and Trainings

Preparing for the Future Guardianships and Power of Attorney	Tuesday, May 1 6:30-8:00 pm Valley Parents Group Children's Village	Call Parent to Parent with questions or to register for childcare: (509)574-3260/(800)745-1077
Infant and Early Childhood Conference	May 3-4, 2012 Greater Tacoma Convention Center Tacoma, WA	To register, visit: http://www.ieccwa.org/index.html (360)629-8181

Parent to Parent

"I am not the only one who has traveled on this path. I will follow the footprints before me and reach back a hand to those who come behind."

-author unknown-



Yakima County Parent to Parent

- ♥ Nurturing kids and families through support and friendship.
- ♥ Fostering attitudes in the community that welcome and value people with special needs.
- ♥ Helping kids realize their dreams!

We offer:

- Emotional support and information for parents and caregivers raising children with special needs
- Parent sharing groups in Yakima and Sunnyside
- Training for parents and caregivers interested in joining the Parent to Parent network as volunteer "Helping Parents"
- Family social events
- Sibshops– Workshops for brothers & sisters of children with special needs
- Parent to Parent Connection– English and Spanish newsletter for families and providers
- one 2 one- Inclusive recreation program for children with special needs
- The Kids on the Block– Disability awareness program

Visit Parent to Parent on the Children's Village website under the "Family Support" tab:

<http://www.yakimachildrevillage.org>

Yakima County Parent to Parent is supported by:



Yakima Valley Memorial Hospital
The Memorial Foundation
Yakima County Department of Human Services
United Way of Central Washington
Division of Developmental Disabilities
Washington State Parent to Parent/
Department of Health



STAY INFORMED

Would you like to be added to an email or regular mail distribution list to receive up-to-date information about classes, events and resources? Please send an email with this request to:

traciehoppis@yvmh.org

Or, call Parent to Parent at: **(509)574-3200**



Waves by Laurie Juarez

Sometimes Autism overwhelms us, washes over us, and nearly drowns us.

Frigid fingers cling to us pulling us down into its black depths.

We flounder and try to reach the surface.

The depth is too dark, too deep, the current too strong.

We are so deep sometimes, our soul near shattering, that we swear there is no light above.

We are frantic and weak.

Sometimes we tread still waters and dream of what could be.

A little blue eyed girl who asks for what she wants, doesn't run away, says our names.

We meditate on staying afloat. We pray for strength.

We try to accept. We do not sink with despair. We wait for change.

Sometimes we reach the shore.

We bask in the love of our daughter. Her climbing, hugging, silly ways.

We celebrate what we have, with no thought to what is missing.

We laugh and love.

Autism ebbs and flows. It can dominate and defeat. It can focus and clarify.

Autism teaches us what matters and what we will forget about next week.

We will not let Autism drown us with despair.

We will celebrate the sunsets as often as we can.

April is Autism Awareness Month

Autism Prevalence Rises to 1 in 88

The Centers for Disease Control and Prevention (CDC) updated its estimate of autism prevalence in the United States to 1 in 88 children. 1 in 54 boys and 1 in 252 girls

For more information, visit: <http://www.autismspeaks.org/>