



1650 South Avenue, Suite 200
Rochester, NY 14620
starbridgeinc.org

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Bridges

Bridges continues the legacy of *The Bridge*, connecting people with disabilities, their family members, and people who work with them, with resources, support, and information.



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What's Inside...

This issue of *Bridges* highlights **Grandparents**.

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CELEBRATION OF *Champions*

Our first Celebration of Champions as Starbridge was hosted at Locust Hill Country Club on Saturday, November 14. Nearly 300 guests enjoyed music from Mambo Kings, a wine pull, a photo booth, and a silent auction. Ginny Ryan of 13 WHAM-TV served as emcee, presenting the stories of our Community Awards recipients. Senator Rich Funke was on hand to congratulate the recipients. Corporate and private sponsors, as well as event guests, raised more than \$26,000, which will support children and adults striving for success in school and employment.



Community Award Winners



Left to right: Adam Anolik, Julie Whittemore, Sarah Jane Clifford, Stephanie Scism, Patricia Muir, and Jack Milko

Community Impact Award

The **Community Impact Award** honors an individual or organization creating inclusive opportunities for people who have disabilities. This year's award winner is **Sarah Jane Clifford**, owner and operator of The Gymnastics Training Center of Rochester for nearly 30 years.

In 1989, Sarah Jane developed a gymnastics class for children who have developmental disabilities. In response to growing enrollment, she worked with Monroe County Special Olympics to start a training club, and facilitated competition in local, regional, and state tournaments. When necessary, she drove athletes to competition sites and flew them to national meets.

Today, about 20 athletes with disabilities train and compete from the Penfield facility at no charge. Sarah Jane pays the coaches, and if a child can't afford to travel to a meet, Sarah Jane will help cover their costs.

James and Mary Holleran nominated Sarah Jane for

creating opportunities for children throughout the community, as well as for their own daughter, Katie. "Her commitment hasn't wavered throughout the 20-plus years that our daughter, Katie, has competed. Sarah Jane isn't the only reason for Katie's success, but she is a prominent contributor who instills confidence, instructs on athletic and life skills, and teaches young athletes to pursue their dreams."

Education Award

The **Education Award** honors a devoted individual in the field of education whose extraordinary efforts empower students who have disabilities to succeed. **Stephanie Scism**, Instructional Specialist at Monroe #1 BOCES, is the 2015 Education Award winner.

An educator for more than 14 years, Stephanie supported students with disabilities first as an aide, then as a teacher. Now as an instructional specialist, she shares methods and experiences with teachers throughout the area.

Nominator Julie Buick describes the impact Stephanie's work had on Julie's sons, Billy and Bobby.

"With Stephanie's enthusiasm and encouragement, Billy overcame his social anxiety through a plan which incorporated the support of a classroom of students who were a grade higher. For the first time in school, he felt like he truly belonged." For Bobby, Stephanie provided "consistency, patience, and high expectations" to help him make huge improvements both behaviorally and academically. She then advocated for more inclusive opportunities. That year, for the first time, Bobby was included. "Just like his brother, Bobby too felt what it was like to truly be accepted just the way you are."

Julie noted, "Not only has Stephanie directly impacted students who have disabilities, she has also left a lasting impression on teachers, administrators, and general education students through her efforts around inclusion.* Stephanie doesn't ask, 'Can we do it?' Her attitude is 'We are going to do it.'"

*Inclusion refers to the rights of students with disabilities to have access to the general education curriculum and to be educated alongside students without disabilities.

Founders Award

The **Founders Award** honors a parent or family member of an individual with a disability who exemplifies our founders' commitment through his or her efforts to improve the quality of life for people who have disabilities. This year's award winner is **Patricia Muir**.

Pat has been advocating on behalf of people with disabilities for 32 years, beginning with her son, Nate. Nominator Mary Ellen Carpino wrote, "Pat has worked tirelessly to provide Nate with the best care possible and to make sure he has the opportunities and supports he needs to live the most meaningful, productive and happy life possible."

In recent years, Pat recognized that she was not alone in her concern for her son's welfare in the face of a critical shortage of supervised or supported housing options in NYS. So she founded Family Advocates United, a collaborative group to unite family advocacy groups throughout the Finger Lakes and Western NY regions. The group supports legislation mandating supports and services critical to the needs of people who have intellectual/developmental disabilities. Pat is an expert spokesperson for the cause, appearing on TV, newspaper, and in social media. She conducts flag rallies, where hundreds of yellow flags with the words "Still Waiting" are planted in the ground, one for every individual who is still waiting for a safe, supportive living option to open up.

Jackie Yingling, NYS Partners in Policymaking Training Coordinator, noted, "Pat develops positive working relationships with legislators, community agencies, families, and individuals. She is making the world a better place."

Self Advocacy Award

The **Self Advocacy Award** honors a person with a disability who leads the direction of his or her daily life through advocacy, personal choice, and responsibility. **Julie Whittemore** is the 2015 award winner.

Julie struggled for years without a diagnosis. Her poor coordination, behaviors, and social skills delays led to many difficulties with peers at school. In spite of this, Julie stood out academically, received many academic awards, and was well-liked by school staff. As a teen, Julie developed a serious eating disorder. She reached out to high school staff for support, and managed to continue with her studies and graduate.

Finally, at college, with the help of the Utica College Counseling Center, Julie was referred to local autism specialists who evaluated her and diagnosed her with Autism Spectrum Disorder. After a youth spent wondering why she struggled to fit in and why she felt so sensitive to her environment, this diagnosis changed Julie's life. Armed with the right information, Julie was able to understand herself better and to express herself better.

Julie graduated with a BA in Spanish, and joined AmeriCorps VISTA, a national volunteer program dedicated to mitigating poverty. Julie moved to Niagara Falls to serve at Community Missions of Niagara Frontier. There she developed programming and resources for local youth in the juvenile justice and mental health systems, many of whom also have developmental disabilities. Julie recently received an award from the Health Association of Niagara County for her work with youth. She is an active member of the Autistic Self Advocacy Network.

Nominator Esther King wrote, "Julie is an inspiration. She works extremely hard not to let autism stand in the way of her career in social services. I believe the hardships she has overcome in searching for her diagnosis and her dedication to community service make her especially deserving of recognition."

Youth Award

The **Youth Award** honors an individual, age 21 or younger, whose efforts make a positive difference in the lives of people who have disabilities. This year's winner is **Jack Milko**.

continued on next page



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Community Award Winners

Jack's introduction to disabilities came about when his younger brother, Theodore, was diagnosed with autism. As a family, the Milkos found support in UNYFEAT, now known as AutismUp.

Jack tagged along to Teddy's programs, participated in Sib Shops, and helped his family raise money to support the organization.

Nominator Beth Ciardi notes that "Jack instinctively became one of Teddy's greatest therapists, his favorite playmate, one of his strongest advocates, and his best friend." As Jack entered his teen years, he became one of AutismUp's most valuable program volunteers, directly supporting Teddy and his peers. Jack's mother, Sarah, now serves as Executive Director of AutismUp.

Beth Ciardi wrote, "Jack has humbly chosen to turn his family's struggle into his purpose, and is determined to be a part of ensuring Teddy and others lead happy, healthy, and successful lives."

Jack has enjoyed playing basketball for years, and wanted to find a way for Teddy and others to learn to play basketball and share in a team sport. With his father's help, Jack led the effort to create AutismUp's basketball program last year. Jack recruited student volunteers from McQuaid and Mercy High Schools to support participants in the basketball program as they learn ball skills and game strategy along with team social skills.

Jack is currently a senior at McQuaid Jesuit High School. He is a High Honor Roll student and a founder of the McQuaid Sports Network where he is a play-by-

play analyst. Jack hopes to pursue a bachelor's degree in sports broadcasting and journalism.

Outstanding Community Partner Award

The **Outstanding Community Partner Award** honors an individual or organization who has demonstrated generous and sustained support of the work of organizations like Starbridge. The 2015 recipient of this award is **Adam Anolik**.

Adam joined the Board of Directors of The Advocacy Center several years ago and continues on the Board of Starbridge today. He is an active philanthropist on behalf of our agency and other community initiatives, including the Developmental Disabilities Giving Circle of the Rochester Area Community Foundation. In his professional life, Adam serves as the Chief Financial Officer for Strong Memorial and Highland hospitals and Associate Vice President of University of Rochester Medical Center.

Adam and his wife Jennifer are the proud parents of two daughters. Both parents have worked to make sure their daughters both had opportunities to choose paths towards fulfilling lives. Their younger daughter Sarah has graduated from Boston University, and is now living and working in New York City. Their older daughter Ellie, after graduating from the LifePrep at Nazareth program in May of this year, is now on a new journey at the Community Arts Connection,

a program through the Arc of Monroe. In August of 2014, Ellie moved into her new house, which she shares with two roommates and a very cute Siamese cat.

Adam notes, "Although her transitions are not without challenges, Ellie is someone who always has a smile on her face and endears herself to anyone she comes in contact with. As Ellie's parents, we are extremely proud and humbled by how she has become a truly independent young woman."

Allyn Stelljes, Vice President, Strategic Transformation, notes that "Adam stands out in his ability to bring others on board, as board members, donors, event sponsors, and supporters. Adam has a great way of communicating our mission and vision and getting others excited about it, too."

Joyce Steel, Director of Family Advocacy, shares that "Adam walks the talk – he is respectful and kind to everyone he meets. The following quote makes me think of Adam: 'If your actions inspire others to dream more, do more, become more, you are a leader.' Adam personifies what it truly means to be a leader, a humanitarian, a father, husband, friend and all-around great guy."



Starbridge Workshops, Conferences & Special Events

Check our website event calendar for updates! www.starbridgeinc.org



Friends Helping Friends Monthly Meetings

3rd Wednesday of each month,
from 5:00 pm – 7:00 pm.

**January 20, February 17,
March 16, 2016**

Starbridge, 1650 South Avenue,
Rochester, NY 14620

Friends Helping Friends is a group for self-advocates and their supporters. Friends believe all individuals have value, talents, and gifts. We will not be defined by a label or the limitations of disability. We believe that with determination, we can achieve anything we put our minds to.

Join us on Facebook by liking the [Friends Helping Friends page](#).

For more information, call us at (585) 224-7212 or email ebarto@starbridgeinc.org.

Lunch & Learn 2016

Join us in the new year for one hour sessions on a variety of special education topics. Planned sessions include:



**Preparing for the Annual Review
Maintaining Caregiver Wellness
Identifying Effective IEP Goals
Addressing School Avoidance**

Check our website calendar at www.starbridgeinc.org for updated information, or call Registration at (585) 224-7399

Save the Dates!

The Inside Scoop

Webinar Series 2016

How to meet children's complex medical needs in their home, school, and community, will be offered this spring on

**Wednesdays, March 23,
March 30, and April 6.**

Check our website calendar at www.starbridgeinc.org or phone (585) 224-7399 to check for updated information.



*Congratulations to all the
2015 Community Award Winners!*



Grandparents of Children with Disabilities

10 Ways for Caregivers to Nurture Themselves

1. Eat well-balanced meals

And do so on a regular schedule. Take a daily multivitamin. Drink six to eight glasses of water a day.

2. Exercise every day

Move your body daily, even if it's simply 15 minutes of stretching, yoga, calisthenics or walking. Use the stairs to keep your circulation going.

3. Get outdoors

Fresh air renews the body and spirit — even if you only have time for a brief outing. When possible, open a window.

4. Get your zzz's

Strive for a minimum of seven to eight hours of consecutive sleep in a 24-hour period. Nap when your loved one naps.

5. Treat yourself

That is, get treatments for your own aches and pains before they turn into something more serious.

6. Don't ignore your emotions

Pay attention to your own feelings and emotions, and seek counseling if needed. Vent feelings to trusted family members or friends.

7. Take time for yourself

Use relaxation or stress management methods such as meditation, visualization and yoga. Books and videos are available to guide you in these techniques.

8. Read, pray or meditate for at least 15 minutes a day

Consume daily prayer books and helpful magazines like *Today's Caregiver* and *Caring Today*, or books such as *Chicken Soup for the Caregiver's Soul* to uplift your spirits. If you're religious, seek the counsel of a spiritual leader you trust and respect.

9. Chuckle more often

Lah, reminisce and share stories of happy times.

10. Ask for help

Friends, family and religious groups may be eager to assist and are only waiting to be asked and directed. Doing everything yourself deprives others of an opportunity to serve.

Grandparents are our connection to the past, and often the key to what shapes our future. Grandparents are our history, and we, in turn, are reflections of their lives and experiences. Grandparents set the values and standards by which families live, and it is through traditions that are passed along through generations by grandparents that families remain strong and together. Something as simple as a special family recipe or an annual family reunion can serve to remind us of the importance of our own heritage and our grandparents' role in preserving it.

- Grandparents as Caregivers, by Josefina G. Carbonell, National Family Caregiver Support Group

Grandparent Support Suggestions from the National Association for Down Syndrome

What if I don't know what to say? It can be very difficult for you when your friend or family member has just had a new baby with Down syndrome. Not only do you have to deal with your own emotions and attitudes about a baby with Down syndrome, but also your sadness for your friend or relative. Your support at this time will be very important to them and can lead to a much stronger and deeper relationship.



Do be aware that there are revolving cycles of grief: Feelings of depression, anger, non-acceptance or sorrow usually surface around birthdays or milestones, such as when your grandchild "should" be walking. Knowing ahead of time can prevent the reaction from becoming extreme.

Do be aware that most schools, agencies and parent groups welcome grandparents: Some associations even have grandparent groups. This is a good way of keeping abreast of your grandchild's specific disability and, more importantly, showcases your overall support and love for your grandchild.

Do remember that if you have a positive, tender, loving attitude towards your grandchild, others in the family will feel the same way: The more support from family members, the better the parents feel.

Do remember that non-verbal expressions, such as a loving pat to your grandchild's head, a warm hug to your son, daughter and their spouses convey what words sometimes cannot express: By the same token, pitying glances, an overall look of sadness or an anxious tone of voice are not comforting and do not convey a reinforcement of support.

Do let your children know that they can rely on you in good times and in bad: Many grandparents have flexible schedules that can be arranged to meet the needs of the grandchild. Just knowing that this kind of love and help is available can lessen anxieties and strengthen family bonds.

Excerpt from the [National Association for Down Syndrome](#)

About Shaelynn

by Barbara Chambers

Running, laughing, picking leaves from trees and bushes, and playing in the snow are just some of Shaelynn's (Shae) favorite things. Shae is a curious, very active, affectionate, sweet, adorable and happy little girl, who loves mirror play, playing in water, looking at books, curling up in small places, and eating salty crunchy foods. She likes animal shape toys and blocks. She is rarely upset, but if she is, hugs and kisses will calm her down. At home she loves exploring the outdoors, swinging and jumping on the trampoline, or watching the fish in the tank by the front door; most times you find her there or looking out the window. She really prefers to be outside.

Shae is 5 years old, has autism and is deaf, with global developmental delays which profoundly affect her ability to learn, socially interact, and communicate. She is a Gates-Chili student currently attending Mary Cariola Children's Center, where she is learning to communicate through the PECs (Picture Exchange Communication system) program.

Shae does ok in new situations because she is very curious and friendly. She pays more attention to adults than children. She loves exploring faces and shiny

objects like earrings, watches, or bracelets. She will walk or run up to strangers and either just look at them, or ask them to pick her up, or will sit by them, or on them! She has to be constantly supervised or she will put almost anything in her mouth. If there is something she wants or likes, she will pick it up and run away with it to keep you from taking it from her. She thinks it's a game, which can be a safety issue. Sometimes she will cry when you take things from her, but most times she will just hand things over to you without a fuss, especially when she knows she is not supposed to have it. She's opening doors now and has escaped into the yard on several occasions.

I am Shae's great-grandmother. I have been involved with Shae since her birth. There were many days I said "what have I gotten myself into?" Shae came to live with me when she was 3 months old. She is such a wonderful little girl, and I am so proud of her. I have watched her grow and overcome many obstacles. Just the fact that she has overcome so many obstacles when the odds were stacked against her encourages me to continue to fight for her. The road we have traveled has been rough, but I am so happy I made the decision to care for Shae.

Of course I did have a lot of help along the way. I have been very lucky to get support from Arc



of Monroe, Stepping Stones Learning Center, Catholic Charities, Rochester School for the Deaf, Kirsch Developmental Center, The Advocacy Center, and now, Starbridge. I did a lot of research and talked to anyone that would listen and help. There were many doctor appointments, especially in the first three years. So much therapy. Through it all, Shae was a trooper. Shae had a very good pediatric doctor who informed Shae's mother at birth that the baby would have some problems because of the detection of the cytomegalovirus.

Grandparents who are in a similar position have to make sure they are up for the challenge. It is a big commitment. It really changes your life. For me the rewards of seeing her grow, tackle, and overcome the challenges she faces without any complaints makes it well worth any commitment I have made.

The unconditional love I feel from her is amazing.



Five Tips for Grandparents of a Child with Autism:

1. Expect the unexpected – be prepared.
2. Change what you can and let the rest go.
3. Savor the moments and make memories.
4. Learn to love the quirks, work with them and use them.
5. Be reliable and available, when possible.

- Autism Speaks website. Read the complete post [here](#) by Jane Springer.



Then...

Letter to a Granddaughter

By Sandra J. Weber, The Bridge, Vol. VI, Issue IV, 1996, Excerpt

Dearest Ellen,

Five years have passed since we saw you in your parents' arms – a tiny bundle with the pink, kitten-like face of all newborns. A little question mark, as all babies are. Then, we all feared the unknown, as adults often do. Forgive us, we lack the trusting intelligence of children. And we want everything to be perfect for our little ones, without worry or pain.

The very words "Down syndrome" scared us, even as we saw that you were adorable and responsive. Our minds leaped ahead to worry: how would you develop? Would you have friends and go to school as other kids? Would you grow up to ride a bicycle, study the world around you, have meaningful work? Above all, would you feel good about yourself and your world? And would you have fun?

But we worried needlessly. Here you are at age five, capable and strong, despite a medical problem that has complicated your little life and caused genuine concern to those who love you (and they are many!). Thanks to all the love of family, neighbors, friends, and teachers you have developed like other kids, learning to sit, stand, feed and dress yourself, sing songs, play let's pretend, and much more.

And this abstract thing, this "Down syndrome", has proved less important than most thought when you were born. Yes, an invisible difference in your



genetic makeup may cause you to develop at a slower rate than your peers. But all children vary in their development in some way or another. And this genetic difference has linked you and your family with a large and loving community of others who share your difference but are, like you, quite individual.

In short, you are no "syndrome," but a little girl with reddish-blonde hair and a button nose who has definite ideas and feelings, just like your playmates. At five, you already express yourself with confidence and skill. Remember when you recently took a tumble and your mom asked if you had fallen? You replied firmly, "No, I tripped." You will do well.

and Now...

A World of New Opportunities for My Granddaughter and Others

By Sandra J. Weber

Twenty-four years ago Ellen Beisheim was born to our daughter, Sarah, and her husband, John. When I first saw her cradled in her mom's arms, she looked perfect; the surprise of her birth with Down syndrome was largely hidden in her genes.

Fortunately, years earlier I had worked in a center for people with developmental disabilities. There I learned that no matter what birth defect or disability people may have, labels should never define them, reduce their value in society, or limit what they can become.

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DEAR Gramma,
how do I feel about you?
I really like dancing with you.
I like cooking with you.
And I like when you take me to starbucks.
I just love you.

Love, Ellen

Today we know, as never before, that when loved, accepted, and encouraged for who they are, Ellen and others like her can and do develop in unique and wonderful ways. Baby Ellen began by contradicting the doctor who predicted she would have weak muscles by doing little push-ups on his examining table.

Along the way Ellen hit softballs, shot basketballs with her dad, swam with the school swim team, learned to ski big mountains without poles, and sang and danced her way into adulthood. That isn't to say all this was easy, either for her or her parents. Many families still struggle to secure appropriate education and services, and medical complications and the need for extra attention can make balancing the needs of other family members challenging.

Today Ellen lives quite independently in the home she shares with two other young women. Her busy social life includes cooking and grocery shopping and restaurant outings. She finished high school and college with special degrees and continues to develop new skills; these include volunteering at a cat rescue center and learning American Sign Language. Last year, she joined me in modern dance classes and wowed the instructor with her strength and flexibility.

Compared to the 1970s, people with developmental disabilities are more visible, productive, and encouraged to become all they can. And I feel privileged as Ellen's grandmother to have witnessed what progress has been made.

Parent Center Coordinator Laura Arrington shares the important role her mom, Georgette Nederlk, has played in their family's life.

My mom has been a strong support to us through the years. She is there for us whether we just need to go out to dinner, or run John's younger sister, Jillian, to activities. It has been wonderful because we trust her with John, and he really loves it when she comes over.

John truly has his Grandma wrapped around his finger! She usually brings his favorite things to eat like McDonald's hamburgers and wintergreen Tic Tacs. John loves going for drives in the car and especially going over bridges and train tracks. She has been known to drive him from Webster to Macedon just so he can go to a certain McDonalds and still hit all the bridges and train tracks between Macedon and Webster.

They play a game where John will play the xylophone and play part of a song and then my mom will try and guess what song he is playing. He loves to make sock puppets and she will bring over all the materials to make them. We have about 15 sock puppets.

John loves flashlights and she always keeps one in her glove box and he always looks for it so she makes sure it has batteries and is ready to go.



John's Grandmother, Georgette, describes her initial reaction to John's diagnosis and their close relationship

At first I didn't understand it. It has taken me many years to get to understand autism and learn from my daughter and son in-law. I started reading more information and I wanted to know and learn how it impacted John and then this helped me to understand how to support John. I was never afraid of, it but I just wanted to learn and understand.

I will always be there for him. It started by developing a routine. I try not to overload him with questions

and I ask him permission to chat with him or give him a hug. I think this has helped us developed trust. It's about being patient, open and meeting him where's he's at.

I'm always a grandmother first. As a grandmother you are not the disciplinarian; you are the one to give him unconditional love! One of the best days ever was when we went to see John perform at school and his friends knew me as "John's grandmother." I'm proud to be John's grandmother!

Receive a paper copy of Bridges

If you would like to receive a paper copy of the newsletter, please contact Maria Schaertel at (585) 224-7371 or mschaertel@starbridgeinc.org. Remember to provide your name, mailing address, and phone number.





Resources

New York State Kinship Navigator Program

A *kinship caregiver* is a grandparent, relative or family friend who is a full time caregiver of a child that is not biologically his or her own.

The Kinship Navigator is a statewide program operated by Catholic Family Center and specially designed to provide an information and referral network for kinship caregivers across all of New York State. It is an online resource for information and referral where you can access information on laws, legal rights and issues on custody and visitation, eligibility for benefits and entitlement programs, tax credits, respite care and other local services.

Or Call toll-free at 1-877-454-6463 to speak to a representative.

* * *

Grand Resources: A Grandparent's and Other Relative's Guide to Raising Children with Disabilities, Generations United

Comprehensive resource! Sampling of questions addressed:

- Where should I go first to get help for the grandchild I just started raising?
- I think my grandchild has special challenges. How can I get him tested?
- What type of services and assistance can my grandchild with disabilities get?
- What help is available that can link my grandchild with disabilities and me to service and benefits that can help us?
- I am not comfortable using a computer. Where can I go for help since so many of the resources you mention in this guide are on the Internet?
- Which laws protect the rights of children with disabilities?

Grand Resources, A Resource Directory for Grandparents and Other Relatives Raising Children with Disabilities

[Click here to view both publications.](#)

* * *

The State of Grandfamilies in America report, by Generations United, 2015

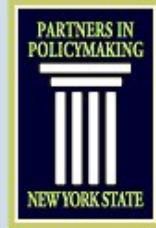
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Caregiving in the U.S. 2015

Caregiving in the U.S. 2015 is a joint research study between the National Alliance for Caregiving and AARP providing new insights into higher-hour caregivers (at least 21 hours of care a week), caregivers ages 75 and older, multicultural caregivers (including African American/black, Hispanic/Latino, and Asian American/Pacific Islander populations), and the challenges facing caregivers in the workplace. A number of reports and publications are included here.

* * *

GKSN: Grandparents of Kids with Special Needs website by Don Meyer, sibling and family support expert.
donmeyer@gksn.org



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Dad's Corner

By David Brazda Poiriot

Marcel is the light in my life. He is bright, curious, loving and just plain funny. He loves the outdoors. We walk, hike, ski, play golf, and love to travel. Golf is his passion, and we both love to play, watch, and even listen to golf on the radio. Yes, hard to believe that we like to listen to golf. I accept him for who he is, and am so proud of him for the courage with which he lives his life. My wife and I share the parenting in all facets. We are true equals in the parenting process. We complement each other. We both have strengths and weaknesses and are there to take over if one of us is at our limit.

Both my wife and I have an excellent relationship with our son. He is the most amazing individual that we have ever met. He has difficulty speaking, comprehending, and has some physical limitations. With all that, he is one of the happiest and funniest people that I know. We spend a lot of time together as a family travelling and doing the general mundane chores of life such as shopping, cooking, yard work, etc. It has changed my perspective on what a full life is. We thought we would have a life with soccer games, baseball games, and him excelling in academics. Well, that is not quite what our lives are about, but we wouldn't change it for the world. We see other parents chained to the norms of society: academic competition, sports frenzy, and what is cool and what is not. And oddly we feel we have the space to be more creative in our life choices. Of course we would love to have Marcel not have any disabilities, but our lifestyle is so satisfying.

My wife and I usually have a plan going into our CSE meetings. We

both have read the IEP and fully understand what it says and have reviewed the goals that are being set for the coming year. Sharing the process provides a synergistic effect. We perceive some of the conversations differently. This allows for greater comprehension of the process and what outcomes are or are not being achieved. We are a formidable team, and it is less intimidating going to a meeting where there are two of you across the table from 8-10 school district personnel.

What our united front shows to our school system is that both

parents are fully engaged in the process of educating our son. The meetings are typically women only and dads are not present. We are there as a united team that shares the task of getting Marcel what he needs to be successful. It changes the dynamic of the meeting. We have observed that there are things that I do or say that have a different impact than if it comes from my wife.

In our society it is often assumed that women take the lead when working to get the desired services for our children. In many cases the man is the lead bread winner, and it is difficult for him to get to the meetings. In addition to that fact sometimes men are not expected to be fully involved. It can be the domain of the mom. Moms and dads need to be part of the process and work to get the education needed for their child. We have consciously built flexibility into our schedules allowing us both to be fully engaged.

Having been through the grieving process of accepting a child with special needs, we understand the stress that it puts on not only individuals, but also marriages. It is important to let yourself grieve and gradually accept your reality. As you accept the situation, the process can begin to create an alternate vision for your child and see that life is worth living even though a person is not so called "normal". My inclination is to want to control situations and fix what is wrong. There is no fixing this situation. The most important thing that I did was to get to some place of acceptance, and play the hand that I was dealt. Grief will come and go and we can learn to let it happen. There is no shame or weakness in that. Along the way both parents must take care of the marriage.

Allow yourself and your spouse to explore outside the caregiver role and live as full a life as possible. If as a couple the marriage fails, it makes it exponentially more difficult to maximize the potential of your child.

In closing, I would like to stress that the journey that we are on with Marcel has dramatically altered our view of the world. It has forced us to contemplate what success is, and what my vision of a full life is. I encourage other men who may not be involved to get involved in the process, be fully supportive of their spouses, and open themselves to the beauty of life's possibilities.

David and his wife, Margit, are 2015 Family Empowerment Series graduates.





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From the Editor:



Sometimes grandparents offer a broader perspective of our children. They are equipped with years of experience and wisdom and are a step removed from the immediate responsibility of caretaking.

When we discovered that our newborn had a disability, Dave and I were gripped by shock, questions, concern, early intervention literature and appointments. My Mom, a.k.a. "Nonni," exclaimed in her heavy Italian accent, "I don't see anything wrong with this baby! The only thing he needs is love and good food!" She snuggled him and kissed his chubby cheeks in her typical rapid-fire style, about 20 times.

That's my Mom. Any challenge can be surmounted by a whole bunch of love and her homemade pasta. Was she in denial? No, she understood that Nick would have challenges, but she also realized that he was a wonderful new little person, whose life was also filled with possibilities. Thanks Mom, for giving us that moment of peace and joy and the reminder that Nick was a baby first and all that other stuff came in second place.

23 years later, she still sees Nick as one of her dear grandchildren first. All that other stuff still comes in second place.

Thanks to all our grandparents who are there for us and our kids. Happy holidays to all our readers! Wishing you a peaceful and happy 2016.

Maria Schaertel 

Bridges

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 Upstate Special Needs Planning
Preserving Choices

This issue underwritten by James Taylor,
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