



Parents Supporting Parents



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Letter from the President

Dear Readers,

In this issue of *Connections*, you will find several papers that discuss the challenges faced by parents of children with disabilities, and about how parent-to-parent supports have been developed to help mitigate these challenges.

All parents face challenges. I know this because I am a father and a grandfather; and I know you can't be a good parent without working day to day to help your children grow up. Although I am not the father of a child with a disability, throughout my professional life, I have come to recognize that having a child with a disability can both amplify common challenges and create new ones. I have also learned how influential the parent is with regard to the success of a son or daughter with a disability in pursuing a typical life in an integrated community. Because parents hold such influence, I think it is important that they share a bond with other parents who can support them emotionally, but who can also support them by connecting them to the right services and helping them to find the right information so they can learn about the best possible life outcomes for their son or daughter.

One disturbing point that appears in several of the articles in this issue is the struggle that many parents face when dealing with educational systems and community agencies. So many times it would be much more helpful if people representing these systems realized the level of stress parents are dealing with. Too often the relationship is described as a conflict instead of a collaborative partnership. Of course these are times when funds are being cut and services are being reduced. Still, though, school and agency

personnel should begin their interactions with parents with a healthy dose of empathy for what the parents have experienced and with a commitment to being as supportive as possible.

But the world also has good and caring people, and many of these are officials in schools and agencies. And they are also other parents, which is the uplifting side of the articles in this issue. Even after some parents have used so much personal energy to support their own children, many of them still have the internal strength and goodness to turn to other parents and offer support. Although this fact cannot make up for the weaknesses we have in our educational and social service systems, it can help us see that despite the shortcomings we will find in our society, we will also continue to find strengths.

I know you will enjoy this issue of *Connections*.



David L. Westling,
President,
TASH Board of Directors



David L. Westling, Ed.D.
President, TASH Board
of Directors

A Letter from Our Executive Director

TASH is a Welcoming Home to Parents

I'm so grateful to the authors and guest editors, Robin Dodds, LaQuita Montgomery, and Louisa Wood for this issue of *Connections* on the role of parents and the importance of parent support in families that include people with disabilities. Parents have been the driving force behind the disability rights movement, leading early and persistently in de-institutionalization efforts, fighting for public funds to support people to live in the community, and having high expectations of schools and other service systems for quality supports that improve quality of life.

Likewise, parents have played a critical role as TASH members. In his brief history of TASH (www.tash.org), founding board member Wayne Sailor shares this perspective:

[Following its founding in 1975] the organization began holding

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Barbara Trader,
Executive Director of
TASH

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annual meetings, mainly with presentations by researchers, many of whom were later published in the AAESPH Review, the first TASH journal. The organization soon grew by leaps and bounds as families, as well as persons who experience support needs, found a welcoming forum for their concerns. TASH differed from existing organizations by creating an activist policy agenda and advancing that agenda with congress and state legislative bodies. It took forceful early stands on such topics as deinstitutionalization, non-aversive treatments and inclusion, and in the process generated much controversy but also very high visibility on the political landscape of disability.

The presence of parents, family members and people with disabilities as equal members has helped TASH stay true to its values – in fact, has ensured our shared commitment to maintaining an activist agenda. Because parents, self-advocates and other allies are equal members with professionals and researchers (and often are professionals and researchers!) TASH continues to work on the “hard” stuff that is most important to those most closely impacted – particularly the intractable existence of segregation in all its forms.

We are proud that parents and family members make up so much of our membership. They serve as board members, authors, committee members, presenters, chapter leaders, trainers, and active participants. Parents share that TASH conferences give them hope and help them envision their futures in new ways. Past TASH Board President Liz Healy, proud parent and Executive Director of the PEAL Center wrote:

When our family was just beginning our journey of planning for my daughter's education and future, we found a community in TASH. Researchers, educators, parents and people with disabilities all come together as equals and as allies united in a vision of building inclusive schools and communities. Today because of TASH we believe that people with disabilities belong in their own homes in the community, and not in institutions; we believe that people with disabilities should hold jobs at the prevailing wage, and not be forced into sheltered workshops where they earn only pennies a day; and we believe that people with disabilities should go onto college and post-secondary education like brothers, sisters and classmates.

In TASH, parents forge connections with other parents, develop relationships with researchers, learn about innovations in services, and are able to make sense of policy and funding. They learn

that it is reasonable – even DESIRABLE – to have hopes and dreams for the future of their children, and TASH provides the opportunity to develop relationships with others who can help them achieve those dreams.

We couldn't do our work without parents. Please welcome the parents you know into the TASH community by sharing with them the many benefits in store!!

In solidarity,



**Here's an insight from parent and TASH's Education Policy Director, Jenny Stonemeier. This blog post first appeared at www.swiftschools.org.

I consider my own identity using many labels; woman, mother, advocate, policy wonk, etc. The trouble is these labels only serve to describe a small part of who I am. I learned this lesson the hard way as I prepared to send my 11 year old son off to 2 weeks of overnight camp for the first time. My son--let's call him by his nickname “Doodle Bug”, let's also agree to not tell him I'm using this name--is many things; smart, kind, funny, tall, goofy. We all have labels.

The Doodle Bug also has a label of Asperger's Syndrome to go along with all of the other labels; and I made the mistake of using that label to describe him to the camp staff BEFORE I talked about all of the rest of the words that could be used to describe him. The conversation with the camp staff started like this, “Doodle Bug has Asperger's Syndrome...” Their eyebrows went up; they raised their chins and nodded slowly. It was almost as if they were saying, ‘Ah, yes, I know this kid’ without hearing another word about him. Then they started the rapid fire questioning, ‘does he have any behavioral outbursts?’ ‘how does he react to loud noises?’, ‘how much support will he need during transitions?’, ‘we can get him a 1:1 staff person if you want’. Oh dear, this had gone seriously off track. They had made up their minds about who my child was and what his needs were based upon the words “Asperger's Syndrome”. The kind of support that my child needed at camp was rendered irrelevant because they had a preconceived notion of who he was based purely on his DISability--based purely on a label.

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While I was at once struck by their eagerness to include the Doodle Bug, I was simultaneously bowled over by the impact that my use of labels had had on these professionals.

The Doodle Bug doesn't know that Asperger's Syndrome might be used to describe him. In my house we don't talk about disabilities, we talk about the fact that everyone has things that they are good at and everyone has things that they struggle with. My daughter gleefully contributes, "That's right Mama, and you're no good at running." I can't argue with the kid, she's absolutely correct. We have these conversations intentionally in an attempt to teach ABLEness, an attempt to normalize the natural differences that exist within our world, an attempt to glorify diversity in all of its dimensions. And here I was--leaving my kid at camp with a bunch of strangers--and I had just broken my cardinal rule. I had used a label to describe my son and now I was back-pedaling as fast as I could to make sure that the camp staff heard ALL of the other things that I had to say about my child.

The lesson—not just for me, but for everyone—whether it's educators, swimming instructors, summer camp counselors, or religious community leaders LABELS DON'T SERVE OUR CHILDREN. They evoke false images of a child's abilities; they speak half-truths about who we are as humans. Labels reduce us to a list of symptoms, they clinicalize who we are, and they allow us to view each other as uni-dimensional.

I challenge us all to use words that describe each other more fully--better yet; I challenge us to say, "Have you met my son Doodle Bug? He'd like to spend some time with you before he comes to camp for two weeks." and let people experience our children without the perceptions of someone else mucking up the works.

We would all be better served by this concept of ABLEness.

P.S. The Doodle Bug had a fabulous 2 weeks at camp and he is already planning how he can subsidize the tuition for next summer so he can go for all 8 weeks.

Letter from the Guest Editor

As we see all too often, special education is often done to students by schools and educators with little input from the individual, their parents and family. Not only does this framework of services privilege professional knowledge, but it divests from opportunities to develop and engage in meaningful dialogue among families, organizations and schools. Conversations with parents, family and the individual are vital to ensuring the holistic support and the success of the individual within school and in the community. In order to ensure that parents have the skills and level of confidence to communicate effectively and work collaboratively with schools and other stakeholders, and in order to advocate and actively participate in their children's education, they need to be given access to various supports within their communities, including other parents and families whom have navigated the process. *Parent to Parent* has been providing this support network for over 36 years across the country. The organization has and continues to sustain parents as they navigate the sometimes uneven and slippery terrain.

In this issue of *TASH Connections*, guest editors Robin Dodds, LaQuita Montgomery & Louisa Wood have come together to bring a collection of authors to discuss the important work that *Parent to Parent* does to provide continuous and ongoing support to parents and families. Throughout this issue, readers will have the opportunity to learn more about the work *Parent to Parent* is doing to connect parents and caregivers with one another, including a discussion on current initiatives, healthcare, and key attributes of successful parent to parent volunteers. The arduous work that parents do to support each other is, at the moment, fundamental to the "work" of inclusion and the support of individuals with disabilities within their local schools and communities.



Carrie Rood,
Guest Editor of
TASH Connections

About the Authors

The authors of this issue are graduate students at University of California, Santa Barbara (UCSB) and share the same advisor, Dr. George Singer, who has been involved with both TASH and *Parent to Parent* for many years, having been a board member of both organizations. A focus on the strength and resiliency of parents of children with disabilities, and the importance of social support interested the editors as researchers and mothers. Parent-to-parent support has generally appealed to mothers of children with disabilities and special health care needs, but as parents share responsibilities more equally, peer support becomes more pertinent to the needs of fathers.

Robin Dodds is a PhD student in the Gervitz Graduate School of Education at UCSB with a focus on Special Education, Disability and Risk Studies. She worked for 11 years as a Special Education teacher with toddlers and preschoolers and is the mother of two children, one with Autism. She has presented at TASH and CalTASH as well as the Disability Studies in Education, UCSPEDR and Parent to Parent USA conferences. Robin's research interests include: Inclusion, parent support, culturally and linguistically diverse families and special education.

LaQuita Montgomery is a mother of two and doctoral candidate in special education, disabilities and risk studies at the UCSB. She became a Board Certified Behavior Analyst in 2001 and three years later started a behavioral consulting company. LaQuita has authored numerous behavior support plans which were implemented in schools, intermediate care facilities, day programs and group homes. Working closely with caregivers in their homes and communities led to her current research interests in parent-to-parent supports, families with children with disabilities from culturally and linguistically diverse backgrounds, and social issues in education. LaQuita has taught courses in special education, general education and applied behavior analysis. She has also conducted workshops, seminars, and trainings and presented her research at Cal TASH.

Louisa Wood is a California State Credentialed Teacher in Moderate to Severe Disabilities and is working towards her Doctoral degree in Special Education, Disabilities, and Risk at UCSB. Wood joined the university community after living for over four years in China, where she first served as a Peace Corps volunteer charged with teacher training in the remote northwestern province of Gansu and later worked in Beijing as a director for Special Olympics East Asia. While working overseas, Wood and her husband co-founded an organization that distributes scholarships to student and teacher writers from some of the poorest regions of western China. Prior to living in China, she worked as a teacher with the Santa Monica-Malibu Unified School District, where she strengthened her interest in and devotion to Special Education. Louisa is also a mother of four boys under the age of six.

*Authors of this issue of
TASH Connections*

*From Top to Bottom: Robin
Dodds, LaQuita Montgomery,
and Louisa Wood*



Articles from Our Contributors

An Introduction to Parent to Parent

Kathy Brill, M.Ed., M.P.S., Executive Director, Parent to Parent USA

Parent to Parent USA's (P2P USA) vision is to have all children with disabilities and special health care needs grow up in a family who supports them to lead full and happy lives in their communities. There is hope, strength, and power in connecting parents of children with disabilities or special health care needs. We believe that every parent's journey has value. We believe in the strength and resiliency of parents. We believe in the power of parents supporting one another, and that support should be available to parents and families throughout the lifespan and across the country. Our statewide P2P Alliance Members serve families who have children of all ages, ranging from pre-birth through adulthood.

P2P USA is a national non-profit organization that promotes excellence in P2P programs across the nation. We provide networking, support, technical assistance, and leadership development to established and emerging P2P programs. However, our P2P Alliance Members and Community Partners are the real powerhouses for ensuring that successful, quality P2P support occurs throughout our nation!

The first formally organized Parent to Parent (P2P) program, called Pilot Parents, was started in Omaha, Nebraska in 1974 by a young mother of a child with Down Syndrome. She worked closely with a social worker at the Greater Omaha Arc who shared her vision of a program to foster one-to-one connections between parents. The program grew rapidly and within a few years the founders received a federal grant to train others to replicate the Pilot Parent model. Parent to Parent programs began to spring up nationwide, fueled by the energies and commitments of parents who believed fervently in their importance.

Since then, Parent to Parent programs across the country have been providing emotional and informational support to families of children who have disabilities or special healthcare needs, most notably by matching parents seeking support with an experienced and trained 'Support Parent'.

Parents who are interested in being matched with a Support Parent often self-refer to a Parent to Parent program or they can request that someone else make the referral on their behalf. Referrals and matches are never made, however, without the expressed interest and permission of the parent seeking the support, and anonymous referrals are never accepted. Usually the person who handles referrals to the Parent to Parent program is a parent themselves, as parents find it comforting to talk to another



Kathy Brill

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parent right away. The referral coordinator, in order to ensure the most successful match, will gather information from the referred parent about (a) the child; (b) diagnosis and specific challenges; (c) reasons for seeking support; (d) the qualities they hope for in a support parent; and (e) any unique preferences or issues related to the match. The referral coordinator will then check the roster of trained and available Support Parents to identify a Support Parent who seems to be the right fit. If the support parent agrees to the match, then contact information for each parent is shared with the other and the match is made. After the match is made, follow-up activities help to ensure the success of the match. An initial call to both parents lets the coordinator know the match has been made and to know if additional support or resources are needed.

Statewide Parent to Parent Alliance Members are currently in 33 states, and an additional 5 states are in the process of emerging. Parent to Parent USA is assisting the development of these programs, with the goal of having quality statewide P2Ps available to families seeking this type of support in all 50

states. We should never have a family unable to find a one to one connection with another family, based upon their individualized needs! This should become a guaranteed form of family support readily available to families in every state. In addition, a new level of membership, Community Partners, is creating an avenue for local, regional, advocacy-specific, or diagnosis-specific Parent to Parent groups to get connected to national resources and support. They will work collaboratively with their statewide parent to parent, if one exists in their state.

Currently, we have one international partner -- New Zealand. New Zealand's P2P has attended our last two P2P Leadership Institutes. Technology has allowed our world the opportunity to take advantage of learning and connecting with others. If possible, it would be gratifying to assist other countries in starting their own P2P programs.

To learn more about parent to parent support, including Parent to Parent USA, P2P Alliance Members, and P2P Community Partners, please visit www.p2pusa.org.

Community Parent Resource Centers: Serving the Underserved

LaQuita S. Montgomery, M.S., BCBA, University of California Santa Barbara

Social support programs are designed to help families navigate the challenges of caring for a child with special needs. Studies show that families receiving social support cope better with the responsibilities and stressors that come with caring for a child with special needs (Singer & Irvin, 1991; Ainbinder, Blanchard, Singer, Sullivan, Powers, Marquis & Santelli, 1998; Park, Turnbull & Turnbull, 2002). When parents were asked about their preferences, most mentioned the importance of finding and having support from other families with similar circumstances (Santelli, Turnbull, Marquis & Lerner, 1995;

Ainbinder et al, 1998; McCabe, 2008). Parent-to-Parent organizations are a type of social support that matches help-seeking parents with experienced parents of similar backgrounds and experiences. Community Parent Resource Centers (CPRC) are parent-to-parent, community-based organizations that provide informational and emotional supports to traditionally underserved families with children with disabilities.



LaQuita Montgomery

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Community Parent Resource Centers: Serving the Underserved

The following interviews were conducted with the leadership of two parent-to-parent organizations that are a part of a national consortium of Community Parent Resource Centers, the Grassroots Consortium on Disabilities. United We Stand, located in New York and Pyramid in Louisiana, have served culturally and linguistically diverse families since the early 1990s. The interviews highlight how each group interprets the unique challenges of its own memberships while shedding light on the overall experiences of traditionally underserved families of children with special needs. The leaders of both organizations spoke of the importance of collaboration and innovative problem-solving in order to meet the needs of the families they serve. The interviewees discussed the challenges families often face such as cultural misunderstandings, language barriers, poverty, and geographic isolation as well as conflicts with schools and the impact of devastating natural disasters (Hurricanes Katrina and Sandy).

United We Stand

Interviewees: Lourdes Rivera-Putz, Executive Director and Amanda Haught, Information Specialist

The author spoke by phone to two of the leaders of United We Stand, Lourdes and Amanda about how the organization maintains a strong presence in the primarily Spanish-speaking community where it is based and continues to work with underserved families.

LaQuita: Tell me the backstory of United We Stand.

Lourdes: United We Stand was developed back in 1990, April 1st. It was created as a result of four moms that lived within a one-mile radius, and just kind of liked getting together for coffee and chat. We were soon discovering that there were issues that we'd like to somehow work through or support parents with so initially it started out as a support group for parents. Then gradually it just evolved into this organization, training and providing information to families within our community of primarily Spanish-speaking families.

LaQuita: What are some issues parents typically face when they come to the organization?

Amanda: Well I think parents come to us with a whole bunch of things. Not only issues in regards to services or lack of services in the schools but their day-to-day. Maybe they have more than one child, need food stamps, help applying for certain government programs. Not just from an educational standpoint, parents

contact us for help with the day-to-day and information on services provided in the community.

LaQuita: When do families typically come to you?

Amanda: I think it varies. Some families, more now than before, contact us when they've just gotten a diagnosis. But for a long time parents have contacted us when it was like the last straw in regards to issues that have been already building in the school settings.

Lourdes: I think that for us it really depends upon where the referral comes from. A referral that comes from another community-based organization (CBO) or a church that we may be active in or from a board member, would probably be a family who's just received a diagnosis. But parents that find us, or come to us directly without a referral, are parents that have been through the whole disability thing and are now just struggling getting through the bureaucracy of our school system. And then will, as a result of that, find out about us and come directly to us without a third-party. Just kind of like you know, maybe they get a little handbook when they sign consent and it will have our name in there and they'll reach out to us. So I agree with Amanda that it really varies. And I think it goes through different periods or stages throughout the year. So obviously when school starts, usually around the end of August into maybe October, November, a lot of the calls that we're getting are parents that are already in the crux of stuff trying to secure placements or they are having school-related issues. In the spring or late winter we get more parents whose child was recently diagnosed or in the process of trying to get a diagnosis, or there are issues pertaining to promotion.

LaQuita: How do you go about informing and educating families?

Lourdes: One of the things that I did very early on as we quickly evolved was reach out to community-based organizations, primarily because in order for us to survive we needed collaborations. We started in 1990 and had no real funding other than a \$5000 grant. So we knew that we needed to establish partnerships with other community-based organizations. So it was kind of like we want to be able to bring information to families, would you open your door to us? We'll come and host an event and that's pretty much how we were able to even hold support groups. Believe it or not, we went to a pool hall where we knew people loved to go in the neighborhood. We said, "wouldn't you like to be able to offer something different to the community other than just a place for people to come hangout and play

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pool?” So the owner opened his pool hall to support group meetings. It was unbelievable! That was where we would have the largest group to come out. And so we started out by developing those kinds of partnerships and learning how to collaborate. That has been our area of strength and has been key to our success throughout the years and why we are still here today. So surely funding through foundations or government grants helps support us but it’s also those partnerships to which we owe the success of the organization. We’re in the community and other community organizations know who we are. If they are trying to bring information to the families they serve and they have families having issues with their kids getting services within the special education system, they know that they can reach out to us and invite us to come in because we’re in the community. We know the community and we have no problem coming in and being able to offer whatever information is needed. And the same thing for schools because we know the schools in the community. It’s not always feasible for families to come to us so we know that it’s more important for us to be able to bring the information to them where it’s most accessible.

LaQuita: You had mentioned earlier that there was a lot of bureaucracy that families face, could you elaborate on that a little bit and what that experience is like?

Lourdes: So that is probably what is most challenging about any school system but especially New York City. It’s a huge system with hundreds of thousands of children. And as a result it makes it that much more difficult. It’s not a parent-friendly type of system and it makes it very difficult to develop real engagement or communication between families and schools. We all know that is key to success for students when families and schools are able to work together. And on top of all of that, we have something like over 30 languages in our school system? We are dealing with barriers, culture and language and then all the other issues that you find in an urban city in much larger numbers. Not that you don’t find that everywhere but in urban cities you find it in much greater quantities. You have homelessness, issues around poverty and domestic violence, all things that are very prevalent among the many families that we work with. Which is another reason why these partnerships with other community-based organizations are so important. It helps us to be able to tie families into different resources that may be necessary to them. Very often, parents are calling because they have an issue that relates to their child with a disability but it isn’t long before we’re in a conversation and trying to assess other issues. We know families struggling with putting food on the table, afraid that they

can’t tell the school or make waves at the school because they’re undocumented and don’t want to get immigration involved. These are all issues that are very real to them and that they will shortly after beginning to feel that sense of trust from our conversation start to disclose. These are underlying issues that we know if they’re not resolved, it’s going to make it very difficult for them to give the amount of commitment they’re going to need in order to support their kids educationally. We connect them with other resources, in the hope that with the initial support in these other areas, they’ll be able to focus and open themselves up to be able to work or identify how they can best support their child in school.

LaQuita: In what other ways do you collaborate with other organizations?

Amanda: Right now I work with an agency to address everything that happened with [Hurricane] Sandy. Obviously there have been a lot of holes that people are starting to realize because of Sandy. One huge issue was the fact that a lot of families weren’t able to receive any help because family members or individuals who had significant disabilities could not understand the severity of the dangers that were arising. So there’s this borough-wide group, for all five boroughs, trying to figure out how to address those needs, making sure people have their medication, transportation getting them place-to-place, things like that. I sit on a youth advisory board focusing on systems that serve youth like mental health, foster care, juvenile justice and special education and trying to figure out what changes can be made from a youth perspective. So I sit on that board trying to do the special education component to give a voice of how we can support our youth in the school system so that they don’t fall within the school-to-prison pipeline.

LaQuita: What accomplishments are you most proud of with United We Stand?

Amanda: I think that for me the accomplishment that I’m most proud of is to really be known within the community. I think that for United We Stand to really continue that presence people know who we are, they know what we do, they come and they feel open enough to come in and say I have something going on. So I think that is an accomplishment that really goes unnoticed. We are still very much alive within the community.

Lourdes: I have to say that, there’s a couple of things that are really key for me. One of them is our work in the area of conflict resolution. We’re pretty well known for that. I think that through

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the course of the last really ten, fifteen years we have been able to show that it is in fact the best way to build bridges and to improve education. By utilizing a process that allows for people to once again build bridges that help them work together on achieving the same goals. Everybody wants the students to do well. So that's something that has worked well for us. And the other thing that I'm really proud of is our Students Achieving Success (SAS) project. It gives us an opportunity to really get into the schools, work directly with students, parents and teachers and help them build on skills that help provide them with the ability to have ownership over their own futures. As well as how it is that schools play a role in that and why it's important to understand that disability is a positive thing. And clearly something that can help you, once you understand it, to reach all those dreams. And I think that for me that's just amazing to watch the kids as we work with them throughout the two-year program and then assess them on the third year again to see where they've come and it's just wonderful to see the strides that they make as a result of those projects.

Amanda: There's stuff that we do that really is all about the students and we try to include their voices as much as possible. One of the ways that we're doing that is the Students Achieving Success program.

Pyramid Community Parent Resource Center

Interviewees: Karran Harper Royal, Assistant Director and Lynne Farlough, Parent Associate/LaSig Family Facilitator

The author spoke by phone to two of the leaders of Pyramid, Lynne and Karran, about the experiences of families in the New Orleans area. The conversation touched on a number of issues and how Pyramid, through its blog, radio show and accessibility to the community, serves families with children with special needs.

LaQuita: Tell me about Pyramid.

Lynne: Pyramid is a Community Parent Resource Center (CPRC). We fall under the umbrella of Parent Information Training Centers (PTIs) but our distinction as a CPRC is that we serve traditionally underserved parents in the New Orleans area. When we say traditionally underserved we mean not having as much education as other people. We're talking about poor people in poor areas. We're talking about language barriers when we say traditionally underserved people. We've been around in an official

capacity since about 1991. And our directors, Ursula Markey, who has now passed and her husband D. J. Markey, started Pyramid because they saw a need in the New Orleans area that wasn't being met for parents. They had two children with autism spectrum disorder, went on their journey and felt like the things that they learned they could share with other parents. So that's the gist of Pyramid, that's why we do what we do. It's Karran, myself and we have D.J. and Tiffany so we're a small group.

Karran: We help parents of children with disabilities navigate the public school system.

LaQuita: When families come to you what are their biggest challenges and concerns?

Karran: I would say the concerns parents have the most are gaining access to a school in New Orleans, finding a school that can serve their child's special needs and dealing properly with the behavior that some of our children may exhibit.

Lynne: Parents call because their children are being threatened to be removed from school or they're [the school] telling them to go find another school. Typically they'll ask parents to locate another school because that school is not working for them.

Karran: Sometimes it's not that blatant. Sometimes they simply don't serve the child well so that the parent gets frustrated and leaves. Also behavior referrals, constant behavior referrals.

LaQuita: What is your interpretation of how Katrina factored into to all of this?

Karran: Well what happened after Katrina, our schools were taken over by the state, most of our schools. And neighborhood schools were eliminated. All children with disabilities had a right to neighborhood schools and it was very difficult for schools to turn people away. I don't ever remember schools turning children away. However now, because schools have to keep their students, children with the greatest need become a liability. But they try to make parents think they have hope and they just need to go out there and choose a school that meets their child's needs. But in truth, none of these schools want the children with the greatest needs so parents end up moving their children 3, 4 and 5 times in elementary school. So that's how Hurricane Katrina has affected our families, it has completely destabilized lives of children with special needs. Really all children but children with special needs are particularly harmed by a system that is in constant states of change.

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Lynne: And plus we're dealing with educators who truly are not trained to serve the children.

Karran: Yes, that is the other part of this. The vast majority of our teachers were hired after Hurricane Katrina. And as new schools were started, most of which were charter schools, many of these new schools start up with a lot of teachers, most of whom do not have the credentials and come in with a five week training program where they touch on special education but they certainly don't come in with a vast amount of experience necessary to deal with the problems that some of our children have.

Lynne: You also need for a teacher to be culturally aware, know where he or she is and to be able to understand the student that he or she is teaching.

Karran: This is really a global issue, it's not just a special education issue. Some real structural changes being made to special education throughout this country and indeed throughout this world. You know, the implementation of a market-based public education system is not the best way to educate children and it's certainly not the best way to make sure that children with disabilities get the help that they need.

Lynne: And our director D.J. likes to say that this is about de-professionalizing teaching.

Karran: With the influx of amateur or novice teachers from [a national, non-profit organization], de-professionalizes the profession of teaching to make it seem that anybody with a degree can teach children in a public school system especially in our urban centers. And so making policy changes at the state level and even at the national level that encourages more temporary amateur teachers, that is de-professionalizing teaching.

LaQuita: What are some other challenges that you see?

Karran: One of the main challenges we face is that prior to the changes made in our public school system, it was easier to work with a school district to resolve problems that were systemic. And now with over 50 different private boards operating in our city it is very difficult for a small non-profit organization like ours to provide enough systemic help to working with the school system. Initially we had 50, 60 different little school systems within our city and with so many of our schools, 85% of our schools being charter schools who get to set a lot of their own policies, even though they all should follow federal law for educating children with disabilities, they seem to be a little too enthusiastic about how far their autonomy goes. They just trample on the rights

of children with disabilities. And without our state providing adequate oversight to so many local education agencies, children with disabilities end up being discriminated against over and over again and our organization can only reach a small number of these students when we're working on an individual basis and not able to work systemically as well as we were able to work systemically with a school district before.

Karran: It is very important for disability rights advocates to recognize that some of the changes that are being made in the school systems like New Orleans and Washington, D.C., Chicago and Detroit, those structural changes are impacting special education overall. I just want people not to think this is just a problem for urban areas. There is going to be a reauthorization of IDEA at some point and we need to in the disability rights community, we need to be paying attention to if there will be a weakening of IDEA as schools across this country are given more autonomy through chartering. We need to pay attention to that in the disability rights community. As those of us who have been fighting for years need to make sure that children with disabilities are able to be included, need to be in this fight with so many other advocates across the country because I see a re-segregation of public education where there will only be a handful of schools for children with disabilities because all of the schools and school districts will be allowed to specialize due to chartering. I just wanted to make sure that point came across and is made clear to the many people in the disability rights community. They need to have this on their radar and get involved with the various efforts throughout this country to make sure that public education remains public education.

LaQuita: What are you most proud of for Pyramid?

Karran: What I am most proud of is when a parent comes back and tells us one of the strategies they were able to learn from us that they were able to use to get a problem solved for their child. And that happens a lot. Where you see parents taking it to the

Learn More

To learn more about Pyramid or United We Stand visit the organizations' websites or call:

Pyramid Parenting Center
www.pyramidparentcenter.org
www.pyramidparenttalk.com
Helpline: (504) 218-8922

United We Stand of New York
www.uwsofny.org
Phone: (718) 302-4313

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next level and share that information with other parents. I really appreciate that because then you know that parent is moving beyond just helping their own child, as Lynne and I have done, as we learned to help our own children we helped other's children. And that's the foundation of how Pyramid was built and how it works and why it is a pyramid.

Community Parent Resource Centers like United We Stand and Pyramid provide information and emotional supports to traditionally underserved families with children with disabilities in their communities. These organizations serve as valuable resources for families to not only receive information but also share their experiences in support of one another.

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Parent-to-Parent Support for Diverse, Low-Income Families: A Study of the Voice of the Life World in a Medical Context

Parent-to-Parent Supports as Part of Comprehensive Medical Care

Louisa B. Wood, M.A., University of California Santa Barbara



Louisa Wood

Introduction

Research has shown that linking together families of children with special healthcare needs and disabilities with other families who share similar experiences can have many benefits (Ireys, Chernoff, DeVet, & Silver, 2001; Ainbinder, et al., 1998, Singer, et al., 1998; Corcoran, 1981). Trained peer supports can provide caregivers with emotional and social supports that lead to a decrease in the levels of stress, anxiety, and feelings of isolation. These added supports also can lead to an increase in engagement, and, for some, empowerment and access to more community resources and better healthcare (Ainbinder, et al., 1998; Bhasale, 1998; Singer, et al., 1999).

The purpose of the current study was to examine the impacts of adding a parent-to-parent peer support program to primary care medical home clinics along with outreach specialty clinics serving low-income, diverse families, including underserved and underrepresented families (i.e. families living in rural communities, families from diverse cultures and families new to the United States) of children with special health care needs and disabilities (CYSHND). The Parent-to-Parent Program, created and implemented by Family Voices of Minnesota, was granted by the United States Department of Health and Human Services Health Resources and Services Administration¹ to improve medical clinics for children in urban and rural areas of Minnesota.

¹ HRSA Grant: D70MC23047

Peer support is a topic of interest in research on disability, and medical and mental health. It represents an adjunct to traditional professional services, and may offer unique and supplemental forms of helping (Ainbinder, et al, 1998). This study was completed to identify the social exchanges that take place in a parent-to-parent support program, and investigate how they are understood and valued by the participants when parents acting as support providers join with medical personnel to serve families who are often underrepresented and underserved with children with special needs.

Method

Fifteen individuals were interviewed for this study. Participants included family members of children and youth with special healthcare needs and disabilities (CYSHND) participating in a parent-to-parent program and healthcare providers referring patients' family members to the parent-to-parent program. All participants recruited for the interviews were parents and professionals that represented four distinct roles in the program including: 1) Health Care Providers (physicians, nurses, mental health professionals, etc.); 2) Program Coordinators and Parent Support Navigators (leaders from a parent-to-parent program); 3) Parent Support Volunteers (matched one-to-one with parents attending the clinic); and 4) Referred Parents (help-seeking parents of children with health and disability-related challenges). In total, three of the interview participants were health care providers, four were program coordinators or parent support navigators, four were parent support volunteers and two were referred parents.

The recorded interviews were fully transcribed and coded in three phases. A master list with major themes and respective sub-codes was compiled. The coding followed a set of procedures recommended by Charmaz (2006) as a revised form of grounded theory. It is an approach to data analysis that tries to let meanings

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surface by completing a careful coding procedure which involves coding transcripts and organizing small units of meaning into larger concepts and themes.

Results

Following interview data analysis, themes identified in the interviews were reduced and grouped into five master categories, which included: 1) Awareness and Understanding; 2) Trust and Empathy; 3) Resources and Accessibility; 4) Mutual Respect and Partnerships; and 5) Empowerment and Advocacy.

Trust and Empathy

Trust and empathy are essential elements of parent-to-parent programs. Trust is the belief that someone or something is reliable; empathy is the feeling that one understands and shares another person's experiences and emotions. When participants were initially asked about their experiences with the parent-to-parent program, a majority spoke about how the program gave families a way to connect with another veteran family that they could trust with their feelings and questions. They found the experienced parents to be empathetic to their experiences.

One parent interviewed for this study discussed how, prior to becoming a support parent with the parent-to-parent program, she had not been able to find another caregiver whose child had the same diagnosis as her own: "Just connecting with other people... is really hard to do on your own," the support parent expressed. "It's a big world out there," the parent continued, "and just trying to find someone similar to you is almost impossible... After all these years, I am finally getting connected with families [through the parent-to-parent program] despite years of trying." This ability to connect with other families and/or caregivers for the first time establishes a "sense of belonging." One support parent explained that talking with similar others gives her "a greater sense of community and... not feeling alone..." There is a sense of relief being connected with another family member who has "walked the same path" and that someone was "actually listening" to them for the first time. One Referred Parent expressed how speaking with an experienced parent was unique compared to other forms of support available:

The other types of support actually backfire. Normal avenues backfire when you get in these crisis situations [when your child has a medical emergency] and you need someone who has been there so they can cut through all of that and give you what you need in order to strengthen you instead of making you feel more

torn down or confused or helpless and alone too. And someone who has been there can make you feel less alone.

Resources and Accessibility

After successful matches of help-seeking families with trained support families have been made and positive bonds have been developed, information that is regarded by families as more reliable compared to other sources of information is shared and a process of learning may begin. Interviewees report that information coming from another parent with shared experiences could be considered unique, and therefore more trustworthy compared to the information received from perhaps a healthcare professional or another individual who does not have the same experiences as the caregivers themselves. One parent support navigator characterized this phenomenon by saying:

A lot of times the information that comes from a parent has a little bit more validity because... they can tell you about how [a resource] actually works. You can read about it, but then you don't know how [the resource] is going to work in your life. [The family member] can tell you about an experience they had with their child that you might be getting into and you can get a much more valid opinion than you can from a physician. I think [families] come at it with a perspective and an insight that no one else can provide.

Additionally, caregivers often find that information from other sources, such as from popular instructional parenting books, cannot provide the much-needed answers to vital questions because much of the information provided is for typically developing children and youth, not for those whose children have special needs. The information within these types of books, therefore, was irrelevant. One Referred Parent described how she was finally able to locate the answers she was seeking for her child with special needs not within these types of books but from an experienced parent:

I think it's so scary when you walk into the special needs world and you don't know what the heck to expect. All of the parenting books out there... really don't tell you what to do when your child doesn't sit up and he's seven years old. They don't take into account those things. So, it's learning... and being able to share some of those experiences [with another parent] and help each other. They can tell you what's worked for them, what hasn't worked for them. It doesn't mean it will work or won't work for you, but they can give you some ideas.

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Awareness and Understanding

The beneficial outcomes from the parent-to-parent matches can stretch beyond the referred family that has been matched to other individuals in the program including support parents, program coordinators and parent support navigators, and even to the healthcare providers through awareness and understanding.

Interview data show that there are many different types of diagnoses and the effect of a diagnosis on a family member can vary for each individual, which is not solely dependent upon the severity of that diagnosis. Rather, family members all respond in very different ways. Further, informants described how family members who make the matches for the parent-to-parent program (i.e. the program coordinators and parent support navigators) continue to learn from the individuals they are assisting, even well after the match has been created. One parent support navigator stated that when she first became linked up with other families, she noticed when the diagnosis of another families' child was less serious than her own child's, but then learned that a diagnosis can be challenging for everyone, no matter the severity:

I think that [working for] the parent-to-parent program has done a good job of helping me gain some perspective... Sometimes [families who are referred to the program] may have a lesser diagnosis [compared to my family or other families], but it's all about how you interpret it. For some people it can be devastating that you have a diagnosis at all associated with your child. And for some it's more about trying to figure out how you deal with very severe disabilities.

Through trainings conducted by the parent-to-parent program coordinators and through their own experiences referring their patients' families to the program, healthcare providers become more aware and have an increased understanding of the needs of their patients and their families. Healthcare providers report that just being trained in the goals of the parent-to-parent program and knowing how and when to refer families for peer support makes providers more aware of the needs of their patients and of the patients' families. For example, one Healthcare provider discussed that solely having the parent-to-parent program as a referral resource made her more conscious of the families' needs:

I think... just even having that opportunity to make a referral [to the parent-to-parent program]... I think just availability of it makes me think a little bit deeper into the needs of our families.

Further, interview participants report that often healthcare providers do not understand or overlook how stressful life can

be for a caregiver of a child with disabilities when creating treatment plans for the child and are not aware that compliance with providers' orders can sometimes be challenging. One Mental Health Care provider explained how being connected with the parent-to-parent program has made her more aware and understanding of the day-to-day life of her patients' families:

I think that the big thing I have learned through [my families who are linked with parent-to-parent] is it doesn't matter how much experience I have [as a professional], I don't have a child with special needs. And I think [for] a parent, everyone's telling them to do this, that, and the other. And then [the professionals] get to leave at the end of the day to go home. I think talking to a [another] parent that doesn't get to walk away is special. There's that 'you know what I'm going through' [when talking with another parent] is very important.

Mutual Respect and Partnerships

When families of children and youth with special healthcare needs and disabilities connect and share similar experiences leading to new awareness and understanding for all stakeholders, mutual respect begins to develop between family members and professionals. Once respect is established, family members and professionals can form constructive and meaningful partnerships leading to more effective caregiving for the child. In order for effective partnerships amongst individuals to form, respect must be reciprocated and shared between both parties. Informants report that the parent-to-parent support program provides individuals with understanding and respect between families with shared experiences and healthcare providers.

Interview data show that once there is new awareness and understanding for one another, healthcare providers and families begin to feel more comfortable, which enables each party the ability to communicate more effectively and able to ask and answer questions unreservedly. One Healthcare provider explained how her patients' families were able to communicate their needs more effectively, ask better questions, and embark on a more bidirectional conversation after the family became linked to the parent-to-parent program:

I feel like the people who I have referred [to the Parent-to-Parent Program]... are more effective and more activated [in making healthcare decisions]... and I feel like they're more engaged in a conversation with me as opposed to... waiting for me to tell them the right thing.

Interview participants report that when families and healthcare

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providers begin to have mutual respect, are more comfortable and are able to communicate more effectively with one another, both parties may become increasingly motivated to support each other. In fact, interview data indicate that caregivers who feel their knowledge is valued by healthcare providers may be more willing to offer their expertise to the provider in how to better support other family members with children and youth with special healthcare needs and disabilities. One Healthcare provider discussed how she became more inclined to request guidance and assistance from caregivers as the family members became better at communicating how significant his or her perspective can be when it comes to the healthcare needs of a child:

I think when families continue to say, 'remember that we as the family have incredibly important viewpoints and can be a resource for you' has really helped me trust and let go of some of that 'I don't know if I want to ask them' [for help].

Moreover, families may become more sensitive and appreciative of the tremendous amounts of pressure facing many healthcare providers today and may become willing to assist professionals in their daily practice. One Program Coordinator discussed how once the relationship with healthcare providers had been established and both parties respected one another, she recognized that her expertise could help support hard-working professionals:

My impression is that providers are... overwhelmed sometimes partially because of the types of families that they serve, but also I think by the complexity of the needs of a lot of the children that they see. [The providers are] so busy that they don't necessarily have time for creative ideas... of how to do things in their practice. So we [the families] are ones that need to come up with the ideas and say, 'Well, how about if we try this?'... And then [the providers] are very excited about it.

Empowerment and Advocacy

The final theme that developed from this interview study was that of empowerment and advocacy. Interview respondents reported that, after the establishment of mutual respect and a strong partnership develops among professionals and caregivers of children and youth with special healthcare needs and disabilities, many family members move to a new stage in their journey from needing to care for their own families, to becoming empowered to support others through advocacy. This important stage in a caregiver's journey begins with the ability to advocate for the needs of one's own child and family. One Referred Parent explained how the support parent she had been connected with

was able to encourage and empower her to speak up for the needs of her child with disabilities when communicating with other families and with professionals:

[The volunteer support parent] was very good about encouraging me, affirming me about being assertive with my needs, my family's needs, my son's needs and... taking ownership of being the point person for his services and for the whole, the big picture of what his life will be like as [we] navigate through the system... and I really liked that... it felt really great to have another parent say, 'You gotta take the reins and go with it.' It's a lot of responsibility and yet I know it's important.

As caregivers grow more comfortable with "taking the reins" and develop into more effective advocates for family members with special healthcare needs and disabilities, these individuals start to appreciate their unique parenting experiences (Murphy, Christian, Caplin, & Young, 2006). Reminiscent of many families of children and youth with special healthcare needs and disabilities (Gibson, 1995), one support parent explained how she believed there was an extraordinary reason she had become a mother of a child with special needs and wanted to help others in similar situations:

I feel like I've been put in this position as [my child's] mom for a reason and [I] try to reach out and help other people... so they don't have to have such an uphill battle trying to figure some things out, whether it's medical or what doctor to go to, or getting help through the county. I had to do that all on my own and it was a lot of work and a lot of time. For all these years, I've been saying '(sigh) I wish I'd connect with someone'. And when the opportunity came up [to support parents] it was... just what I had been wanting for years... I wanted to be able to help other families to make it easier for them. And I knew I could help.

The sense of fulfillment that develops when caregivers support others can expand the level of empowerment, which can in turn further motivate the individual to continue collaborating with others with shared experiences. A support parent illustrated this point by saying the following:

Not only does [supporting other parents] give you a sense of belonging, and a sense of hope, and a sense of community, and a sense of understanding, it gives you a purpose here and maybe you're put into this position [as a parent of a child with a disability] for a reason... knowing that you can affect other people's lives and make them better or easier for them.

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Once family members reach the point of taking on the responsibility of supporting others through a parent-to-parent program and advocating for those who have challenges advocating for themselves, interviewees report that often family members move towards leading others and advocating at the local, statewide, and even federal level. One Program Coordinator described a sense of satisfaction in helping to empower families by saying, “I like the fact that we’re focused on supporting and helping families in the broad sense, but I particularly like to see the growth of individual families in becoming leaders.” Some families work to help change current policies for individuals with special healthcare needs and disabilities.

Supporting the journey of family members with a child with special healthcare needs and disabilities through the guidance of a veteran family through a parent-to-parent program can be incredibly beneficial. One Program Coordinator described the evolution a family can experience that begins with trust and empathy and culminates in empowerment and advocacy:

[There is an evolution] of family leadership that happens beginning with the idea that the family first has to learn how to cope with their own situation and have some control over their own family and family situation. And then... when families

have that sense of being able to cope well in that situation ...they expand out to being able to look at their community a little bit more broadly and maybe more looking at other families within their community. They're able to look at their community and then look at the needs of families in their state, then at the needs of families in the country and at what the policies are that are... impacting families at all of those different levels. But it is truly ... an evolution of leadership that happens and has to start at that very center piece; within the family itself.

Discussion

Results from this investigation indicate that many individuals who participated in the parent-to-parent program showed higher levels of understanding of medical services, increased access to healthcare and insurance, increased ability to advocate for self and others, decreased levels of anxiety, stress, and loneliness, and an increased understanding of the community resources available. In the future, the researchers will analyze quantitative data from over 100 respondents to see if it triangulates with qualitative reports. This study adds to a small empirical literature on parent-to-parent programs.

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Fathers of Children on the Autism Spectrum: Are They Receiving Enough Support?

Katherine Johnston, M.A., University of California Santa Barbara



Katherine Johnston

Introduction

I recently designed and conducted a study about fathers raising a child on the autism spectrum. I was drawn to this topic for two reasons. As you probably know, the number of children diagnosed with autism has significantly increased in recent years. The Centers for Disease Control (CDC) reports that 1 in 68 U.S. children has an autism spectrum disorder (Falco, 2014). Additionally, many studies have focused on the experiences of mothers raising a child with autism (Boyd, 2002; Koegel et al., 1992; Tomanik, Harris, & Hawkins, 2004), while few have looked solely at fathers. Because mothers and fathers often play different roles in their child's life, I felt it was important to take a closer look at fathers. Specifically, I was interested in examining how they adapt to their role, the stress they experience, and the support they receive. For the purposes of this article, I will focus on what I learned about the support they receive.

Recruiting fathers for this study proved to be a challenge initially, but I eventually found nine who were willing to participate. Before sharing my findings, let me tell you a bit more about these fathers. All of the fathers lived in California. Five fathers were White, three fathers were Hispanic, and one father was Asian. Seven fathers reported some college or a 4-year college degree, and six fathers had a household income of \$120,000 a year or more. Seven fathers were married, one was divorced, and one was separated. As for the children, they ranged in age from three to 19. Eight were boys and one was a girl. This high ratio of boys

to girls was not surprising, as boys are significantly more likely to be diagnosed with autism than girls. The children showed some similarities in communication, problem behaviors, and social skills, but also had many differences. As I explain my findings, I will do my best to paint a picture of each child.

Methods

Once the fathers agreed to participate, I interviewed them over the phone. Prior to conducting the interviews, I was slightly concerned that the fathers would be reluctant to open up to someone they had never met. To my relief, this was not the case. The interviews lasted between 30 minutes and two hours, and the fathers spoke about their experiences with honesty and sincerity. I asked them six questions about the support they received, including "What kind of support do you receive from friends?" and "What kind of support do you receive from your spouse?"

Findings

One major source of support for these fathers was their spouse. Many fathers described coordinating caregiving responsibilities with their wives, so that caring for the child was a team effort. Thankful for her support, one father recalled a time when his wife was out of town:

She was actually out of a town for a week, so I did get to do it all myself and it's not easy. I couldn't imagine doing it for any length of time by myself. It's just a lot of work.

In addition to a three-year-old with autism, this father also has a two-year-old and a seven-year-old. Certainly, this gives the phrase "a lot of work" a whole new meaning. Several fathers also appreciated the emotional support they received from their wives. When I asked the father of a nine-year-old how his wife supports him, this is how he responded:

Mostly by her belief that I'm really a good dad, and that through all that of the fighting and all the writing the letters and arguing with the insurance carriers trying to get coverage for speech

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services, through all that, the feeling that she thought I was doing a Herculean and heroic effort and doing it better than anyone else could do it.

This father described raising his daughter as a “journey,” and after hearing his story, I can see why. When his daughter was diagnosed with autism, he responded by becoming her biggest advocate. During his interview, he described staying up late to write letters and attending countless IEP meetings. In his words, “it was like having a separate full-time job.” He also remembers the dread of coming home to his daughter’s tantrums. Luckily, these tantrums have decreased as she has gotten older, and along with them, so has some of his stress.

Unfortunately, not every father felt supported by his wife. The father of a 15-year-old shared that although he and his wife initially planned to work as a team, “that didn’t work out.” He explained that his wife worked and went to graduate school while he cared for their son. Staying home meant handling his son’s violent behaviors. He described an occasion where his son became upset, and after looking for something to destroy, pushed him into the wall. I sympathized with this father when he stated:

And I realized at that point that though I’ve never wanted to think of it, I can’t take care of him anymore, you know? And not only is it a safety issue, but I can’t get him moving forward. I can’t get him to thrive. I’m not helping him anymore.

To further complicate this father’s situation, his son was hospitalized after becoming violent and frightening his mother. Listening to this father’s experiences and how he has learned to cope with his son’s autism was truly eye-opening. No matter what challenges come his way, he perseveres.

Several fathers also described receiving support from their parents or in-laws. Some examples of this support included taking the child to therapy, cooking meals, and babysitting. One father called his parents “angels” explaining, “my folks were retired and lived close, so they were tremendous assets . . .” Another father shared that his mother-in-law lives with them, and is “fully involved” and a “third member of the team.” This father’s son does not yet use speech to communicate and receives many services, including occupational therapy, physical therapy, speech therapy, and behavioral therapy. Each of these appointments requires transportation and a caregiver who can carry over therapy activities into the home, so it is easy to see why he values his mother-in-law’s support. Laughing, he added that they have even argued over who will get to take his son to horse therapy, which is

a preferred activity for both the child and the adults.

This same father was also keenly aware of the differences between his own parents’ views on childrearing and the views of he and his wife. It is not surprising that some adults hold different views than their parents, but this difference can be magnified and intensified for the parents of a child with autism. This father’s frustration was evident when he stated:

It took a good two years for them to understand that something was going to be different. I don’t know whether they choose not to know, not to understand, or don’t recognize what they’re doing. I just think it’s because culturally it’s not how they were raised, or what they’ve learned, or how they raised their kids.

This example not only highlights the generational disconnect between this father and his parents, but also reveals that we need to continue raising awareness of the needs of families of children with autism.

The fathers also highlighted the value of the support they have received from other parents of children with autism. These relationships occurred in person, by phone, and online, and included both emotional and informational support. One father referred to the parents in the autism community as a “brother/sisterhood of people” and stated, “I was extremely amazed at how willing the parents of one autistic child are willing to extend themselves to help someone else who’s first coping with the diagnosis.” Another father noted that after his son was diagnosed, he and his wife spoke with his wife’s friend who also has a child with autism. In addition to helping him realize “there’s other people going through the same thing,” he shared, “She was really helpful and when we were going through meeting with the school district and the IEPs and all that stuff . . . she was giving us tips on that whole process.” It turns out, though, that this father’s preferred way of communicating with other parents is on the Internet. After admitting that he is not always comfortable meeting new people, it became clear why connecting with other parents online worked well for him:

It was just easier for me cause I could just sit there and read instead of having to say something or type something. I could just go through and read it, and then once I got a little more comfortable, then I could ask questions and stuff.

For the father whose 15-year-old son engages in violent behaviors, talking with other parents of children with special needs has been the most helpful type of support. Not having to explain his son’s behaviors to these parents is one aspect he likes best:

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I mean, we just can commiserate. You know, when you don't have to explain a certain behavior that your child has displayed in a conversation . . . that makes it a lot easier to just know that the other person understands what you're talking about. And so I think I tend to gravitate towards people who also have children with special needs . . .

Clearly, these fathers have benefitted from talking with parents who are going through similar struggles. This finding is not surprising, as previous research has shown the effectiveness of Parent to Parent programs, which provide informational and emotional support to parents who have children with disabilities by matching them up with other parents whose children have similar disabilities (Singer et al., 1999). An evaluation of Parent to Parent programs conducted by Singer et al. (1999) found that many parents who participated in the programs reported how comforting it was to talk to other parents who were experiencing similar challenges. Before conducting this study, I had the opportunity to assist with the evaluation of a Parent to Parent program in Minnesota. Speaking with both a program coordinator and a support parent gave me a firsthand look at how beneficial guidance from other parents can be. With my study, I have again seen the benefits of parent to parent support, and can now say with confidence that every father raising a child on the autism spectrum should give it a try.

Some of these fathers also commented on the support they receive from professionals. The father whose five-year-old receives several different types of therapy was grateful for these therapies and his son's "ability to just thrive under the mentorship of the therapists." Another father described how helpful applied behavior analysis (ABA) has been for his six-year-old son, and openly shared that "if it hadn't been for ABA, I don't know what we would have done. [My son] would probably in all rights be institutionalized." This father explained that he and his wife take shifts to care for their son because he can never be left unattended or "something bad will happen." Later, the father described incidents where his son became violent and scratched his eyeballs or gave him a black eye. While I had never imagined that a six-year-old could harm an adult in this way, it was clearly a reality for this father, and I was impressed by his unwavering commitment to his son.

Most of the fathers also described positive interactions with their local Regional Center. One father was especially pleased with the services he and his wife receive:

Like I said, Tri-Counties Regional Center has been just really, really great with us and our coordinator there has been super

helpful, and we can call him up and ask him questions or if we have problems with anything. He's been very, very helpful in getting us set up and coordinating different services . . .

Another father had a less pleasant interaction with Regional Center when they tried to significantly reduce his daughter's hours with a behavioral therapist. In response, he filibustered at a meeting until he got "pretty much what [he] was hoping for." While this father had to fight for Regional Center's support, he seemed to be the only one. The general consensus of the fathers was that support from Regional Center either met or exceeded their expectations.

When I asked fathers whether they attend a formal support group, I discovered that most of them do not. Some of the reasons they gave for not being part of a support group included not having the time and not needing the emotional support. One father of a six-year-old explained, "the kids go to school and during the summertime, most of the focus is on entertaining the kids rather than finding helpful support groups." Furthermore, as mentioned earlier, several of the fathers prefer online support groups. For the father of two young children on the autism spectrum, one online support group has been particularly helpful:

There's a support group, quite honestly, that I do online. If you sign up for it, it's a great tool . . . great, great information. That's probably the best support group I've belonged to, and it's all online.

Informal online support groups were so popular among these fathers that one father said that if he designed his own support group, it would be online.

I also wanted to learn how these fathers feel about the quality of the support they receive. Not surprisingly, their responses varied. One father characterized the support he and his wife receive as "helpful" and "genuinely nice," but in the same breath, noted that it was still "so little." He reported that he and his wife primarily receive support from organizations they are involved with, but that caring for their children comes before their participation in such organizations. Another father wished for more support from "key people" in his life:

I think that we lost touch with some friends because they . . . didn't think that they could relate and/or that they didn't know what to say, and so we lost a handful of friends. And we'll still send Christmas cards and all the other good stuff, but it's different, and I wish we'd had the opportunity to re-engage those people . . . because if they got to really know [our son] the way that we are,

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and what's he's been able to accomplish, it would be less scary.

To my surprise, this father was not angry with his friends, and instead tried to understand their perspective. The father of a 16-year-old felt “a little mixed” about the support he receives. While he is pleased with the support he has received from Regional Center, he has been disappointed by the lack of support from parents of other children. Frustrated by parents of typical children who did not return his phone calls when he tried to arrange a playdate, he stated:

. . . the number of families that are supportive and participate with their child, you can count 'em on one hand. You know, a lot of kids want to play with kids that do their own stuff, where they don't have to spend an afternoon with Johnny the autistic kid, and that's hard and it's frustrating and it's hurtful, and that's a constant struggle.

These examples reveal that although the public's awareness of autism has increased, it has not changed the way both adults and children react to individuals on the autism spectrum. Although it might take more time and effort, including a child with autism in a play date is beneficial for everyone involved.

Moving Forward

A main goal of this study was to better understand the support received by fathers of children with autism, and the role of this support as fathers decide how to best raise their children. By conducting this study, I have gained insight into what it might be like to be a parent of a child on the autism spectrum. I am inspired by how positive these fathers were despite the many challenges they faced. Their “glass half-full” approach and ability to put their children's needs before their own was inspiring.

I think there are several things we can take away from my conversations with these fathers:

1. Although these fathers received support from a variety of sources, many of them still felt they could use more. As professionals, it is our job to inform fathers of valuable resources, whether it be information about a clinic that can assist with a child's difficult behaviors or the name of an online support group.
2. It is important that we continue to promote not only autism awareness, but also autism acceptance and inclusion. While more people are educated about autism than ever before, these fathers' experiences suggest that some people still lack understanding.
3. Given the benefits of connecting with other parents of children with disabilities for these fathers, as well as for many parents in previous studies, educators and other professionals should encourage fathers to seek parent to parent support.
4. Finally, further exploration into fathers' apparent preference for online support versus face-to-face support is warranted. This will give us additional insight into this group's specific needs and help us to create online support groups that are tailored to these needs.

In conclusion, while we cannot control the quality of support fathers receive from their family or friends, we can control the quality of support they receive from us. Taking action in the above areas will bring us that much closer to providing fathers of children on the autism spectrum with the support they need to facilitate their children's long-term success.

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What Does it Mean to be Ready? An Interview Study of Parent to Parent Leaders

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Robin Dodds

One important element in the success of parent to parent programs has not been studied, the characteristics belonging to the individuals who successfully provide the support. The present study was prompted by a request from members of the Board of Directors of Parent to Parent USA asking for guidance from research-based knowledge. The question was stated in terms which seemed to reflect the persistent belief that parents initially experience considerable sorrow about their children's disabilities: "Are parents ready to serve as volunteer help-givers if they still cry a lot?" The question of readiness was important to these parent leaders because a major on-going effort in these grassroots organizations is recruitment and training of peer support providers.

Ten interviewees participated in this study. They were all identified as persons who had experience in recruiting and training volunteer parents in State, regional, or local Parent to Parent programs, and most had been a support parent themselves. The average length of experience in Parent to Parent leadership was 17.3 years with a range of four to 26 years. Nine of the ten participants were biological or adoptive parents of at least one disabled child. One participant was the aunt and primary advocate of three nephews with special needs.

The two most relevant themes emerging from this research are described below:

Theme 1: Signs of (Approaching) Readiness

Initially when posited the question, "How do you know a parent is ready to support another parent?" many participants responded that it was a gut feeling that they had about a parent. Interviewees discussed their own introduction to and subsequent volunteer work for Parent to Parent, and cited examples from their own experiences. Alternately, when further pressed to describe how a ready parent talks or acts Interviewees gave examples of parent's they have recruited and trained as coordinators for the Parent to Parent program in their area. From these two sources subcategories within the larger theme of "readiness" emerged. These included; building relationships, positivity, building capacities, communication skills/listening, having /sharing successes, having a future orientation, and feeling the need to give back.

Building relationships

The first step to achieving a sense of equilibrium when faced with an overwhelming challenge such as raising a child with a disability or chronic health need is often to reach out for help. When a parent in need reaches out to the Parent to Parent network, they are greeted on the telephone (or internet) by another parent of a special needs child who listens to the parent's concerns, offers information and asks if they would like to be connected to a support parent. A support parent is a parent who is matched to the parent seeking help who is trained to provide emotional support. According to a Parent to Parent coordinator in the South, "There's a real connection that happens that never happens anywhere else." The foundation upon all peer-support programs are built is the cultivation of relationships and "creating a sense of belonging." Once a parent feels they have found someone who understands their feelings and experiences as a parent of a child with a disability, a bond is developed and feelings of isolation dissipate.

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Positivity

Many participants expressed that an important attribute for support parents to have is a positive appraisal of their life. When a person emits this positive energy while balancing the complicated situation of having a child with a disability or chronic health condition, the effect can be especially powerful and transformative for the individual and the people with whom they come in contact. One informant discusses her initial experiences as a support parent: “[B]eing a positive in people’s lives when they get so much negative was really strong for me.” This early experience may have shaped this coordinator’s recruitment practices, leading her to look for positivity in potential volunteers. This positive appraisal of their life overall can be observed by Parent to Parent coordinators in the way a parent volunteer talks about their special needs child, and is often revealed in conversation or through the sharing of her story during training: “They can share some of those real gifts and talents, that their child loves this, that their child is great at this.” Many parents who display this positive outlook were also described as religious or spiritual by Parent to Parent leaders: “They really have just a really strong sense of faith, that their faith in mankind, or their faith in God, or, they really believe that inherently things are good.”

Building capacities

The participants in this study described a process by which parents who have received support begin to learn and develop new skills. These enrichment and educational activities were seen as valuable attributes for volunteer parents by Parent to parent coordinators and seen as a sign of readiness of a recruit to support another parent. The term “building capacities” was chosen to encapsulate activities which parents of special needs children went about to learn more about their child’s disability, and acquire skills or techniques to assist them self or their child in daily activities. Attending conferences, doing research on the internet, navigating school and government systems, and being trained in specific methodology were cited by participants as ways in which parents built up a skill set that was seen as being both beneficial in their own household and valuable to others within the disability community.

Communication skills/listening

Parent to Parent supporting parents are generally trained in a face-to-face training that takes place over a two or three day period. During this training volunteers are invited, formally or informally, to share their journey as a parent of a child with a disability or other health impairment. In these narratives of their

life with their child with disabilities, recruits often discuss the pain of diagnosis, day-to-day struggles, and what they are doing to make their family life work. Parent to Parent coordinators pay close attention to how these stories are framed as an indication of a parent’s overall readiness to provide support. As most support is provided over the telephone, communication skills are very important as an attribute for a support parent. When parents can share in a way that is most helpful to another parent, those narratives commonly contain certain qualities, and let a coordinator hear the sharer’s readiness to be a support to others.

A parent who probably is not ready to support another parent can also be identified by the way they share their story. One Parent to Parent coordinator stated that the use of too many “I” statements when sharing can indicate lack of readiness, because it, “doesn’t help them say what they’ve learned from this experience and how might this be helpful to another person.” Additionally, inclusion of too many unnecessary details can indicate that a parent has not reached a point where they are able to reflect on their journey. If a parent can’t get through their sharing of their story because it is too difficult or brings up too much anger or sadness, they often choose not to complete the volunteer training.

Parent to Parent support parents also need to be “champion listeners” which according to one participant, entails “allowing our minds to be quiet . . . understanding that we’re always going to have thoughts going through our brains [but] setting them aside to really listen.” These skills are emphasized in many Parent to Parent trainings through role-play or video examples.

Having/sharing successes.

When the coordinators who recruit and train new parent support providers talk about parents who are ready to help others, they usually told a kind of idealized developmental story describing the positive steps these likely candidates have already taken prior to be recruited and trained. The ten coordinators characterized good candidates for parent volunteer supporters by explaining the kinds of prior experiences these parents often have had before contacting the P2P program with an offer to volunteer.

Parents who were perceived to be good candidates for becoming support parents could report that they had sought out information and training, finding strategies that worked for them, their child and their family. They had made communication boards, adapted existing equipment in novel ways, and gained access to funds through systems navigation. These experiences are important to have had, as they build up the base of knowledge of

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the recruit and increase the amount of informational support they may be able to provide to another parent.

Future orientation

In addition to a positive outlook, according to the coordinators, parents who were ready to support other parents exhibited a future orientation. These parents could appreciate their child for who they are right now, and had developed a long-term vision with and/or for them. A participant defines what she means by the term “acceptance” of the child as a requirement for a parent volunteer, “[A]cceptance means that they have dreams for their child, that they can articulate what those dreams are.” They were able to discuss realistic life goals for their children and family, and had thought about the intermediary steps needed to achieve them. Often these future visions included increments toward independence, carefully measured and individualized for their child’s specific needs.

Feeling the need to give back

Once a parent has experienced multiple successes with their child or in their family and feels a sense of empowerment, participants indicated that there then comes an urge to give back to the disability community. Some seasoned parent’s feel that it is a responsibility to “pay back” the support they were given. One Parent to Parent Coordinator shared her desire to become a support parent with Parent to Parent, saying that she wanted “to be a support to other parents because [she] got some good support when [her] children were born.” Another motivation cited by participants that parent volunteers share is to save others some of the difficulties they have experienced along their journey.

Parents can also feel the need to give back to other parents to impart a sense of hope. They can share how they have progressed through difficult times such as health crises and self-injurious behaviors to find a sense of humor and strength in their role as a parent of a special needs child. When a parent begins to talk about wanting to give back, it may mark a realization on their part that they have acquired skills, contacts and understandings that may benefit others. This transformation from being the parent in need of support to the parent ready to provide support requires the parent to find meaning in their journey, and imbues them with a newfound confidence and resilience.

Theme 2: Red Flags

Interestingly, many participants independently offered paradoxical examples describing behaviors and personality traits of an

individual who would not be ready to take on the role of support parent in response to the main question of, “How do you know a volunteer is ready?” Participants may have found it easier to pinpoint such “red flags” when asked what a parent who was “ready” would say or do. The sub-categories included in this theme are: negativity, being stuck, being judgmental, looking for cures, being in crisis, overwhelmed, having uncontrolled emotions and needing or seeking help.

Negativity

Coordinators were responsible for identifying who could be an effective supporting parent and who might not yet be ready. They reported certain warning signs in listening and observing a parent who attended a training session and expressed an interest in becoming a help-giver. In the course of these meetings the coordinators had the opportunity to observe how candidates talked about their experiences as a parent of a child with special needs.

Communicating negativity was a common “red flag” related by participants. Some parents were described as expressing a negative appraisal of their current situation. Examples of parent negativity could also involve the way in which a parent spoke about stakeholders in their child’s health or education. Although discussions regarding dissatisfaction with services for their children and specific service providers are common in a Parent to Parent match situation, one coordinator described consistent negative attributions about professionals as a sign of unreadiness: “Do they complain about the doctors on the interview with us? Do they complain about teachers?” This inability to control the urge to express discontent with service providers could be problematic if shared with a help-seeking parent.

Being “stuck”

Parents who express negativity in sharing their story are often seen as being stuck in this state, unable to move beyond their current unhappiness. This inability to move forward is often associated with the “pain of diagnosis.” Participants mentioned that this initial pain is one that persists through the lifetime of a parent, but is counterbalanced by feelings of pride and positive adaptation which occurs as a parent learns more about their child and adjusts their expectation for their child and family accordingly. However, a parent who is stuck will “rehash the same stuff” every time she speaks with another parent in a way that indicates that she is “angry and not in a good place.” Parents who are stuck may not even be ready for a match with a support parent of their own, as being “stuck there it prevents you from

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being somebody who can have a relationship.” These parents may be referred to mental health services for counseling in order to “find some place to be okay with what’s happening” before establishing contact with a support parent volunteer from Parent to Parent.

Being judgmental

Being judgmental can be readily identified through careful listening during conversation. Parent to Parent coordinators tune in to the way a parent volunteer speaks while telling their story at a training, or in role-play activities as a way to screen for parents who may need additional training or support before they are able to be of support to someone else. Parents who tell others what they have to do rather than phrasing their sharing as what worked best for their family or child may be judgmental and make others feel they have limited choice and power in their lives. This attitude is harmful to help-seeking families, who are looking to discover the array of options available for them along their journey with their child. Coordinators listen carefully for “loaded, value-laden words” and negative talk about specific stakeholders.

Looking for cures

Some parents are unable to come to terms with their child’s disability and will put a great deal of energy into finding a cure. This searching behavior may inhibit the process of a family’s adaptation to the child’s disability, and decrease the time the family spends together as a unit. Some diagnoses have received more attention in the realm of cures, and parents may put a great deal of money and energy into special diets, therapies or holistic or experimental medical procedures in hopes of having a “normal” child. Participants often cited Autism as being a particularly difficult diagnosis to accept as everywhere you look on the internet, there is someone saying: “Do this and your child will be cured of Autism.”

Being in crisis/ Feeling overwhelmed

There are many circumstances in which families of children with disabilities or special health needs may be in a state of crisis. These include but are not limited to, hospitalizations, new diagnoses, transitions from school to school, program to program or school to work, an increased burden of care due to assisting an ailing or aging parent in addition to a disabled child, or experiencing economic insecurity.

Research indicates that although parents of children with disabilities in general are no less happy and healthy, a particular

sub group who under socio economic strain are much more likely to experience negative impacts. This strain of not having the basic necessities (food, shelter, health care) may limit their ability to cope, and they may not be able to help another parent until these basic needs are met. Parents who are in crisis may need to be connected to additional supports in the form of someone to listen as well as outside agencies for access to food, funds and counseling.

Similarly to being in crisis, being overwhelmed by one’s circumstances leaves little cognitive and emotional energy to give others. Many parents of children with disabilities who are dealing with a recent diagnosis, difficult behaviors in their children, acute health needs or have very young children may not have yet established familiar routines, or found strategies that work for them.

Uncontrolled emotion

This subcategory is of particular interest, as the question of readiness was originally posed as a series of hypotheticals; “What if they are still crying a lot?” “What if they are very angry?” Participants frequently shared that a parent who has little control over their emotional state may not be ready to be a trained support volunteer, and that frequent tears when sharing could be a red flag. Listening to a parent interact with another parent and discuss their child provides an opportunity not only to hear the words they say, but to see their emotional state as well.

Along with sadness, anger was also observed in parents who were deemed unready to provide support to a peer, and was included in one participant’s mental checklist for red flags. A reason why this unfettered anger is unhelpful and potentially harmful to other parents may be that the energy the parent expends may become misdirected. Similarly, uncontrolled crying may transmit those negative emotions to others the parent volunteer is assigned to support.

Future Directions

The data gathered in the above study will be used in the development of a measure to assess the readiness of volunteers for providing support to other parents of children with special needs. This will be a useful tool in the recruitment and selection of high quality volunteers and will be of particular value to Parent to Parent groups in certain geographic areas who rely on online training recruitment and training.

Association News

Book Your Room Today for the 2014 TASH Conference in Washington, DC

Online hotel reservations are now being accepted. TASH has a dedicated booking website for our conference event so attendees will be able to make, modify and cancel their hotel reservations online, as well as take advantage of any room upgrades, amenities or other services offered by the hotel. This year's hotel is the Renaissance Washington, DC Downtown Hotel, located at 999 9th St. NW in our Nation's Capital. TASH attendees will enjoy a special rate of \$169 per night plus tax (the rate is usually around \$400).

[Make your reservation today by visiting:
https://resweb.passkey.com/go/TASH14](https://resweb.passkey.com/go/TASH14)

Master the Use of Discovery To Improve Transition Outcomes at the TASH Regional Conference in Atlanta

Promoting Self-Determined Futures

Wednesday, September 10, 2014
Loudermilk Center
Atlanta, Georgia

Mastering the use of discovery to improve transition employment outcomes and to promote career development will be one of the objectives you will accomplish by attending the TASH Regional Conference "Promoting Self-Determined Futures" on September 10th at the Loudermilk Center in Atlanta, Georgia.

To learn more about the conference learning objectives, visit <http://tash.org/blog/2014/07/30/master-use-discovery-improve-transition-outcomes-tash-regional-conference-atlanta/>.

[Visit www.tash.org/psdf](http://www.tash.org/psdf) to register!

Call for Nominations | TASH Connections Editorial Board

Deadline: August 1, 2014 or until Board is named

TASH Connections is now seeking nominations (including self-nominations) for members of the Editorial Board. Members of the TASH Connections Editorial Board are appointed to a term of three years, with the possibility of renewal. TASH Connections is published 4 times a year by TASH.

To learn more about the responsibilities of the Editorial Board, go to <http://tash.org/call-for-nominations-tash-connections-editorial-board/>

Chapter News

Welcome the New Illinois TASH Chapter

Illinois TASH is please to announce that they are an official TASH Chapter once again. By a survey of their members as part of convening the chapter, IL-TASH has determined that their advocacy issue for the year is Inclusive Community Transition. “Inclusive Community Transition” relates to times of transition we can face throughout our lives, including going into the school system, out of high school into adulthood, and aging into our later years of life. Regardless of the focused mission, IL-TASH will strive to advocate for all individuals, young and old, and their families. The Interim Board is presently planning their year’s activities.

Congratulations and welcome to Co-Presidents Kira Meskin and Lisa Cushing, Vice President Paula Wills, Secretary Tonya White, Treasurer Yun-Ching Chung and Steering Committee Co-chairs Lisa DiFranco and Nancy Wrobel.

You can join the IL-TASH Facebook page at <https://www.facebook.com/TASHilchap2014>.

Summer Retreat & Welcome New Board Members

KY-TASH has scheduled its summer retreat for August 23, 2014 in Lexington. The board will meet to review what has been accomplished in 2014 and begin to plan goals and activities for 2015.

For more information about KY-TASH, visit <http://tash.org/chapters/kentucky-tash/>

KY-TASH would also like to welcome new board members Darrell Mattingly and Stella Beard to their three year terms.

2014 Think College Wisconsin Conference: Raising Expectations

Friday, October 17, 2014
Cardinal Stritch University, Milwaukee, WI

This conference is for everyone interested in post-secondary education for students with intellectual disabilities. The conference will engage: higher education and K-12 faculty, staff and administrators, individuals with intellectual disabilities and their families or caregivers. Participants will hear from one of the founders of the national Think College movement and network with other colleges and school districts in various stages of planning and implementation of college initiatives. F

or more information about this event, please contact Beth Moss (beth.moss@wisconsin.gov) or visit <https://www.regonline.com/Register/Checkin.aspx?EventID=1557665>.

2014 TASH Conference Sponsors

TASH is hosting three conferences in 2014 — a national conference in Washington, DC and two regional conferences in St. Louis, Missouri and Atlanta, Georgia. We would like to thank all of the sponsors who are supporting our conferences.

TASH National Conference - Washington, DC

DC Department on Disability Services
Quality Trust for Individuals with Disabilities
Maryland Developmental Disabilities Council
ArborSoft
National Youth Transitions Center
Institute on Educational Leadership
Public Consulting Group
MetLife Center for Special Needs Planning

TASH Regional Conference - St. Louis, Missouri

FACT
Down Syndrome Association of Greater St. Louis
Missouri Developmental Disabilities Council
Special School District
St. Louis Arc
Midwest Easter Seals

TASH Regional Conference - Atlanta, Georgia

Technical Assistance and Continuing Education (TACE) Center Region IV (Southeast TACE)
Georgia Council on Developmental Disabilities
Georgia Advocacy Office
Georgia Department of Education
Georgia State University Center for Leadership in Disability
Amerigroup

Thank You to Our Donors!

TASH relies on the generosity of our members to accomplish our work. Because of your support, we are able to continue to work for equity, opportunity, and inclusion for people with significant disabilities. We are grateful for the support we have received from the following people and organizations:

Adelaide Comegys

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If you would like to consider making a gift to TASH, contact Dawn Brown at 202-509-9596 or at dbrown@tash.org.

Thank you, donors!



TASH

Membership Application

Effective June 15, 2012

New Membership Membership Renewal Referred by _____

Member Type: Individual Organization (*org. member name*): _____

First Name: _____ Last Name: _____

Address: _____

City/State/ZIP: _____ Country: _____

Phone 1: _____ Primary E-mail 1: _____ Primary

Phone 2: _____ Primary E-mail 2: _____ Primary

(*Organization Members Only*) Are you the primary contact? Yes No

Primary Contact Name: _____

Phone: _____ E-mail: _____

Membership Level

TASH offers membership at a variety of levels. Please review the details below and choose the membership level that is appropriate for you. Individual and organizational memberships are available. Membership is valid for a 12 month term. A complete summary of member benefits can be found at www.tash.org/membership.

	Basic \$30	Standard \$75	Premium \$150	Student* \$45	Small Org \$250	Large Org \$350
Research and Practice for Persons with Severe Disabilities, the official TASH research journal (print copy)			X		1 COPY	1 COPY
Research and Practice for Persons with Severe Disabilities, (online access to current and archived issues)		X	X	X	X	X
Connections, the quarterly magazine written by and for TASH members (includes current and archived issues)	X	X	X	X	X	X
TASH in Action bi-weekly e-newsletter	X	X	X	X	X	X
Training discounts for webinars, publications and other offerings	X	X	X	X	3 STAFF	5 STAFF
Reduced registration rates for TASH Conference and events	X	X	X	X	3 STAFF	5 STAFF
Affiliation with a TASH Chapter	X	X	X	X	X	X
Advocacy Alerts & Updates	X	X	X	X	X	X
----->	<input type="checkbox"/> Select					

*Student members are required to identify university: _____

Demographic Information *(optional)*

Which of the following best describes you? *(select all that apply)*

- Person with Disability Family Member Student Professor/Researcher Early Intervention
 Adult Service Provider/Related Services Special/General Educator Govt/Legal/Public Policy
 Other _____

What is your race or ethnicity? *(select all that apply)*

- American Indian or Alaska Native Asian Native Hawaiian or Pacific Islander Black or African American
 White/Caucasian Hispanic/Latino Other _____

Are you affiliated with a university? If so, please specify: _____

Please indicate your areas of interest *(select all that apply)*

- Community Living Early Childhood Education Self-Advocacy Public Policy International Issues
 Employment/Transition Positive Behavioral Interventions and Supports Cultural Competency/Diversity
 Human Rights/Social Justice

Payment Information

Credit Card *(select card type)*

- American Express Visa
 MasterCard Discover

Check *(make payable to TASH)*

Purchase Order

P.O. #: _____

(send copy with membership form)

Card #: _____ Expiration: _____

Name on Card: _____ CVV: _____

Authorized Signature: _____

Would you like to make a tax-deductible donation to TASH?

- \$10 \$25 \$50 \$100 \$ _____

Total Payment *(add membership total and donation, if applicable)* \$: _____

Please submit this membership form via mail, fax or e-mail. With questions, contact (202) 540-9020.

TASH
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Washington, DC 20006

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E-mail info@tash.org

www.tash.org to learn more about TASH

www.tash.org/member to log in to the membership portal

www.tash.org/membership for an overview of member benefits





TASH Connections

Equity, Opportunity and Inclusion for People with Disabilities since 1975

TASH is an international leader in disability advocacy. Founded in 1975, TASH advocates for human rights and inclusion for people with significant disabilities and support needs – those most vulnerable to segregation, abuse, neglect and institutionalization. TASH works to advance inclusive communities through advocacy, research, professional development, policy, and information and resources for parents, families and self-advocates. The inclusive practices TASH validates through research have been shown to improve outcomes for all people.

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities. Items in this newsletter do not necessarily reflect attitudes held by individual members of the Association as a whole. TASH reserves the right to exercise editorial judgment in selection of materials. All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as “the mentally retarded,” “autistic children,” and “disabled individuals” refer to characteristics of individuals, not to individuals themselves. Terms such as “people with mental retardation,” “children with autism,” and “individuals who have disabilities” should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement. For a copy of TASH's publishing and advertising policy, please visit www.tash.org.

TASH Mission & Vision

As a leader in disability advocacy for more than 35 years, the mission of TASH is to promote the full inclusion and participation of children and adults with significant disabilities in every aspect of their community, and to eliminate the social injustices that diminish human rights. These things are accomplished through collaboration among self-advocates, families, professionals, policy-makers, advocates and many others who seek to promote equity, opportunity and inclusion. Together, this mission is realized through:

- ♦ Advocacy for equity, opportunities, social justice and human rights
- ♦ Education of the public, government officials, community leaders and service providers
- ♦ Research that translates excellence to practice

- ♦ Individualized, quality supports in place of congregate and segregated settings and services
- ♦ Legislation, litigation and public policy consistent with the mission and vision of TASH

The focus of TASH is supporting those people with significant disabilities and support needs who are most at risk for being excluded from society; perceived by traditional service systems as most challenging; most likely to have their rights abridged; most likely to be at risk for living, working, playing and learning in segregated environments; least likely to have the tools and opportunities necessary to advocate on their behalf; and are most likely to need ongoing, individualized supports to participate in inclusive communities and enjoy a quality of life similar to that available to all people.

TASH has a vision of a world in which people with disabilities are included and fully participating members of their communities, with no obstacles preventing equity, diversity and quality of life. TASH envisions communities in which no one is segregated and everyone belongs. This vision will be realized when:

- ♦ All individuals have a home, recreation, learning and employment opportunities
- ♦ All children and youth are fully included in their neighborhood schools
- ♦ There are no institutions
- ♦ Higher education is accessible for all
- ♦ Policy makers and administrators understand the struggles of people with disabilities and plan – through laws, policies and regulations – for their active participation in all aspects of life
- ♦ All individuals have a way to communicate and their communities are flexible in communicating in alternate ways that support full participation
- ♦ Injustices and inequities in private and public sectors are eradicated
- ♦ Practices for teaching, supporting and providing services to people with disabilities are based on current, evidence-based strategies that promote high quality and full participation in all aspects of life
- ♦ All individuals with disabilities enjoy individualized supports and a quality of life similar to that available to all people
- ♦ All individuals with disabilities have the tools and opportunities to advocate on their behalf