



Spirituality: From Rights to Relationships



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So Many Answers Left Unquestioned ...

The 2012 TASH Conference is coming to Long Beach, Calif., November 28-December 1! Attendees from around the world will come to learn about emerging practices and the latest research, network with others in the field of significant disabilities, and stake their claim in a movement to include people with disabilities in all aspects of life.

This year we are reminded there are *So Many Answers Left Unquestioned*, a theme inspired by a poem from Megan Jones, a self-advocate in North Carolina. It challenges us to think deliberately about the way systems work, programs are funded and people are supported. We will revisit long-held beliefs about "disability," and pose questions to many of the "answers" that have limited the ability of people to access inclusive education, integrated employment and lives in the community.

Expert Panel on Inclusion November 28, 2012

What have we accomplished in advancing inclusion? Why haven't we done more? What can we do to ensure progress is made? We can learn a lot about the future of inclusion by understanding the challenges of yesterday and today. Join us during the 2012 TASH Conference as an expert panel on inclusion tackles these important questions.

Featuring

Madeleine Will (Moderator)

Director, National Down Syndrome Society

Norman Kunc

Disability Rights Activist, Author and Speaker

Charlie Lakin

Director, National Institute on Disability and Rehabilitation Research

Barbara Ransom

Attorney

Wayne Sailor

Professor, University of Kansas; Founding TASH Member

Keynote Amy Brenneman December 1, 2012

Amy Brenneman, a parent, actress, producer, and advocate, received her degree in Comparative Religion from Harvard University and was a founding member of the award-winning Cornerstone Theater Company. Most recently, she has played the role of Violet in the ABC series, *Private Practice*. As the parent of two children who attend a fully inclusive school, Brenneman has worked to promote the importance of transitioning from segregated models of education toward innovative and fully inclusive schools where children with and without disabilities learn together.

2012 TASH Conference
Long Beach, California
November 28 - December 1, 2012
www.tash.org/2012tash



So Many Answers Left Unquestioned

LONG BEACH / CA / NOV 28 - DEC 1, 2012

- More than 200 concurrent and poster sessions
- Short-course workshops with leading experts in the field, included as part of registration
- Full-day skills-building post-conference workshops*
- Town halls, forums, film screenings and special events
- Exhibit hall

* Additional registration required for post-conference workshops

Equity, Opportunity and Inclusion for People with Significant Disabilities Since 1975
Learn more at www.tash.org or www.tash.org/2012tash

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Letter from the President and Executive Director

The editor and guest editors of this issue of *Connections* are to be complimented on producing a weighty issue on an important and sensitive topic.

More than 90% of Americans believe in God and about 40% attend religious services at least once a week (Pew Forum on Religion and Public Life, 2010). People with significant disabilities are represented in these statistics—or perhaps would like to be—as much as anyone else. Members of TASH, and all who support self-determination for people with significant disabilities, should take it upon themselves to ensure that everyone has the chance to express their spirituality and the opportunity to do so in the way they wish, whether as a private affair or as part of a congregational event.

It seems fair to expect institutions of faith to develop social infrastructures that are supportive of the full distribution of humankind. What good is it for a spiritual organization to offer guidance, solace, or support only to a narrow band of those that seek these human needs? As we see in the articles in this issue, this shouldn't be too difficult. Involving people with disabilities or special needs in faith communities offers these communities the opportunity to express values to all who seek them. Although it might seem initially challenging, the most important act of these congregations is simply to say, "welcome!" Afterward, some effort may be required for finding the necessary supports and accommodations, but as we see in this issue, once the invitation has been offered, ways to include will be discovered.

But the communities of faith can't be expected to act alone. Service providers, family members, friends, and co-workers of with people with significant disabilities must investigate their interests and support decisions about spirituality and religious observation. In this realm of life, there is an excellent opportunity to promote and honor self-determination. This does not mean that public agencies must promote religious tenets, but it means that, within the framework of service provision, choices for individuality are respected. To this end, advocates and



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President, TASH Board
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Barbara Trader,
Executive Director of
TASH

professionals alike can play a critical role in learning about desired religious directions and assuring they are honored.

As an organization that supports full-inclusion, TASH realizes that this only occurs when the term is broadly interpreted. The topic in this issue of *Connections* shows an important avenue for supporters of TASH values to pursue, and offers useful guidance for doing so.



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



Barbara Trader
TASH Executive Director

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Pew Forum on Religion and Public Life (2010). U.S. Religious Landscape Survey. Retrieved September 4, 2012 at: <http://religions.pewforum.org/reports#>

A Letter from Our Editor: Charles Dukes

What is the meaning of life?

Why are we here, in this place, at this time? Are these not the quintessential philosophical questions? There is a good chance that all of us have thought about our personal existence and the significance of our lives. For some, such questions are easily answered, while others spend an entire lifetime looking for some semblance of satisfaction. Religion and more broadly spirituality can be difficult to define, as there are not many other aspects of the human experience that can have the power to unite and perhaps even more so, divide.

TASH has always been at the forefront of the movement to include people with disabilities in every aspect of life, including spirituality. While spirituality means different things to different people, it is likely that many contemplate the meaning of life and the search for value and meaning of relating to others and a Deity. It is not easy to define spirituality and shortsighted to define one pathway to a spiritual life. In other words, there is every reason to promote a spiritual life for everyone, including people with disabilities, with no limitations about what that means. Inclusion of people with disabilities seems to follow a similar path, no matter what the issue. While people may express a favorable attitude toward an inclusive philosophy, it is the practice of inclusion that is of the most importance. Spirituality

is no different, a number of religious organizations have “open door” policies, but ensuring that people with disabilities can participate is another matter. The point here is not to criticize policy, but to bring attention to the necessity of policy accompanied by authentic action to include.

In this issue, we present a strong collection of articles that truly offer a deep examination of spirituality, including stories from self-advocates. I commend our Guest Editors, Bill Gaventa and Erik Carter and each of the authors for treating spirituality in a manner that I think readers will find quite illuminating. Please reflect on your own experiences and any personal quests for deeper meaning and I think you will find that the authors in this issue have skillfully addressed questions about spirituality and these experiences can and should be shared with others.

Charles Dukes

Charles Dukes
Editor, TASH Connections



Charles Dukes, Editor,
TASH Connections

A Letter from Our Guest Editors: Bill Gaventa and Erik Carter

TASH is firmly committed to helping people flourish.

Indeed, this is the mission of this organization distilled to its very essence—supporting people with disabilities and their families to thrive in all aspects of their life. And simultaneously helping friends, neighbors, co-workers, and fellow citizens realize that they too will thrive all the more when their communities include people with significant disabilities. While flourishing can take as many different forms as there are people in the room, it is also true that spirituality and faith are essential dimensions of the lives of a substantial proportion of people here in the United States and around the world. For many people—including people with significant disabilities—spirituality and connections to a faith community contribute greatly to their personal well-being, belonging, and sense of purpose.

Paying attention to the power of spirituality and inclusive spiritual supports in the lives of individuals with significant disabilities is about much more than honoring the sacred American value of the right to religious freedom and to worship as one chooses. In most service systems, the right to religious freedom and worship is already codified in policy statements of “consumer rights—a right more often known by the absence of practice and the rare examples than it is by common example. There is a parallel in faith communities as well, where invitations often state “Everyone is welcome” and foundational belief systems affirm the importance of “all of God’s people.” Yet, far too many individuals with significant disabilities and their families have had experiences that belie the very bedrock of their own faith tradition and wonder if statements about “all of God’s people” really means “all.”

A Letter from Our Guest Editors continued from [page 5](#)

Service agencies may say, “We would like to do more to support spirituality, but we don’t know how.” Congregations see individuals and families served and supported by systems professing all kinds of “specialized services and programs” and they end up believing “We would like to welcome everyone, but we don’t know how.” And both are likely to say together, “We never got any training for this.” In both arenas, fear of the unknown then takes precedence. The sad irony is that fear shifts the focus away from the desires and needs individual and their family to the anxieties of two systems of care and concern, both of whom have the capacity to teach what the other needs to know.

It does not have to be this way. As you will read throughout this issue of TASH Connections, there are more and more individuals, networks, and organizations exploring ways in which both systems of supports might work in tandem (along with people with significant disabilities and their families) to promote full inclusion,

belonging, and a place of contribution for everyone interested. Indeed, TASH is among the few national advocacy organizations with a resolution on Spirituality (see Box). With its unique membership—comprised of parents, people with disabilities, professionals, advocates, and others—TASH is in a unique position to ensure this aspect of the lives of people with significant disabilities is solidly supported.

We are pleased to present this issue of TASH Connections, which includes a series of compelling articles addressing the place and power of spirituality and faith in the lives of people with disabilities, their families, their congregations, and the systems that support them. We hope these stories and ideas will spark new conversations about what it means to help people with significant disabilities truly flourish in all aspects of their lives.

TASH Resolution on Spirituality

Statement of Purpose

The rights, needs and wants of many individuals with disabilities, including the basic need for freedom of spiritual expression, have been denied consistently. Many people with disabilities experience limited opportunities for spiritual expression. Especially acute is the denial of opportunities and supports related to spiritual exploration and expression for those who live in institutional and other restrictive settings.

Rationale

Faith and spirituality may offer positive supports to people with disabilities, as they do for others in our communities. Because we firmly maintain that an individual’s spiritual beliefs could be representative of an entire array of beliefs, definitions, expressions, and faith communities, TASH supports a range of expressions of spirituality that communicate value and respect for all individuals. The

Spirituality Committee of TASH exists to support various spiritual issues of people with disabilities but does not advance any specific faith or religion. TASH supports opportunities for spiritual expression for individuals with disabilities, both privately and in community.

THEREFORE BE IT RESOLVED THAT TASH, an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field, believes that all people with disabilities have the right to spiritual expression including the reflection upon and sharing of spiritual purposes for their lives. TASH further supports the right of individuals with disabilities to participate in spiritual expression or organized religion as they so choose and promotes the provision of any and all supports needed by people with disabilities to so participate.

Adopted 2003

Articles from Our Contributors

You Have Probably Never Met Anyone Like Me

By Jacob Artson

You have probably never met anyone like me who can't speak but can communicate by typing on the computer.

I am an example of how someone can be impaired in one area but have great strengths in another. That is true of most people, but it is true in the extreme about people with autism.

When I was diagnosed at age 3, I couldn't speak or move my body properly, and 15 years later I am still extremely impaired in both areas. But if success is measured by being a mensch and helping make this world a better place, then I would classify myself as a success. You can be the judge.

When I turned 6, my family moved to LA in search of opportunities for me. Our journey took us to many purported experts, but they all saw me as merely my extremely impaired verbal and motor abilities and assumed my cognitive abilities must be similarly nonexistent. After several months, my parents and I came to the last place on our list—the “autism doctor.” I am not really sure what I was expecting, but Dr. Ricki looked

nothing like I expected. She wore a fashionable sweater with a colorful necklace. But

mostly I noticed her smile. I had been to so many doctors at that point I couldn't even remember all their names or specialties. But not one had ever smiled at me like Dr. Ricki. She kept smiling, watching and waiting for me. For the first time in my life, I was able to smile back. I stayed for an hour and we played with puppets, but mostly I was just watching Dr. Ricki in complete fascination. I had expected that she would have some medicine or treatment to prescribe and that would be the end of the appointment. But she said nothing about any pills or therapies. She just smiled at me for an hour as though I was a person worthy of respect and dignity. I had always thought of myself as a defective human being. It had never occurred to me that a doctor would see me as a person with the potential to be a productive member of society.

At that transforming moment, Dr. Ricki taught me that despite my disability, I was as worthy of love and respect as any other



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child. That smile gave me hope, and hope gave me the motivation to begin the battle to conquer autism before it destroyed me. So I began my journey of millions of small steps. Along the way I found supporters as well as detractors, and the steps sometimes did not appear to be going forward, but I persevered because I had hope and people who believed I could fly. Today those steps brought me to [write] for you.

So that is my story. I think it is also the story of many autistic kids I have met as well as many other kids from disadvantaged or minority backgrounds I have known at school. I think most kids who fail do so for the same reason I did—I didn't believe I was capable or worthy of success.

What makes a child believe in himself or herself? These are the factors that have made a difference in my life:

First and foremost, my family has never wavered in their belief that I am a child of God with an equal claim to dignity and respect as any typically developing child. I know that it has taken a heavy toll on them, but it has been a lifesaver for me. My twin sister is my best friend, fashion consultant, role model, and cheerleader. My mom has been my tireless advocate and my rock. My Abba, whom I adore more than anyone on earth, has given me a model to strive to emulate.

Second, I have been blessed to have many wonderful mentors throughout my life, including teachers, Dr. Ricki, my horseback riding instructor, the coaches at my basketball programs and, most recently, my new adult case manager. All these people believed I could achieve greatness despite my body's limitations and the naysayers around them. Kids with special needs don't need to be reinforced like dogs with good job and good listening and similar phrases as if we are in puppy obedience training. What we need instead is stimulation, patience, and someone to believe in us and notice our little triumphs.

Third, I have found great support in God and Torah. I think that people vastly underestimate the importance of spirituality for people with special needs. Of course, I have some friends who are confirmed atheists, but many more for whom Judaism is a lifeline. My body and emotions are very disorganized, but the one time that my mind, body and emotions feel totally connected and in harmony is when I pray. I have also learned many important lessons from listening to my rabbis' sermons because we all need to live with meaning and know that we are not alone in our struggles.

Finally, Judaism has taught me the importance of gratitude. For much of my life, my existence was controlled by autism. Autism was at the root of every experience I had or didn't have. I lived with constant anger at my disability and fear that it would isolate me forever. Then one day several years ago, my wonderful physician and mentor, Dr. Ricki Robinson, asked me what is the opposite of anger. I realized that it is not the absence of anger, but rather acceptance, laughter and joy. I also realized that fear and anger just produces more fear and anger, while acceptance brings connection to God and humanity. For many years I had been praying for God to cure my autism and wondering why God didn't answer my prayer. I realized at that point that I had been praying for the wrong reason. I started to pray for the strength to accept autism and live with joy, laughter and connection. My prayers were answered more richly than I ever imagined! Sometimes I still hate autism, but now I love life more than I hate autism.

But there is one part that is still incomplete before I can truly believe in myself and that is a sense of belonging. Everyone needs a sense of belonging and many of you probably are involved in your local faith community for precisely that reason. In Los Angeles, there are now several wonderful programs for Jewish kids with special needs, and they deserve your support. My peers and I have been fortunate to have had inclusive opportunities in part due to the fact that our typically developing peers had to fulfill their community service requirements. But now my peers are adults too, so there are no more community service requirements and no one to reach out to all of us formerly cute kids who are now trying to make our way in the world as adults. I love my autistic friends, but I do not want to spend the rest of my life in a special needs cocoon.

So here are some “mensch” ideas I would like to propose for your consideration:

1. Inclusion isn't just about me, it is about everyone. I have seen the incredible stress my family has endured because of me, and being excluded from our Jewish community, or having to constantly fight to be accepted as part of it, has greatly magnified our stress. After ten years, we finally left our synagogue and joined a new one where people smile at me even if I am sometimes too loud or excited and no one stares at me like I am a piece of trash. The kids engage with me even when they are not getting community service credit for doing so. I often wonder how many non-disabled families have the same experience of feeling ignored in their synagogue. The truth is that a shul that welcomes me is

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- a synagogue where everyone can find a place and people will want to join and be engaged and involved. This is not something a rabbi can do alone because one of the rabbis at our prior synagogue was and continues to be very supportive of me personally. A synagogue is a community and we all have to reach out to support each other.
2. The best peers and aides I have had didn't have any special background. It doesn't actually take any training to be a leader who models inclusion. It just takes an attitude that all people are made in God's image and it is our job to find the part of God hidden in each person.
 3. My favorite Jewish holiday is Passover because it is the story of our people's journey from degradation to liberation. That is the story of my life and the lives of many of my autistic friends. Our lives are not determined by where we start. God lures us to find our gifts and to choose liberation. My journey has taken me through the desert and toward the Promised Land. I look forward to our journey together toward the day when we can all stand together at Mt. Sinai as one people, the day when everyone is included and together we bring God's glory to all of humanity.

More than a Handshake and a Hello

By Myron Otto

My name is Myron Otto. I come from a Mennonite family. I was born January 11, 1969, in Harrisonburg, Virginia to Emory and Idella Otto. Mom was out of college but Dad was still working on his degree when I was born.

Before I was born, my parents knew I wasn't 100% physically healthy. I'm 41 yrs old, almost 42 and still alive and kicking. I've stumped doctors who predicted I wouldn't make it past age 10. I've obviously done a whole lot better physically than doctors expected. I have had foot surgeries, eye surgeries, tubes placed in my ears, heart surgery, and amputation below the knee. Somewhere between 15 and 20 surgeries in total. I wasn't expected to walk or talk but anyone who knows me at all knows the non-talking part didn't happen. At one point, I even had my jaw wired shut and that still didn't stop me.

Through the programs and work of the Friendship Community, I live independently in my own apartment at the Old Mill Apartments in Ephrata. I workout twice a week at the Universal Health Club. I have a part time job at the east Earl Goodwill Store. I attend three disability support groups, Game Night at Neffsville Mennonite Church, participate in Special Olympics

Bowling, Walk and Roll which supports Joni and Friends ministry, and I am part of the Quality Improvement Committee for the Friendship Community. Finally, I sing with the GAP Male Chorus: 12 concerts at area churches and 10 rehearsals a year.

I attend New Covenant Mennonite Fellowship, a congregation of a little over 100 people, located on Farmersville road in New Holland.

The Church has not only made me feel welcome, but has demonstrated their acceptance of me by allowing me to participate in several different tasks.

For example, every fifth Sunday, I arrive 20 minutes early before Sunday school and welcome people as they enter the Church and give them their bulletin. Then, after Sunday school, I hand out the kids' bulletins as they are coming from class. I keep a list on my calendar of men's and boys' birthdays. Each Sunday I create a card for them on my computer, and that Sunday I hand them their birthday card. One Sunday every quarter, I help set up and tear down chairs in the Sanctuary and put out the songbooks. Sometimes I do the overheads during the Worship Time. Because I don't drive, it is difficult to attend small group, so I meet with the small-group leader on Sunday morning. I also participate during the Family Altar Time by giving personal announcements,

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or prayer requests and praises. Church members help me get back and forth to church, and sometimes to my parents' house.

It is very important to not just welcome people who have disabilities with a handshake and a hello, but to find ways that

they can actively participate in the work of the church. There is no better way to make someone feel welcome than to include them and involve them by participating in the regular weekly church activities.

Bill

By Milton Tyree

We didn't learn his last name – 'til he died. His first name was Bill, the only one we were allowed by the state to know. Only 54, the brain tumor hastened Bill's earthly days.

Bill had lived at a nearby institution for people with intellectual disabilities. About once a month he worshiped with us—always accompanied by the institution's chaplain. Our weekly congregational newsletter announced Bill's passing and included this revealing sentence: "We will remember Bill for his joyful participation in worship."

While Bill was an unknown person to many in our congregation, he was not an unnoticed person. You might say that Bill had some unconventional, or at least un-Presbyterian ways of worshiping. He swayed to the music. He swayed to the sermons. Following a particularly rousing anthem, Bill may act on the impulse that many were feeling, and applaud—perhaps punctuating his solo ovation to the glory of God with the exclamation, "They're good!" If a rhetorical question from the pulpit queried one to think in the affirmative or negative, or if "Jesus" could be a fitting response, then Bill would voice his answer with conviction.

So what is the church to do for a person like Bill? Or, what does a person like Bill do for the church? Some of us wished that Bill had learned to be more "11:00-Traditional-Service-Presbyterian-like." Such learning by Bill might have been fine, as long as it wouldn't interfere with learning from Bill. No pretense. Bill offered essential instruction in sincerity and transparency. His uninhibited, exuberant worship of the Lord provided a model of Spirit-filled living.

The bumper sticker implores us to "Celebrate Diversity." Bill's presence and participation invited all to Celebrate Commonality—our commonality as brothers and sisters in Christ—learning from one another, striving to know Jesus. No last names required.

Author's Note

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About the Author

Milton Tyree is consultant for congregational inclusion for people with developmental and intellectual disabilities through Presbyterians for Disability Concerns.

Jay at Plymouth Church

By Red Turnbull

Included by permission of Rud Turnbull, from his new book, *The Exceptional Life of Jay Turnbull: Disability and Dignity in America 1967-2009*. Amherst: White Poppy Press. 2011.

Jay was baptized in the Roman Catholic Church, for that was the church of my ex-wife and her family. But he has never attended, for my ex-wife and I, being of different sects, chose not to attend any church.

With Ann, however, there is a different norm. I am a high-church Episcopalian and Ann is a Methodist. In Chapel Hill, we belonged to the Chapel of the Cross, an Episcopal church. When we come to Lawrence, we joined Plymouth Congregational Church.

It was the first church established in the Kansas territory, in the mid-1850s, built by New England pioneers determined to bring their religion, education, and abolitionist fervor to the territory. Its present sanctuary and balcony were built by 150 members to accommodate nearly ten times that number; its design is in the manner of the New England Congregational churches, simple, unadorned, and straightforward.

The Power

We attend church regularly, heading always for the next-to-last pew so Jay and I can leave the service unobtrusively for the restroom. To the left of us, in the same row of pews, is Sue Hill, my senior by about a decade. We are acquaintances, nothing more.

A few weeks after Jay's funeral, Ann and I return to Plymouth, sit in our usual pew, and are lost in our thoughts about Jay. It is time to exchange the Peace Greeting; we reach over to give it to Mrs. Sue Hill. She tells us, "I never spoke the Lord's Prayer out loud when Jay was here. I always wanted to hear him say it. He said it so intently."

And so he did, coming to the phrase "For thine is the Power," and pronouncing the "P" with power, pushing the sound out of



his mouth. Everyone near us can hear Jay. Even Peter Luckey, our pastor, some twenty pews away, picks up on it and smiles his way through the rest of the Prayer.

High Holy-days

As much as Jay becomes agitated by holidays—he wishes them to be over so he may return to his routine—he also knows how to celebrate them, especially Christmas. Christmas Eve at Plymouth Church has its absolutely rigid routine: hymns, lessons, sermon, and then, at the end, the congregation's soft singing of "Silent Night," the congregates holding lighted candles.

Jay sings it, but is not silent. We try to mute him, and succeed only when, in the second and third choruses, it is time to light the candles and hold them aloft. Then, Jay is silent, but instead of holding his candle high, he blows out the flame, his and ours, too. The symbolism bypasses him; his concern is for safety.

At Easter, Jay is uncontainable. He conducts the choir and brass band, both arms pumping to the rhythm, his voice loud on the "Alleluia" choruses.

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He could not read the word “God” even if it were printed in large letters alone on a page. But he knows God; he has the Spirit. He receives and emits it. Jay is simplicity itself: free of knowledge, he yet knows in a different way.

The Plymouth Covenant

Our church services always close with the entire congregation reciting the church’s covenant. In it we commit to pursue justice, labor for knowledge, seek the reign of peace, and celebrate our shared humanity.

Jay insists on his version of justice, of what is due to him; and we advocate for it. He pushes us to pursue the truth of our lives, and we find that truth: in service to a cause. He insists on knowledge, and we develop and transmit it. He seeks peace—his own kind, the harmony of his behaviors and his inner nature; in time, he and we find that peace. And, most of all, he celebrates shared humanity, creating community and bringing disparate people together.

The Long Goodnight Prayer

Jay has a remarkably strong long-term memory. The proof lies in the prayers he recites. Some nights, it is as though his memory is blocked; he prays for people now in his life, a “short list” or “A-list” as it were. Other nights, it is as though all of his memory circuits are open; he is “firing” and “hot.”

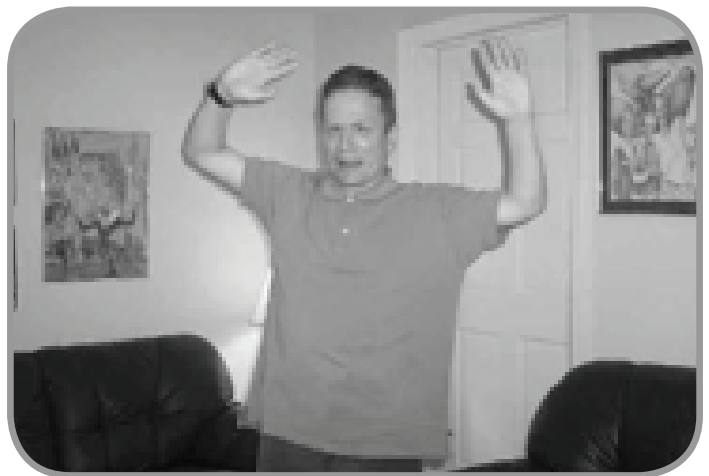
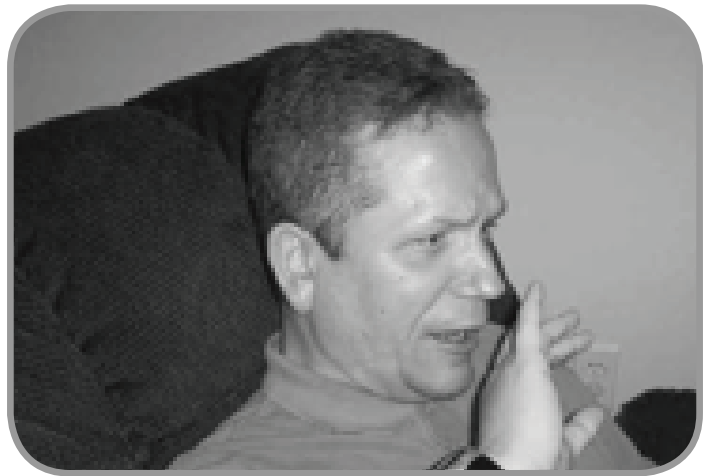
On those nights, he recites the “Lord’s Prayer” and then begins the lineage litany—the recitation of the names of his friends from long ago, a line-up of to-be-blessed beloveds.

First, Jay’s family, including Granddaddy Turnbull, “in Heaven with Baby Jesus, smoking a pipe;” then Grandmommy Ruthie, singing “Bye Bye Blackbird;” then Ann’s father, A-Dad, singing “You get a line, I get a pole, we go down to the crawdad hole.”

Then Amy and Kate, next Rahul, Amy’s husband, and our grandchildren, Dylan, Cameron, and Maya, and then Kate’s boyfriend Chip. Thereafter, Jay reaches far back in time. He remembers his house-parents and roommates from his group home in Massachusetts. Then he blesses his Chapel Hill teachers and friends.

At this point, he has named more than two dozen people.

The “short” version of the prayers can last a minute or two; the



long one, a good quarter of an hour.

We have no idea what unlocks his memory, but we know that relationships count in his life and we join Jay in prayer, giving thanks to the many people who have blessed him and us.

Jay’s prayer litany—whether the short or long version—has a uniform concluding request. When he has exhausted the list of named individuals whom he asks God to bless, Jay always says, “And God bless all the good people.”

Ann’s father, A-Dad, observes, “Jay won’t pray for any S.O.B. ”

Indeed that is so, but Jay knows there are many good people. He cannot remember all of them, and he cannot anticipate which of them will come into his life. But he knows enough to bless them all.

He is a collector of those from his past, present, and future.

Articles from our Contributors

Jay at Plymouth Church continued from [page 12](#)

Uniformed for God

Jay has a uniform for all high occasions, holidays, photographs, church, birthdays, and transition parties: white shirt, red tie, blue blazer, gray or khaki pants, and dark shoes. He wears these at his transition party from our home to the adult agency, at Amy's wedding, and at Amy's and Kate's graduation parties. He wears them to church (and his funeral); no other clothing is fit for worship—he refuses all alterations to this, his “dress” uniform.

The Salvation Army Christmas Bucket

It is Christmas season, 2008 Shelby Tasset, Jay's job coach and friend, takes Jay to Hy-Vee, a large grocery store, to shop. She drops him off at the front door and parks the car. She sees him approach and then walk away from the Salvation Army bell ringer. She asks the bell ringer if everything is OK. With tears in his eyes he answers, “He opened up his wallet and gave me everything in it.”

Jay is following Tom Ri el's example, for Tom always opens his wallet and gives the bell ringer money every day when they shop at the local supermarket. Jay usually carries \$8 in his wallet—part of his daily wage, paid in cash as the immediate reinforcer for working well. He gives it all away. He does not understand much about money but he totally understands about giving to others.

Beyond Church: Gentleman Jay, A Gift to Our Communities

Jay's great skills are his gentlemanliness, his obviousness about what he likes and whom he cares for and does not, his authenticity, his inability to feign and dissemble. He is an utterly honest person. He endears himself in part because of his social graces.

All the money spent on teaching him new skills would have been relatively useless for his inclusion in our communities if he had not also learned the social graces of being a gentleman—“gentleman Jay,” as he called himself.

Ann and I have taught him his social graces: for life in Chapel Hill, it's knowing the “Tar Heel Fight Song;” for life everywhere, it's his cordial greeting of friends and strangers, and his table manners. Others teach him unique ways to connect with people. Corey Royer, the fraternity man who launched Jay into living in his own home, and Jay's sister Kate teach him a way to change his voice to emphasize the hard consonants and minimize the



soft vowels—this “T-Talk” that so delights him and his inner circle of friends. Pat Hughes and Corey teach him the hitherto secret SAE fraternity handshake – the one reserved for members of the fraternity. Jay now replaces the fraternity handshake for his regular one, substituting it for the e “high five,” once he lives with them.

Instinctively, Jay knows that, when he uses the SAE handshake, he connects in a unique way with others. He usually declines to use an ordinary handshake, preferring the fraternity one. He then offers his own version of a “high five,” rubbing the back of his right hand against the back of his partner's, repeating the gesture with his left hand, and finally ending the ritual with a snap of the fingers that Rahul taught him. We admonish, “Use your church handshake,” referring to the regular way of shaking hands, emphasizing he should especially resort to this in church.

But Jay is adamant: my way or no shake at all. We are helpless to prevent him from using it. Some people “get it” from the beginning, following him easily; others struggle; but all remember him. He signals, “I am different but gentlemanly.” He creates his own special connections to his community. He radiates beyond our church.

This just one of the many stories that detail the special connections Jay made in his life and, just as importantly if not more importantly, the power he had to transform people and the power others had to include and enjoy him. If ever proof were needed that we did right by him by giving him to our community, these stories provide the proof.

The Exceptional Life of Jay Turnbull: Disability and Dignity in America 1967-2009. Amherst: White Poppy Press. 2011 is now available through www.amazon.com.

Inclusion from the Inside Out

By Cindy Merten, First Presbyterian Church, Birmingham, Mich.

Very soon after my arrival at First Presbyterian Church, Birmingham, Michigan in 1999, I met with a group of parents and Dr. Ernest Krug, a physician in our congregation who specialized in developmental pediatrics. This handful of parents had among them five-year-old triplets who were on the autism spectrum, a toddler who had multiple disabilities including cerebral palsy and visual impairment, and a preschooler with Down syndrome.

As Director of Christian Education, it was my job to consider how we would “do” Christian Education with all of our children. With the help and expertise of many people, our congregation began a ministry of inclusion from the inside out.

From the beginning we learned that inclusion is more about relationships than method. While we hoped we could find a formula for inclusion or a model for ministry we could adopt, we learned that we first needed to cultivate a culture of inclusion in the church. Our pastors frequently spoke from the pulpit about racial and cultural diversity, people of various sexual orientations, and people of all abilities in the context of being a welcoming church. We formed committees that focused on inclusion issues, and we eventually hired two part-time Inclusion Coordinators to support this ministry who now meet individually with families.

Little by little, we have experienced congregational transformation through relationships one person at a time. Each child, youth and adult with disabilities has revealed new ways for us to be the church.

Let the Children Come

Welcoming children in worship, our congregation is now accustomed to unpredictable sounds and movements, and heads no longer turn with disapproving stares when Clayton repeatedly calls out, “You gotta have paaatience,” or a child melts down because of a change in our order of worship. Since we have learned that worship is richer when we are all there together, we find ways to make that happen.

When our children are in the second grade they attend a sacraments class with their parents. Following the instruction, they lead the congregation in our communion liturgy. This past year we created a visual and auditory story about communion in order to prepare Nicholas to participate with his peers in this

event. We took photographs of our process of communion and then recorded a message on each page of a recordable photo album. Nicholas used the book at home with his mother to prepare, and on that special day when he and his class led worship at the communion table, the congregation experienced the gifts of God for the people of God in a new way.

Voices of Youth

As we undertook this journey with an early confirmation class, we learned the importance of constant communication with parents, teachers, and peers about inclusion. I recently saw a photograph of three eighth grade girls in that confirmation class which still fills me with deep sadness. Two stood smiling with arms draped around one another's shoulders, while the third stood slightly off to the side looking painfully uncomfortable. Emily had a rare developmental disability, and we struggled that year with fully including her in confirmation. In our journey toward inclusion we now seek ways to help our youth, who are often uncomfortable in their own skin at the age of 13 or 14, to include their peers with disabilities.

A part of our confirmation experience includes the public presentation of faith statements. That expression of faith may be a verbal statement or an artistic representation such as a poem, a song, a collage, or a painting. When Nicky read his faith statement, it was the most extended time anyone had ever heard his voice. What a gift that was!

The same recordable photo album used for Nicholas was used in another application to help Elizabeth present her faith statement. As Elizabeth's mother said in her introduction, “Elizabeth doesn't have speech, but she certainly has a lot to say.” On each page of her photo album, a 10 second message recorded by one of her friends accompanied a script and pictures. Elizabeth then pushed



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Inclusion from the Inside Out continued from [page 14](#)

the button on each page to play it for her audience. You can see a video of both Nicholas and Elizabeth presenting their statements of faith on our church website at www.fpcbirmingham.org/christian-education/disability-inclusion-ministry.

A Whole Church Ministry

What began as a children's program has become a whole church ministry as this journey of inclusion continually leads us to new people and opportunities to celebrate the gifts of all God's people. A year ago we became a part of a network of churches which hold a worship service at least once a month celebrating the gifts of people with disabilities. This Rejoicing Spirits ministry (www.rejoicingspirits.org) has led us into new relationships with people of all ages and abilities, and we are seeing a compassionate community emerging through this unique worship experience.

Six months ago we connected with an Angel's Place home, a residential home for people with developmental disabilities. In response to this connection we learned that Kevin's neighbor was a church member and she began bringing him to church. Kevin, a resident of Angel's Place, is currently in our new member class and loves to greet people. His smile and enthusiasm are gifts we celebrate.



Our church recently adopted a new vision statement that says: As everybody's church, we are committed to serving Christ by cultivating mission, inclusion and community. As we seek to carry out this vision, our prayer is that we will continue to find new and creative ways to partake of the gifts of God for all the people of God.

Don't Keep TASH a Secret.

As a valued member of TASH, you can impact our community by sharing your experiences with friends, family, colleagues and others who have an interest in equity, opportunity and inclusion for individuals with significant disabilities.

Help us *SHARE TASH* by telling others about the benefits of membership, and the impact we can have in our communities and around the world by working together. We invite you to participate in this membership campaign by reaching out to those who share your passion for creating real, positive and lasting change in the world.

SHARE TASH

Visit www.tash.org/share where you can:

- Download a membership application
- Share names of people and TASH will reach out to them directly
- Find information that will help you share the benefits of TASH membership with others

For your support, we'll announce special prizes for those who participate in the *SHARE TASH* campaign. Thank you for helping us *SHARE TASH*.

www.tash.org/share

Growing Up: Islam, My Childhood, and Disability

By Hamza Jaka

Islam has always been a part of my life, from the day of my birth, as has my disability.

When I say, the day of my birth, I really do mean that. My father named me Hamza, after the famous early Islamic warrior, whose name goes down in stories as “The Lion of God,” in the hope that I would overcome many obstacles. And this was before I even was diagnosed with CP. Oddly fitting, huh?

I grew up in a loving, traditional Muslim household (even though I was in a small town in Fontana, Wisconsin) and grew up well, eating chicken biryani nearly every night, with a great group of friends, but something always felt weird. Whenever we drove up to Milwaukee, where the larger Muslim community was, the accessible parking spaces were always taken. People looked at me awkwardly when I rumbled into the prayer area of the mosque with my shoes on. Generally, shoes are removed before entering the prayer area. I could not, and my family was concerned about me losing my shoes in the rush of people leaving for prayers, which does happen quite a bit. After a while, with an explanation and some education, people began to see my disability as something normal around the mosque and I became a beloved member of the community. In fact, one of the best friends I have ever known was a guy who helped me get around the mosque and did my attendant work when I would go there. The community—with the efforts of my dad, the imam, and the family of my friend Abdul, who is also a chair user—began to realize that parking spots did have meaning for people with disabilities, and placed an elevator in the mosque.

Things were changing for the better, and then came 2001. After the events of that day, I began to feel more and more isolated in my small town. (I was treated well, it just felt different, like I was an outsider.) I involved myself more and more in the activities of my mosque, but again, I felt strange. It felt like I didn't fit, and there were some members of the community (not many) who felt my mother had sinned, and thusly gave birth to a child with a disability. I found my place, thanks to a phone call from an old friend who invited me to star in some of her troupe's shows, which showcased actors with disabilities. I found my calling. I loved theater, yes, but I really enjoyed discovering that disability was just a part of my life, and it enabled me to do amazing things.

It was also at this time that I began to dedicate myself to my religious practices, including praying five times a day (one at 5 am in the morning) and looking at the Qur'an in depth, not just as a flip-through book. For me, Islam was always a part of

my identity. Now that I had discovered the disability part of my identity, I decided to re-discover my religious identity, which I had neglected. I had always wondered whether advocacy and religion fit together. I had felt some uncertainty; at least until I met our new imam, with whom I became fast friends due to our mutual love of the Green Bay Packers. He explained the meaning of some hadiths (sayings of the prophet) and various verses of the Qur'an that revolved around disabilities, including one admonishing the Prophet (SAW) for ignoring a blind person who came to him, in which something along the lines “God has made life easy for him” is said. Now, this verse is often used as reasoning by many people to say that people with disabilities should not be burdened with any responsibility. But to my imam, it meant that we must never forget that people with disabilities are people too, who deserve equal rights. Those words have been etched into my memory ever since, and they've been a large part of my motivation for advocacy.

Fast forward a couple of years, and I've continued my advocacy career, working with Kids As Self Advocates (whose advisory board I now co-chair), but it didn't seem like my religion and advocacy really ever intersected, other than being based on similar principles. Just when I was beginning to wonder about my future as a Muslim with a disability, I got a call from my aunt, encouraging me to visit a school for kids with disabilities that she had helped sponsor in Pakistan. Little did I know, two of the biggest facets of my life were going to merge and stay merged. I'd been to Pakistan before, but as a tourist. I never had seen the side of the country that dealt with disability, and it wasn't great. You see, much like the members of my mosque back home, people cared, they just didn't understand. Unfortunately, they often deified people with disabilities or had them out on the street begging. Indeed, I remember being told on multiple occasions



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that if I went to a certain clinic, I would be cured or I was asked to pray for others (as I was closest to God). They just didn't get it, due to low exposure to disability, but fortunately, there were many who did understand. I spent the winter of 2009 working with them, traveling cross-country, giving speeches on inclusive education, lecturing to classes that studied disability, and holding workshops at local Centers for Independent Living. For my dear friends and I at the Milestone Center for Independent Living, Islam was a wonderful part of our lives. Advocacy was tied to our spirituality. This experience helped me understand that advocacy was a very personal (and for some) spiritual activity, which strengthened not only my commitment to advocacy, but my faith as well.

When I returned to the US, I began the process of creating a non-profit to help those whom I had worked with. The first place I went was my old community back home. They helped me raise \$10,000 to help build a youth leadership center in Pakistan and also to provide access to assistive technology. Later that year, I headed on over to Syria for the Open Hands Initiative Youth Ability Summit, as one of ten Americans, and two Muslims, selected to travel to Syria, network with youth and write a comic book, now known as the Silver Scorpion, featuring a wheelchair user who gains the ability to manipulate metal.

I headed to Berkeley to begin my first year, and I found myself loving it. The Muslim and disability communities are welcoming. There's so much halal food (meat slaughtered according to the requirements of Islam), I'm loving it. (In fact, my favorite moment of these past two years was being able to eat an authentic Philly Cheesesteak.) However, I wondered whether I want to continue a career in disability rights as I moved further along. I decided to explore this by taking an internship at the American Association of People with Disabilities (AAPD) in Washington DC in the summer of 2011.

While I was there, completing an awesome internship with the Department of Labor's Office of Disability Employment Policy (ODEP), I engaged in some great discussions around religion and disability with my dear friend Ginny Thornburgh, AAPD's director of Interfaith Initiatives. We discovered that in spite of our differing religious background, we shared similar philosophies on life and disability.

She also helped my brother and I get adjusted to DC. Thanks Ginny! These conversations, along with one with my phenomenal mentor Lawrence Carter Long, and my colleagues at ODEP, reminded me that all of us have different forces that shape us. For me, Islam is one of those forces, through the love of my family, my community, and our spirituality. It has always been one of the driving forces in my life and will continue to be so. I want to educate people of all races, religions, orientations, and cultures that disability is a beautiful part of human diversity. I do what I do to make the world a better place. It's my way of having fun and fulfilling my duties. I encourage everyone to find something that they love to do.

Author's Note

Hamza Jaka is a sophomore at University of California-Berkeley. He can be reached at hamzajaka@gmail.com.

Internship Opportunities with TASH

TASH internship opportunities are available throughout the year for interested students who want to expand their knowledge and experience in:

- Communications and Marketing
- Disability Studies
- Public Policy
- Much much more!

Internships are available with flexible working hours between 20-40 hours per week. Students of diverse backgrounds and abilities are encouraged to apply. For additional information or for an application, please contact us at info@tash.org or call (202) 540-9014.

Interested in professional development opportunities on issues impacting the disability community?



Join TASH for an innovative webinar experience featuring leading experts and advocates discussing the latest research and practices in the field of significant disabilities.

TASH offers webinars on a variety of topics throughout the year for professional development, advocacy and skills building and other updates to keep you well informed. Each webinar provides an in-depth exploration of an important topic led by some of the most influential presenters in the field.

The new TASH webinar platform allows participants to view each session where they want and when they want. All you need is an Internet connection to get started. Each webinar is available 24/7 so you can view it at your convenience, start and stop as you please, or review the material more than one time.

All webinar participants also have access to the TASH Forums, where webinar presenters have identified discussion questions based on the material. Respond to discussion questions, ask your own and see what others are talking about on the forums.

Common topics include:

- Employment, Discovery and Transition
- Sexuality
- Accessing the General Education Curriculum
- Supporting Adults in Community Settings
- Positive Behavior Support
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Adath Israel Welcomes Everyone!

By Rabbi Daniel Grossman, Hedda S. Morton, and Sharon Frant Brooks

What Does it Mean to Welcome Everyone?

At Adath Israel Congregation, it means a synagogue where Jacob who limped could enter, Isaac who was blind could find a braille prayer book, and where Moses who stuttered, could be a leader of prayer. We say this not in jest, but in recognition of the reality that many communities educate individuals with special needs. These communities concentrate their efforts on the goal of Bar or Bat Mitzvah, but they frequently do not take the final step, that is for these young men and women to then become participants, and maybe even leaders, in the daily rhythm of the congregation.

As a welcoming congregation, let us share some memories. Recently, a mother of a child with special needs reminded Rabbi Grossman that many years ago, as she walked into the sanctuary with her noisy and disruptive child, the first words she remembered hearing were, "Welcome. Find a seat anywhere." She reminded him that within minutes she was ready to leave because she was sure her son's behavior would not be tolerated, or worse, would be the subject of comments. It took some reassurance that they were indeed welcome and that they should stay put. Rabbi Grossman told her that he did not remember in detail this first encounter and she gently said, "That's only because I have seen the same kind of welcome for others since we have become members. For you, it is not unusual to ensure that everyone feels at ease."

Welcoming is neither a nametag nor an usher at the door, but it is a congregational attitude best described in the following phrase, "Everyone really does have a place within our walls."

As a welcoming congregation, it is natural for us to encourage, and to develop leaders from our entire membership. Over time

we have had a president with spina bifida, a USY advisor who has multiple sclerosis, and Torah readers, some who are deaf, and others who have a range of learning differences.

Physical Space

Adath Israel is a totally physically accessible space. There are ramps, assisted hearing devices, braille and large print prayer books, and guided texts for sign-language use. The Torah



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Students learning Hebrew and Torah in Adath Israel Congregation's Resource Center

scrolls in the Holy Ark are positioned in a manner that allows accessibility even when seated in a wheelchair, and the pews have random open spaces for wheelchairs so that individuals can sit anywhere they choose in the sanctuary. These structural modifications to our building make the sanctuary the chapel, the library, all classroom and meeting spaces as well as the administrative wing, accessible to everyone. Over the years, Adath has hosted the NJ Conference for Persons with Disabilities (1997), the First Conference for Students with Learning Differences (2005), and most recently, in partnership with Enable, we hosted a conference titled *Enabling Faith: Honoring our Disabilities, Finding a Spiritual Community* (April, 2010). At that conference a participant who used a wheelchair commented that she had been concerned about how she would maneuver in our building. To her wonder, she found that she could go anywhere and sit anywhere in the building with total comfort. The keynote speaker, Dr. Dan Gottlieb, a nationally recognized therapist who also uses a wheelchair, agreed to speak in our building because of its complete accessibility.

Educational Opportunities

Adath Israel has an amazing Resource Center where the goal is to create a meaningful, focused, and appropriate Jewish educational experience for all learners in this synagogue's Religious School regardless of unique learning styles, needs, and varying potentials of all students. Many of these students will continue their Jewish learning well beyond the celebration of becoming a Bar or Bat Mitzvah.

Our Resource Center, under the Coordinator Sharon Brooks and teacher Elaine Wiznitzer, Director of Congregational Learning, Hedda S. Morton, and Rabbi Daniel Grossman, have each been recognized by the NJ Coalition for Inclusive Ministries, United Synagogue, and several other institutions for creating a full learning environment. In addition, we have crafted individual instruction year after year depending upon the wide range of needs of our students. Learning and education are lifetime endeavors. Adult members of the community with a variety of challenges have participated successfully in various education programs.

Over the years the congregation has seen the celebration of life-cycle events in our sanctuary: weddings between couples with special needs and Bar and Bat Mitzvah ceremonies customized for students who have muscular dystrophy, fragile X syndrome, autism, Tourette's syndrome, profound deafness, as well as a combination of differences.

In conclusion, it must be stated that because the culture of Adath Israel has for more than 20 years made accessibility and inclusion inherent in every aspect of the congregation's life, it is interesting to note that when congregants are questioned by outsiders about the issue of inclusion, they often respond: we haven't even noticed it because it is so natural. Here are several comments:

- **Carl Shipper, Past-President:** "I've never been treated any way other than as an equal.... Once you start to talk to people in the congregation, they judge you by your abilities—what you do and what you say—not by your disability."
- **Jeff Reisner:** "Being part of this congregation heightens a person's awareness. It goes a long way to helping the [individual with a disability] learn how to interact with all people and it helps the [individual with a disability] function from stimuli and not from a stigma."
- **Joannie Applebaum:** "As a parent, what a self-esteem builder it is to be here!" Our doors are always open. We'd love to welcome you and share our experiences with you!

About the Authors

Daniel Grossman is Rabbi at Adath Israel, Hedda S. Morton is Director of Congregational Learning, and Sharon Frant Brooks is Resource Center Coordinator.

Please visit our web site and learn more about us:

www.adathisraelnj.org

Strategies for Supporting the Spiritual Lives of Individuals with Disabilities

By Lida Merrill

Last week a Direct Support Professional (DSP) shared a simple story illustrating the profound impact being part of a faith community can have on individuals with and without developmental disabilities. The DSP supports Chris, a man who is non-verbal, utilizes a wheelchair for mobility, and requires many supports and services in his life.

One day, while Chris was being assisted onto the van wheelchair lift in a parking lot, two women came running up to him, calling him by name—happy to see and greet him. The DSP did not know these women. They explained they went to church with Chris. His eyes sparkled as his friends from his church spoke with him for a few minutes before departing. Don't all of us want to be part of a community where we are so valued that people will run across a parking lot shouting our name to greet us? As the 1980s song goes, don't we all want to go "where everybody knows your name and they're always glad you came?"

What happened in the background of Chris's life that led to this simple and powerful example of friendship that results from belonging to a faith community? Faith is important to Chris and his family. They have attended the same church since his childhood. When it was time for him to be cared for outside of their home they sought a residential provider with a reputation for offering holistic care. They decided that Heritage Christian Services (HCS) was the best place for their son because they believed that all of his needs—body, mind, and spirit—would be addressed in all aspects of planning his services.

How could Chris's parents be so confident that their son's physical, emotional, and spiritual needs would be explored, valued, and addressed at his HCS group home and day habilitation program? Because of the culture of care that defines what we call the Heritage Difference. We believe the Heritage Difference grows out of our corporate mission statement:

Our mission is to provide a living and working environment that reflects the love of Christ in action; support and respect for each individual's gifts, strengths and needs; opportunities to mature, to learn and to grow; a life of dignity, worth and expression to which all are entitled as God's created children. This is their rightful heritage.

All of the relationships of people affiliated with HCS—people supported and their family members, as well as those who do the supporting—are guided by these words. Love in action, dignity, respect, opportunity, and expression are words we take seriously.

Before a potential employee is interviewed he or she must watch our Realistic Job Preview video. The DSPs who speak in the video discuss how they support individuals as whole person: body, soul, and spirit. There is a discussion in the video about spiritual expression for the people whom we support and how that often includes attendance and involvement in a faith community. Throughout the entire hiring process, the applicant gains an understanding of our holistic approach to care that involves opportunities for the expression of spirit and faith for the people we support. Employees are expected to support each individual's spiritual and faith expressions, regardless of their own personal belief systems.



Christopher Phillips

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Strategies for Supporting the Spiritual Lives of Individuals with Disabilities continued from [page 21](#)

The Heritage Difference—described in an employee booklet—provides a framework for employees to honor the individual choices of the people we support. Individual choices ranging from the color of their bedroom, to where they work or volunteer, to how they do (or do not) vote, to clothing styles, to religious expression are all honored, even when they are not what we, as employees would choose for ourselves. Two phrases we often say are: “It is not about me and my choices, but about the person I am supporting” and “Know the person.” All of the subsequent trainings and education employees receive after being hired reinforce the message of honoring individual choice and knowing the person. For Chris and his family, the Heritage Difference means they know that the HCS employees supporting Chris understand that his choices are to be honored.

When Chris moved into his group home, a team of people including residential leadership, clinicians, day habilitation, Chris, and his parents developed an Individualized Service Plan (ISP). A routine part of the ISP development involves questions about natural supports, including a faith community. Chris is non-verbal and expresses himself via facial expressions. He indicated his desire to continue attending his church and to have regular times of prayer by smiling and looking up when asked. Valued outcomes in various areas in his life were developed, including outcomes related to his spirituality and the natural support of his faith community:

- Chris enjoys outings to the mall, going to church, and visiting his family. Chris would like to continue to do these activities, as well as other community outings.
- Chris would like to continue to grow in his spiritual faith by attending church.

Approximately two months after Chris moved into his new home, an individualized Spiritual Life Plan was created. This plan is a document containing the history of his religious community involvement, dates for any sacraments that are part of his faith community, a section for recording information specific to his faith, observations of his spiritual gifts and strengths, how he personally practices his faith, who his spiritual companions are, information about his individual faith community, and a final section detailing how he is encouraged and comforted spiritually. The Spiritual Life Plan is not completed prior to an individual moving into an HCS home because the nature of the questions requires us to spend time getting to know the individual first. This document is part of the training packet for new employees

in Chris’s home. This form ensures that his personal faith traditions are known and honored.

The employee mantra of “Know the person,” along with the ISP and the Spiritual Life Plan, guide spiritual and faith expression. For Chris, this includes regular attendance at his church. Employees at his group home drive him to church and attend the Sunday morning service with him. As his parent’s age, they are less able to facilitate Chris’s involvement in his faith community so the HCS employees have assumed more responsibility as part of their natural support of Chris. Chris’s mother shared with me that she believes her son’s mission is to, “Teach people to stop and pay attention and get to know other people.” Chris seems to relish this mission as indicated by his welcoming smile and many friends at church. It is because the employees at Chris’s group home believe in his individual faith expressions and his desire to be an active part of his faith community that he is supported in carrying out his personal mission.

For individuals supported by Heritage Christian Services who do not have a strong faith background or who do not seem to have explored their spirituality, we incorporate opportunities to do so into their lives. This starts in the ISP process when an individual is asked about natural supports and if he or she wants to visit different faith communities. If the individual indicates that he or she is interested in visiting, then the opportunities are incorporated into his or her valued outcomes. It is the responsibility of the residence manager and the Medicaid Service Coordinator (MSC) to follow up on the valued-outcomes of the individuals. The ISP is reviewed semi-annually for follow up. The Spiritual Life Plan is where the faith exploration opportunities are recorded. Spiritual Life Plans are reviewed annually. At HCS there are Spiritual Life Coordinators; these are employees who facilitate spiritual growth opportunities. One of their responsibilities is to assist the individual in selecting a variety of faith communities to visit and to prepare the individual and the employees for what to expect if the individual has never attended a service. The Spiritual Life Coordinators are familiar with the faith communities in the region.

Sometimes the individual indicates that he or she has no desire to explore a faith community. If he or she indicates no interest, we still offer opportunities to explore spirituality separate from a faith community and a Spiritual Life Plan is created. The opportunities for spiritual involvement then revolve around the individual’s interests and talents.

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Some of the spiritual exploration opportunities that we have successfully utilized at HCS include:

- If the individual has an interest in gardening, we may explore a volunteer opportunity to do gardening or be part of a community garden at a local house of worship.
- If the individual is interested in a sports team, we may initiate a connection with the team chaplain, as most professional or semi-professional teams have a chaplain.
- Volunteering at a church-based soup kitchen has helped connect people with like-minded, compassionate people.
- Serving or enjoying a local faith community dinner facilitates relationships with neighbors.
- Faith-based civic engagement projects such as a clothing drive for those less fortunate help connect individuals with their desire to make a difference.
- Volunteering at a local food pantry is a way to meet other like-minded, generous people.
- Exposure to a variety of music, including different forms of faith expressions done via music, for those who enjoy music.
- For people who like to clean or organize things, there are opportunities to do these at local faith communities.
- Attendance at services occurring annually such as Chanukah, Sukkot, Christmas, or Easter.
- Volunteering at a nursing home, visiting the residence, or helping them to attend a worship service is also offered.

This all takes creativity and research. But the joy of seeing an individual connecting their interests with something greater than themselves is worth the investment.

We have not felt the need to use a formal spiritual assessment tool other than the Spiritual Life Plan. Because we have a mission and culture that honors the spirituality of each individual whom we support it is part of how we do business to be as mindful of the spiritual and faith needs as we are to the physical and medical needs. Spiritual supports and opportunities are not left to the Spiritual Life Coordinators, just as medical needs are not left solely to the clinical team. Each employee is responsible for striving to address the physical, emotional, and spiritual needs of each individual we support. As employees come to know the individuals they support, they become personally invested in

addressing needs holistically. We have demonstrated that the “Know the person” way of serving leads to employee retention.

The Heritage Difference of serving people body, soul, and spirit has reaped more benefits than just providing a place for people to explore their spirituality and to belong. Our internal measures indicate that 92% of the people who do not go home with their families on the weekend regularly attend religious services. That means that opening their doors and hearts to people with developmental and intellectual disabilities regularly impacts almost 100 faith communities. These faith communities have relayed numerous stories about how the presence of people with developmental disabilities has enriched their ministry and made them stronger congregations.

The relationships with the faith communities has also enriched and strengthened the mission and ministry of HCS. Faith communities are welcoming places for individuals to volunteer to use their gifts. The people we support serve as greeters, ushers, hospitality and maintenance team members, greeting card senders, choir and drama team members, children’s ministry workers, parking lot attendants, snow shovelers, and gardeners. In addition to ample volunteer opportunities, we have found that faith communities are also willing to employ people with disabilities; there are several people we support who are paid employees at faith communities. HCS opened its first home on land donated by a church and that pattern has continued for many of the homes and day habilitation programs we have developed since we opened in 1983. We enjoy having many people from faith communities who regularly volunteer for HCS, from members of our board of directors to mending to hospital visitation to our thrift store; people of faith volunteer and strengthen our mission and ministry. We have received financial support from the faith communities. In this era of insecurity it is vital to have the support of local faith communities.

Our culture and commitment to the individual is what facilitated Chris’s ability to maintain his connections with his faith community, and that, in turn caused two women to run across a parking lot calling his name to greet him and show him that he is a valued member of their community.

About the Author

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Beginning an Inclusive Congregational Network

By Karen Jackson, Founder and Director, Faith Inclusion Network of South Hampton Roads

I remember it like it was yesterday. On a rainy Sunday morning in 2001, I rushed inside the local Catholic Church, dragging my four-year-old and six-year-old children behind me. My husband, whose work often took him out of town, was not there to help so I had made the valiant effort to attend Mass by myself. We snuck into the church and made our way to an open pew, but things began to deteriorate rapidly. My four-year-old daughter, Samantha, diagnosed with autism at age three, could not sit still. As people around us eyed her behavior somewhat suspiciously, the intensely loud organ music accompanying the opening hymn started and Samantha began to scream. She cannot tolerate loud sounds and the organ was just too loud for her. I escorted us all out of the sanctuary quickly to sit in the large gathering room, where we could hear through speakers but could not see the Mass. Soaked from the rain, with tears starting to well up in my eyes, I put our coats back on, packed up our bags, and left. There was no place for us here. I felt left out, helpless, and discouraged. I had no idea how to make church work for my family and no energy left after a challenging week to figure it out.

This story, and the many stories I have heard over the years, are the driving force behind Faith Inclusion Network (FIN), an organization devoted to helping better include people with disabilities and their families into places of worship. Specifically, the mission of Faith Inclusion Network is to promote awareness of and provide support for the inclusion of people with disabilities and their families into faith communities.

In 2008, seven years after my own somewhat discouraging



experience at church, I was ready to effect change in our community. Having already begun advocacy and awareness efforts in our new parish, I was beginning to experience for the first time since my daughter's diagnosis, a feeling of inclusion and acceptance in a congregation. But what could be done for others who lived in our community?

While searching the Internet for "autism and faith" late one night in January 2008, I stumbled upon the New Jersey Coalition for Inclusive Ministries and its Director, Rev. William Gaventa. Within a few days, I had Rev. Gaventa on the phone and one 30-minute conversation later, I had more than two pages of notes on resources and contacts. I started with Erik Carter's book, *Including People with Disabilities into Faith Communities: A Guide for Service Providers, Families and Congregations*, and began to read.

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I wasn't more than half way through the guide when it became perfectly clear I had found my answer. I would begin an interfaith network to bring together all those in the community who cared about the inclusion of people with disabilities into faith communities. Remembering my own experience, I realized there were probably others in my community who found challenges to being included in worship and religious education. I would set out to find those people.

In January of 2008, I began by inviting anyone interested to a luncheon meeting at my church, Blessed Sacrament Catholic in Norfolk, to discuss the state of inclusion in our area's faith communities (see Box- The Development of Faith Inclusion Network: 2008 to the present for a historical timeline of FIN). On May 1, 22 people sat down together to share their experiences and thoughts on inclusion in faith communities. Although we clearly did not quite know what we were doing yet, the most important thing was that we had started the conversation.

“That All May Worship” (2009)

Those who recognize the conference title “That All May Worship” are probably familiar with the work of Ginny Thornburgh. When I first spoke with her, she was leading the spirituality division of the National Organization on Disability (NOD) where she had written several booklets on including people with disabilities, including *That All May Worship: An Interfaith Welcome to People with Disabilities* and *From Barriers to Bridges, A Community Action Guide for Congregations and People with Disabilities*. I eagerly read both these publications and it soon became clear that our community needed an educational event such as a workshop or conference.

At our second FIN meeting in September 2008, we brainstormed ideas for a “That All May Worship” Conference, the first faith and disabilities conference to ever be held in the South Hampton Roads area. On May 30, 2009, almost 100 people attended for our first “That All May Worship” Conference. It was an enjoyable, educational, and inspiring day—a day marking the beginning of FIN's work in the community.

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Our First Board of Directors

In the summer of 2010—realizing that FIN needed to be more formally organized if it was to be more effective in the community—I began the process of establishing a board of directors. I invited 20 people who were integral to the initial development of FIN to the first board meeting; ten accepted board positions and we got right to work. This amazing group of people (a) helped finance the application to get non-profit status, which we were granted in February 2011; (2) helped put on our second “That All May Worship” Conference; and (3) established a new and more user-friendly website. The highlight of the year was the conference that we held in April 2011. In addition to inviting participants from the area, we invited guests from around the country to participate in the conference and meet the evening before for what we coined an “Inclusive Ministries Summit Dinner.”

Although some people were skeptical that we could get out-of-state guests to our FIN conference and dinner, I knew we had a winning combination. With Rev. Bill Gaventa as our keynote speaker, the beautiful Virginia Beach oceanfront for our location, and knowing that the invitation was going out to very passionate and dedicated professionals, I was confident that we would entice at least a few people to Virginia. And that we did. On April 9, our Inclusive Ministries Summit Dinner included almost all of our board members, their spouses, and 16 out-of-town guests from eight different states. The following day we welcomed more than 100 people to a national conference in Virginia Beach, Virginia.

Positive Effects in the Community

Although it can be difficult to measure results of efforts such as those being made by organizations like Faith Inclusion Network, the Board and I are excited and optimistic about some of the outcomes of our work thus far. Last summer, one of our FIN faith communities initiated a summer Vacation Bible School (VBS) at a neighboring residential home for children with severe disabilities. Originally connected through a collaborative project with FIN to start bringing the home’s residents into worship and religious education programs, the one-week summer initiative was the first time this particular church had reached out to the children’s home. The results were tremendous with plans already underway to do another VBS next summer.

Our seminars and conferences have made an impact as well. One gentleman, a longtime leader of a large and successful adult special need Sunday school program emailed me, “You [FIN]

The Development of Faith Inclusion Network: 2008 to present

- (May 2008) First meeting of representatives from faith communities, disability service providers, and parents
- (May 2009) First “That All May Worship Conference” attended by almost 100 people in the community
- (October 2009) Faith Inclusion Network logo developed
- (November 2009) FIN website established at www.faithinclusionnetwork.org
- (January 2010) First FIN meeting hosted by a Jewish congregation, Temple Israel of Norfolk
- (March 2010) FIN represented at Mennonite Health Assembly Conference in Norfolk, VA
- (April 2010) First family FIN event, called “We Gather Together”
- (October 2010) First FIN Board of Directors meeting
- (February 2011) FIN gets 501c3 tax exempt status for organization
- (April 2011) FIN holds second “That All May Worship Conference”
- (June 2011) FIN represented at annual American Association on Intellectual and Developmental Disabilities conference in Minnesota
- (January 2012) FIN holds first community awareness and fundraising event, “Gifts of the Heart Celebration”

just keep challenging me. The first conference in 2009 made me re-evaluate my thinking about true inclusion and the second conference this past April had me thinking again about how to reach out beyond just our denomination.” This is the kind of thing FIN is setting out to do—challenge perceptions and educate those people who already have a passion to include and work with people with disabilities in a faith based setting.

Most recently, I met a gentleman who works in a local religious book store. I walked in, ready to share sponsorship information

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about our upcoming fundraising event, when he stopped me in my tracks. He said, “My wife and I just found out that our five-year-old son has Asperger’s Syndrome. We had already stopped attending church because his behavior just made it too difficult. I miss it, but what can we do?” Feeling like I had been sent into this store on a very specific mission, I gladly shared information about FIN and the many faith communities and resources there to help.

To Be Continued...

We are hard at work here in South Hampton Roads, Virginia, continuing the work of FIN. We are currently planning our first community awareness and fundraising event for January 2012 called “Gifts of the Heart Celebration.” This event will bring our mission out to the community at large and hopefully reach more families who may need our help in finding inclusive congregations. We are also developing new resources and presentations about inclusion to share with our faith communities and are planning a much-needed Autism and Faith Workshop for March 2012.

So on behalf of a dedicated Board of Directors and many amazing volunteers in South Hampton Roads, Virginia, I pray you will support existing efforts in your community or even begin your own network to help fully include people with disabilities in your congregations and communities. Because it is essential that our faith communities embrace and celebrate the inclusion of those who may have different abilities and this can only be done one person, one family and one faith community at a time. Let’s get to work!

Author’s note

For more information about Faith Inclusion Network you can go to www.faithinclusionnetwork.org. If you have questions about or are interested in beginning your own chapter of FIN, you can contact Karen Jackson at faithinclusionnetwork@gmail.com

The Untapped Potential of Inclusive Spiritual Supports: From Unknown to Known

By Bill Gaventa

If you are a service or support provider reading this issue of TASH Connections, a very natural and “normal” response may be multi-layered: “I am not so sure about this spirituality and religion stuff.” “Can we do that with public funds?” and “It is not very scientific.” “We have seen people hurt by experiences in faith communities.” But the most common response may be “We don’t know how.”

Spirituality does not mean an agency has to become “religious.” Many staff and advocates may in fact be religious individuals, and that may be a core component of their commitment and

sense of calling. But in a public arena, the prohibitions against proselytizing or attempting to use public services to establish a particular faith are well grounded in constitutional and public policy. In fact, the language and research around spirituality, from many different theological and human service disciplines, provides a way to bridge language systems and cultures that are incredibly diverse. Helping to find ways for staff and advocates to talk about how their spirituality or faith shapes their vocation and is shaped by the lives and gifts of people with significant disabilities is an area where a whole lot more needs to happen. In an earlier article coming out of our work here in New Jersey on helping to develop ways for direct support staff to be nurtured in their own learning and development (Gaventa, 2008), I tried to flesh out a profound comment once made to me more than 20 years ago by a chaplain turned quality assurance coordinator. He said, “In a system of services that does not have the faintest idea

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of how to nurture professional commitment, at all levels, we rely on compliance instead.” That could be a topic for another whole issue of Connections.

Think about your professional or agency values and mission. Quite likely, faith in the values enshrined in the Developmental Disabilities Act is already reflected in values like independence, productivity, inclusion, self-determination, and cultural competence. I would submit that these values are classic Western ways of asking fundamental human and spiritual questions: Who am I? (Identity), Why am I? (Purpose and vocation), Whose am I? (Community and Belonging), What control do I have over my own life? Will people respect differences that I share with others? Helping people find their own answers to these questions is the place to begin (Gaventa, 2006).

For example, there are now service and support systems that are beginning to pay attention to an individual’s spirituality, his or her preferences and choices, and the traditions and cultures from whence they came or where they live. Spiritual assessments are a tool used in many health and human service systems. There is a very comprehensive tool just developed in New York (Contact: Catherine.Patterson@opwdd.ny.gov). If you are interested in starting more simply, look for the tool out of the George Washington Institute for Spirituality and Health (www.gwish.org).

It is called the FICA process and it includes four questions:

1. **F:** Are you a person of faith or other forms of spiritual expression and life?
2. **I:** How important is that to you? How does it influence your life?
3. **C:** What form of communal expression does it take, if any?
4. **A:** How can we address this area of interest with you?

Person-centered planning strategies offer an obvious method for integrating those questions, especially if facilitators have learned that: (a) this is a legitimate area to be explored, (b) it is permissible to do so in publically funded services and not a violation of “church/state” boundaries, and (c) it can be about much more than “going to church.” Person-centered planning, such as Essential Lifestyle Planning, asks the core question of “What is important to you as well as for you?” Spirituality, as I am using it in this article, is about what is at the depths of one’s life as well as about the ways and communities in which one finds



meaning, identity, and the support for coping with fundamental human questions (Gaventa, 2006).

The same is true for more traditional planning processes. After a presentation many years ago in South Carolina at the Down Syndrome Association conference, I asked the audience to “tell me your church stories.” In one of my favorite stories, a mom got up and said, “We took our minister with us to our IEP. We got everything we wanted....they thought he was our lawyer.” The story always gets a laugh, especially with parents and teachers. But think about the potential if parents extended these invitations to congregational members or leaders and they offered to attend meetings. The IEP might very well be conducted with the understanding that a whole community stands with this family and child, wanting to learn, support, and collaborate for everyone’s benefit.

These efforts require getting to know people in more holistic ways. It can happen through an agency that is “faith based” and lives out a core value of paying attention to spirituality. But it also is happening when “secular” or “public” agencies begin paying attention to faith, doing so as part of their values and missions statements, such as individualized, person-centered supports, respect for cultural and ethnic diversity, self-determination, the right to choose, and, of course, community inclusion.

In most communities, one cannot talk about generic and natural supports without looking at the role of spirituality and faith. One could say, “I know a generic community organization, ubiquitous in its presence, known for proving natural supports to a wide variety of people, where there are opportunities for multisensory experiences involving music and singing, socialization, recreation, and ongoing education; a community that often helps people learn socially appropriate behaviors while also focusing on the importance of taking care of one’s health at many different levels;

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an organization known for assisting people in a crisis, sometimes with funding, one with great experience in helping people deal with grief, loss, transition, and death; a place where one can make a contribution in many different ways that provide opportunities for friendships; and, last but not least, a place where one can network with potential employers or others who can help you navigate the community in which you live.” That being said, the question would become not just how one might visit or attend the open functions of that organization, but how becoming known by people within that organization and becoming a contributing member might open up many more doors than the one into the sanctuary.

Clearly, this process requires getting to know these organizations and helping members get to know the person in need of support and the caregivers who work with them. It means listening to the individual and/or his or her family to understand what they want to learn and “practice.” It means learning the rituals and culture of the congregation and developing relationships with a few that could lead to relationships with many. It means asking for their help in what they know best (i.e., helping someone to learn and practice faith), while you offer to help them learn whatever they need to know about someone’s disability and their individualized supports.

It could mean going for the first time on a day other than a Sabbath to help a person get used to the place, practices, and typical routines so that the first time is not a leap into a big unknown. It means making resources available so that staff who accompany that person to a faith community understand their role has expanded beyond caregiver and companion to “agent” and “teacher,” roles that require a partnership with an individual and others to explore and generate new opportunities for relationship and inclusion. That’s not easy, particularly in areas where a community’s culture and/or particular faith tradition is unknown by, or much different than, the direct care staff person.

In fact, the diversity of religious practices and faith communities is one of the great “unknowns” to service providers. Vice-versa, the confusing diversity of human services, forms of disability, and uncertainty how to access supports is an “unknown” to many clergy and congregational leaders. Both “systems” have their own multiple languages, with terms and acronyms that just add to the bewilderment about where to begin. The language of spirituality, spiritual needs, interests, and gifts, is one of the bridges; as is the language of welcome and hospitality (Anderson, 2010).

Individuals, families, advocates, and service providers also

need to know that within the diversity of faith traditions and communities there are more and more examples of successful inclusive supports, more and more congregations intentionally engaged in doing what they need to do to help everyone feel welcome and included, and an explosion of resources on inclusive supports for faith communities to use in many areas of congregational life.

To cite some more concrete examples:

- Individuals with disabilities and family members are writing about their experiences, developing blogs and websites, and/or helping lead localized or regional initiatives, such as the Faith Inclusion Network in Virginia, the New Jersey Coalition for Inclusive Ministries, Faith for All in Nashville, and many more.
- Many national faith networks have developed their own networks or resources offices to support congregations in beginning or strengthening inclusive ministries. For a good listing, go to the Congregational Accessibility Network (www.accessibilitynetwork.net).
- The intersection of theology and disability is becoming a growing area of scholarly research, writing, and gatherings (see <http://rwjms.umdnj.edu/boggscenter/products/>). The Journal of Religion, Disability, and Health (www.tandf.co.uk/journals/WRDH) is moving into its sixteenth volume, with issues addressing a wide, interfaith variety of perspectives. One new book, *Amazing Gifts: Stories of Faith, Disability, and Inclusion* (Pinsky, 2011) is an interfaith collection of congregational stories.
- Multimedia resources abound, such as the award winning documentary *Praying with Lior*, about Lior Liebling’s bar mitzvah (www.prayingwithlior.com) and *A Place for All*, an interfaith documentary exploring inclusive faith supports (www.divaproductions.com).
- National interfaith and interdisciplinary networks, such as the AAPD Interfaith Initiative (www.aapd.com) and the AAIDD Religion and Spirituality Division (www.aaiddreligion.org) continue to serve as arenas where advocates, families, faith leaders, and interdisciplinary professionals can come together for collaborative learning and initiatives.
- The new national Collaborative on Disability, Religion, and Inclusive Spiritual Supports will bring University Centers of Excellence in Developmental Disabilities together with seminaries and other organizations to build partnerships related to research, training, technical assistance, and

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dissemination of best practices and resources.

Simply put, there are multiple resources and initiatives in both public arenas and faith networks that people simply don't know about. Just as one in the world of disability services might say, "Give me an example of a child or person with any form of disability and we can find a place where inclusive educational and/or community supports are working," the same can be said in the world(s) of religion and faith. Somebody has figured out the "how" and it is making a huge difference to everyone involved.

To go back to the beginning, the potential in all of these initiatives and resources is not simply that rights are respected and honored. We all know, from many different perspectives, that the "right" to be in the community does not mean you are part of a community. People with and without disabilities can attend a faith community and not really be a part of it, or be known by others. That difference, as Milt Tyree pointed out in his article about his friend Bill, is between being "noticed" and "known." That's where the power and potential lies.

In their 2010 book, *American Grace: How Religion Divides and Unites Us*, Robert Putnam and David Campbell lay out, in study after study, how faith communities and their members, though often divided in the public and media sphere, continue to be the preferred resources in times of need and counsel. Interestingly, the largest collection of volunteers in American society, giving (to both their faith community and community causes), and source of community leadership come from the faith community. So when families, congregational members, and disability service providers work with individuals with disabilities to help them be full, contributing members of the faith community of their choice, those initiatives are going to get noticed. Congregational members may well be inspired by seeing service providers trying to live out their own values of assisting people to be part of the community and to help people they support participate in their chosen faith tradition. Service providers are often terrified of

"their people" getting noticed in ways that lead to criticism or bad publicity about their programs and staff. But if we work together, to help people with disabilities become known well by others, not primarily for their label but by their name, think of the public "value added" coming back towards the providers. Another way to say it is the goal and outcome is to help the people we support and serve be known by a faith community as "their people"—valued members and contributors to their community and tradition—rather than being seen as being "consumers," service recipients, or "belonging" to the local service provider.

That is a gift and effort that can unite us across lines of roles, faith, policy, and tradition. But the byproducts may be just as significant as members of congregations get to know the initiative and sensitivity of service agencies, professionals, and staff who are going the extra mile to embody their own values and mission. When people come together across usual dividing lines in a common mission, get to know others in ways that break stereotypes and expectations, and enable experiences of connection, growth and transformation to happen—that is where community is not just found but created. That's where the power of the human spirit, in all of its forms, becomes real.

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Recent Research on Spiritual Supports: What We Know and Where We Might Go

By Erik W. Carter and Courtney Taylor, Vanderbilt University, Melinda Jones Ault, Belva C. Collins, Harold L. Kleinert and Milton Tyree, University of Kentucky

TASH has long demonstrated its deep commitment to addressing those issues that matter most in the lives of people with significant disabilities and their families. Through a constellation of individual and coordinated efforts to change laws, strengthen policies, equip advocates, prepare practitioners, educate communities, and undertake research, TASH members have worked in tandem to ensure people with disabilities have the supports, skills, opportunities, and relationships needed to live rich, enviable lives and to truly flourish in all aspects of their lives—educationally, vocationally, relationally, and also spiritually.

Well-designed research has made substantive contributions toward promoting full participation and quality of life for people with significant disabilities. For more than 30 years, researchers have collectively identified a wide range of effective, feasible, and socially valid approaches for promoting meaningful learning, relationships, community connections, self-determination, and employment for people with significant disabilities. We are convinced that similarly rigorous scholarly efforts also are needed in the areas of spirituality and participation in faith communities. Although there are numerous indicators of the importance of faith and prominence of congregational connections in the lives of Americans and others around the world (e.g., Putnam & Campbell, 2010), we are struck by the dearth of high-quality studies exploring this dimension of the lives of people with significant disabilities and their families. In this article, we address four areas in which some research has accumulated but in which much more work is needed. In each area, we highlight some of what has already been learned through this scholarship and we offer recommendations for future research.

Spiritual Expression, Participation in Faith Communities, and Supports for People with Disabilities

As illustrated elsewhere in this issue, spirituality and participation in faith communities are just as likely to be an important aspect of life for people with significant disabilities as they are for anyone else. Recent data indicate that 83% of Americans affiliate with a religion and 43% regularly attend religious services (Putnam & Campbell, 2010). In its 2000 survey, the National Organization on Disability (NOD) found that almost exactly the same percentage of people with and without disabilities reported that their faith was either somewhat or very important to them (more than 85%). In other words, the presence of a disability label is not a reliable predictor of the importance of a person's faith. Yet, there is strong indication that the spirituality of people with significant disabilities too often is overlooked, poorly supported, or actively ignored. As one example, a more recent national study by the NOD (2010) found that 57% of people without disabilities in the United States said that they attended a place of worship at least once a month compared to 43% of people with significant disabilities, a participation gap also suggested in related studies (Abells, Burbidge, & Minnes, 2008; Minton, Dodder, & O'Brien, 2003; Orsmond, Krauss, & Seltzer, 2004; Wagner, Cadwallader, & Marder, 2003). Moreover, there is no doubt that people with significant disabilities have compelling gifts to share and important contributions to make within a community of faith (e.g., Ault, 2010; Hyman, 2009; Shogren & Rye, 2005; Zhang & Rusch, 2005). These studies suggest missed opportunities for people with disabilities to contribute their talents, gifts, and strengths; to access spiritual and other supports that may contribute to their own flourishing; and to be part of a relational faith community.

What avenues of research might help families, friends, service systems, and congregations ensure meaningful opportunities for people with significant disabilities to discover, explore, and express their spirituality in personally valued ways? First, researchers might explore both the ordinary and uncommon ways

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in which individuals with complex communication challenges or extensive support needs express their spirituality. Unduly narrow expectations of such expressions often lead others to inadvertently assume this domain is entirely irrelevant (or uniformly important) to people with significant disabilities. Moreover, the ways in which spirituality and religiosity impact, interact with, and/or emerge from self-determination has been under-studied. Little consideration has been given to providing access for exploring various religious traditions or for providing choice for a desired level of participation. Second, researchers might explore the ways in which formal services and informal supports could be individually tailored to address this aspect of peoples' lives. For example, circles of support and other person-centered approaches hold great promise in this area (Preheim-Bartel, Neufeldt, Leichty, & Guth, 2011). Third, much more should be learned about fostering leadership development among people with disabilities who are called to this vocation. Supporting people with disabilities to become leaders within faith-based organizations is essential to shifting views of people with disabilities from the focus of ministry to the ones participating in ministry.

Supporting Families

Findings ways to support families well has been an enduring area of emphasis in the research literature. Among the factors that have been shown to help families thrive are the supports that often come from parents' own faith and/or their congregational community (e.g., Poston & Turnbull, 2004; Skinner, Correa, Skinner, & Bailey, 2001). In her systematic review of the special education literature, Ault (2010) identified numerous ways in which spirituality and religion served as a critical resource, protective factor, and source of support for families of children with disabilities. Yet, while many parents speak about the welcoming embrace of their congregations, many other parents speak primarily of missed opportunities. For example, Ault, Collins, and Carter (2011) reported that almost one third of parents surveyed said they had changed their place of worship because their child was not welcomed and less than one quarter said that parent support groups and respite care were available through their community. Efforts to support a high quality of life for families can be enhanced by careful consideration of the contributions that spirituality and religion might make in their lives.

What avenues of research might provide new insights into how to support families well in this area? First, there is much to be learned about the types of support families expect and

desire from their faith communities, as well as the impact these supports might have on a family's flourishing. For example, for specific communities (e.g., ethnically and culturally diverse, rural), congregations can play an especially prominent role as a center of cultural life and support. Second, although numerous opportunities abound for congregations to provide practical assistance to local families (e.g., offering respite care, hosting support groups, providing financial or other resources; Carter, 2011), the extent to which this is occurring nationally is unknown and no rigorous evaluations of innovative efforts have been undertaken. Third, families often report having limited access to guidance on how best to nurture the spiritual formation of their children with disabilities. Exploration of the ways in which families—individually and in concert with religious education programs—might foster the faith development of children and youth with disabilities should be undertaken.

Congregational Welcome and Inclusive Supports

Supporting the inclusion of people with significant disabilities in all aspects of community life is at the heart of TASH's National Agenda. Although much of this conversation has historically focused on classrooms, workplaces, and neighborhoods as contexts for promoting full participation, congregational involvement is also an important aspect of everyday life for people with significant disabilities (Kleinert, Miracle, & Sheppard-Jones, 2007). However, not every person with a significant disability who desires involvement in a faith community encounters a welcoming congregation. Faith communities struggle with inclusion in many of the same ways as do schools, businesses, and neighborhoods. Barriers of accessibility, awareness, attitude, and/or architecture are sometimes encountered more often than gestures of hospitality, welcome, and creativity. For example, LaRocque and Eigenbrood (2005) reported that many of the congregations they surveyed were still in the early stages of becoming more accessible and inclusive.

How might researchers begin to address this gap? First, the critical features of a truly "inclusive congregation" are still not well-defined, making it difficult for faith communities to reflect on where they are and where they might go next as they strive to expand their welcome. Although there is much that can be learned from inclusion efforts in other literatures, researchers could help articulate both common and unique indicators of a welcoming congregation (e.g., Collins & Ault, 2010). Second, while the responsiveness of congregations in this area is certainly

Articles from our Contributors

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uneven, many congregations are striving (indeed, successfully) to include people with significant disabilities into all aspects of community life. Researchers are only beginning to explore factors explaining why some congregations are taking this journey while others are not (cf., Griffin, Kane, Taylor, Francis, & Hodapp, in press). Third, the commitment and confidence of congregational leaders are likely to represent one especially powerful influence. Research is needed to identify the most promising avenues for equipping current and future congregational leaders with the vision, resources, and strategies needed to lead strongly in this area. Finally, as new venues for worship and forms of gathering continue to emerge, efforts are needed to explore what universal design features might look like in the context of congregational life.

Individually Tailored Support from Service Systems

Service systems also assume a prominent role in the lives of many people with significant disabilities. These service providers are charged with supporting the personal aspirations, community connections, contributions, self-determination, and quality of life of the individuals whom they serve. Such responsibilities also include ensuring the spiritual and religious needs of people with significant disabilities are meaningfully addressed when valued by individuals—whether directly and/or by making careful connections to others in a community. As noted in its resolution on spirituality (2003), “TASH supports the right of individuals with disabilities to participate in spiritual expression or organized religion as they so choose and promotes the provision of any and all supports needed by people with disabilities to so participate.” Yet, service providers sometimes struggle to support this dimension of people’s lives well. As a result, the spiritual needs of people with significant disabilities living within service systems are either unaddressed or deferred to someone else (i.e., still unaddressed). There remains a near absence of research addressing how service providers might address this dimension of the lives of people with significant disabilities (cf., Hatton, Turner, Shah, Rahim, & Stansfield, 2004).

What might be next steps for research in this area? First, initial studies might focus on how agencies—both faith-based and government-sponsored—are currently addressing the spiritual and religious needs of the individuals they serve. There is much that can be learned from the innovations within current practices. Second, the field still needs good models for asking

the compelling questions within existing planning processes. How might staff, family members, and others learn about an individual’s beliefs, desires, commitments, and sense of calling in this aspect of life? Third, effective partnership models among service providers, faith communities, and other natural partners are needed. As in other areas, it will take a constellation of efforts to truly help people with extensive support needs live rich and enviable lives.

Where We Might Go

The ideas shared in this article represent just a sampling of those that might help to make a real difference in the lives of people with disabilities. How might we as scholars contribute to this important area of inquiry? Consider the following ideas:

- Consider whether and how this dimension of people’s lives intersects with the research we are already undertaking. For example, spirituality and congregational connections may be especially relevant within research addressing self-determination, community inclusion, family supports, quality of life, individual supports, and many others.
- Collaborate with other scholars who could bring new expertise in these issues to our own scholarly work. Indeed, there is substantive research underway in the fields of health, sociology, adolescent development, religious studies, cultural studies, and theology.
- Explore the ways we can serve as a resource for our own faith communities (for those who participate) to assist in launching efforts of change and providing supports to persons with significant disabilities both within the faith community and out into the community.
- Connect with the newly launched national Collaborative on Religion, Disability, and Inclusive Spiritual Supports to affiliate with other scholars addressing the intersection of disability, religion, and/or spirituality within the context of interdisciplinary work.

Authors’ Note

The Collaborative on Religion, Disability and Inclusive Spiritual Supports has just launched and a website is in development. Contact Bill Gaventa (bill.gaventa@umdnj.edu), Erik Carter (erik.carter@vanderbilt.edu), or Courtney Taylor (courtney.taylor@vanderbilt.edu) to be added to its mailing list.

Articles from our Contributors

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SPECIAL PREVIEW

TASH 2012 Conference

The TASH Conference is the advocacy, networking and educational event of the year, attracting speakers and attendees from all over the world. Each year, self-advocates, educators, service providers, researchers and wide array of other advocates and professionals come together to learn, share and grow. TASH Conference participants hear from the nation's leading experts and advocates on topics such as inclusive education, customized employment, community supports, health and wellness and advocacy. The conference features more than 200 educational sessions and a number of networking opportunities, including the self-advocate and young

professional forums, and opportunities for students. Most importantly, TASH Conference participants contribute to national advocacy efforts that improve the lives of people with disabilities, and advance the work of professionals in the field.



TASH

CONFERENCE

So Many Answers Left Unquestioned

LONG BEACH / CA / NOV 28 - DEC 1, 2012

Special Preview: TASH 2012 Conference

Keynote Speakers

Opening General Session

Wednesday, November 28

Leadership Panel on Inclusion

Inclusion leaders Madeleine Will (moderator), Norman Kunc, Charlie Lakin, Barbara Ransom, and Wayne Sailor help us kick off the TASH Conference with a panel on inclusion.

What have we accomplished in advancing inclusion? Why haven't we done more? What can we do to ensure progress is made? Join us as this leadership panel considers the future of inclusion by understanding the challenges of yesterday and today.

Closing General Session

Friday, November 30

Eva Sweeney

Eva Sweeney is a 29-year-old freelance writer. She graduated from Occidental College with a Bachelor's degree in gender studies. Sweeney also just produced her first documentary, *Respect: The Joy of Aides*, which examines and challenges the relationship between people with disabilities and their aides. In her free time, she likes to have coffee with friends and play with her two dogs.

Amy Brenneman

Amy Brenneman, a parent, actress, producer, and advocate, received her degree in Comparative Religion from Harvard University and was a founding member of the award-winning Cornerstone Theater Company. Most recently, she has played the role of Violet in the ABC series, *Private Practice*. Her previous roles include *NYPD Blue*, which received two Emmy nominations, and *Judging Amy*, which received three Emmy nominations, three Golden Globe nominations, and was the winner of three TV Guide awards for Best Actress, among a variety of other performances.

As the parent of two children who attend a fully inclusive school, Brenneman has worked to promote the importance of transitioning from segregated models of education towards innovative and fully inclusive schools where children with and without disabilities learn together.

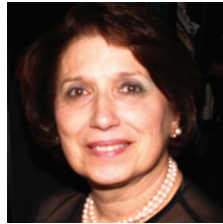
In addition to her work to promote inclusive education, Brenneman is also known for her advocacy on women's rights, gay marriage, gun control, children's health, and more. Amy is married to writer/director Brad Silberling and their two children are Charlotte and Bodhi.

Pre-conference and Post-Conference Workshops

The TASH Conference will feature a series of short-course workshops on Wednesday, November 28, with leading experts in the disability field that allow attendees to dive into popular topics in more depth. These workshops are included with general conference registration.

Post-Conference Workshops at the TASH Conference will take place from 9 a.m. to 5 p.m. on Saturday, December 1, 2012. These workshops are full-day, skills-building workshops that offer opportunities for participants to access detailed information and resources on a particular topic. There is an additional fee to participate in post-conference workshops.

Find a full listing of pre- and post-conference workshops at www.tash.org/2012tash!



Special Preview: TASH 2012 Conference

Conference Schedule Builder

TASH has made it easier than ever to keep track of your schedule with the TASH Conference Schedule Builder. Using the schedule builder is easy! You can find it at www.tash.org/2012tash. Just create a free profile, then search conference events by session name, presenter, day and time, room, or subject area. You can then select the sessions you'd like to attend to create a conference schedule that can be e-mailed, printed, or shared on Facebook and Twitter!

Exhibitors & Sponsors

The 2012 TASH Conference is expected to host more than 1,000 people with disabilities, family members, academics, service providers and others in Long Beach, Calif., from November 28 – December 1. Involvement in the TASH Conference as an exhibitor or sponsor demonstrates a commitment to equity, opportunity and inclusion in schools, workplaces and the communities in which we live. It's a great way to show your support and make a positive impact on the lives of people with disabilities. Exhibitors at the TASH Conference will showcase

their services, products and message from Wednesday, November 28, through Friday, November 30, in the main space of the TASH Conference. And conference sponsors will be highlighted throughout the conference for their support of the disability community. Learn more at www.tash.org/2012tash or e-mail conference@tash.org for further details.

Welcome to Long Beach, California!

Home to the regal Queen Mary, a retired Ocean liner that sailed as a transatlantic cruise liner and troopship from 1936 to 1967, the Aquarium of the Pacific, which features a collection of over 11,000 animals, the Long Beach Performing Arts Center, and hundreds of exclusive dining destinations, Long Beach is an exciting (and warm) destination for the 2012 TASH Conference.

This year's TASH Conference will be held at the beautiful Westin Long Beach, which has four airports and an Amtrak station within driving distance, as well as an LA Metro stop about 5 minutes away, walking.

We hope you'll join us!



Registration

1. Register quickly and easily online at www.tash.org/2012tash
2. Download, complete, and return a registration form (also available at www.tash.org/2012tash)
3. Call us and we can get you setup over the phone

Important Dates

September 2 – November 1: Regular Registration Period
November 2 – On-Site: Late Registration Period

Full Conference Registration			
Registration Type	Deadline	Member	Non-Member
Advocate	Early	\$175	\$205
	Regular	\$225	\$255
	Late	\$275	\$405
Professional	Early	\$325	\$355
	Regular	\$375	\$405
	Late	\$425	\$455
Student	Early	\$200	\$230
	Regular	\$250	\$280
	Late	\$300	\$330

One Day Pass			
<i>Wednesday (Nov. 28)</i> <i>Thursday (Nov. 29)</i> <i>Friday (Nov. 30)</i>	Deadline	Member	Non-Member
	Early	\$125	\$155
	Regular	\$150	\$180
	Late	\$175	\$205

Post-Conference (Dec. 1)		
Registration Type	Deadline	Cost
Advocate	Early	\$60
	Regular	\$65
	Late	\$75
Professional	Early	\$100
	Regular	\$125
	Late	\$150
Student	Early	\$70
	Regular	\$75
	Late	\$85

Wednesday & Saturday Afternoon Workshops & Post-Conference

November 28, 2012

The 2012 TASH Conference features a series of short-course workshops on Wednesday, November 28 with leading experts in the disability field that allow attendees to dive into popular topics in more depth. Listed below is a sampling of workshops that will be available. To view the full list, visit www.tash.org/2012TASH. Wednesday afternoon workshops are included with general conference registration.

Doctoral Students and Beginning Special Education Faculty Networking Workshop

10 a.m. – 5 p.m.

This workshop is for doctoral students who plan to join the faculty at a college or university, and for tenure accruing faculty in their first three years as a college or university faculty member. The workshop will focus on strategies for becoming tenured, publishing papers, writing grants, establishing a network of colleagues, preparing teachers, supporting service providers (e.g., schools, customized employment, independent living), establishing a research/scholarship agenda, and balancing professional and personal lives.

Making Common Core Standards Accessible for all Students

1 – 5 p.m.

Deborah Taub, Mike Burdge, Anne Denham, Jean Clayton and Donna Wickham

Providing students with severe disabilities access to grade level content in the general classroom can be challenging. The students may need supports to address missing foundational skills, behavior challenges and/or emerging communication skills. This session focuses on how we will teach the Common Core State Standards and shares a process for how to make the new standards accessible for all students, especially those with severe disabilities. The presenters will teach participants to use a four-step process (Clayton et al., 2006) that results in access to grade level content for all students while embedding foundational skills that are vital for understanding concepts and learning the content.

Why Kids Bully and What Can be Done About It

1 – 5 p.m.

Julaine E. Field, Christi Kasa and Janet Sauer

This interactive workshop provides background knowledge about bullying and specific strategies to understand and take action when encountering bullying. The presenters will provide video vignettes to illustrate different roles people play when engaging in different forms of bullying. We will provide research-based strategies and seek audience participation in discussing the issues.

December 1, 2012

These post-conference workshops are full-day, skills-building workshops on December 1, 2012, that offer opportunities for participants to access detailed information and resources on a particular topic. A complete schedule of workshops can be found at www.tash.org/2012TASH. There is an additional fee to participate in post-conference workshops.

Accessing the General Curriculum through Assistive Technology for Students with Significant Disabilities

9 a.m. – 5 p.m.

Kathleen Gee, Jacqui Kearns, Jane O'Regan Kleinert, Penina Goldstein, Sam Sennott, and Ann-Marie Orlando (facilitator)

This workshop provides caregivers, teachers, and related service personnel with highly effective, evidenced-based strategies to develop and integrate communication systems for students with complex communication needs into the academic content across the school day. Practical examples of cognitive scaffolding, adaptations, technology, and modifications for students with multiple disabilities will be provided. Also included in this workshop will be two 45-minute panel discussions with the presenters and other experts in the field of AT to discuss the selection and use of IOS applications and AT in the context of Universal Design for Learning.

Keeping Schoolchildren Safe from Restraint and Seclusion

9 a.m. – 5 p.m.

Joan Gillece, Janice LeBel, Peg Kinsell, and Pat Amos

Parents and educators can be strong allies in ensuring that schools create a safe, welcoming learning environment. Restraint and seclusion have resulted in trauma, injury, and death. They teach students that "might makes right" and inhibit cognitive and social development, while offering no positive alternatives. They are now considered unacceptable for use in the mental health system, nursing homes, and hospitals; our schools must follow suit. This workshop will help parents, advocates, and educators understand how to work together to prevent and eliminate the dangerous and traumatizing practices of restraint and seclusion.

The Keys to Making Inclusion Work

1 p.m. – 5 p.m.

This workshop will provide practical tools for the school-level practitioner and families who want to learn about quality indicators and resources to support inclusive practices throughout a child's education. Participants will begin the day with a discussion of nine steps for meaningful inclusion for one child at a time, then dive into the Core Curriculum and differentiation of instructional practices. In the afternoon participants will revisit core indicators of best practices for inclusion and close out the day with information regarding the need for a digital toolkit to support effective inclusion in classrooms. The day will fast-paced, active, and provide a number of very practical classroom and school strategies to support learners.

2012 TASH Conference Registration Form

November 28-December 1, 2012 • Long Beach, California

www.tash.org/2012tash

Conference Registration

TASH Member? ☐ Individual ☐ Organization (organization member name): _____

First Name: _____ Last Name: _____ Badge Name: _____

Organization Badge (if applicable): _____

Address: _____ City/State/ZIP: _____ Country: _____

Phone: _____ E-mail: _____

Registering more than one person? You only need to complete the payment section once, but we ask that you submit conference registration details (this section) for each individual you wish to register.

Registration Type

Advocate: person with a disability, family member, direct support staff or other individual not employed in the disability field.

Professional: person employed in the disability field or related field.

Student: part-time or full-time student in a disability-related academic program.

Full Conference Registration	Early Bird (by Sept. 1)		Regular (Sept. 2-Nov. 1)		Late (Nov. 2-Onsite)	
	Member	Non-Member	Member	Non-Member	Member	Non-Member
Advocate	<input type="checkbox"/> \$175	<input type="checkbox"/> \$205	<input type="checkbox"/> \$225	<input type="checkbox"/> \$255	<input type="checkbox"/> \$275	<input type="checkbox"/> \$405
Professional	<input type="checkbox"/> \$325	<input type="checkbox"/> \$355	<input type="checkbox"/> \$375	<input type="checkbox"/> \$405	<input type="checkbox"/> \$425	<input type="checkbox"/> \$455
Student	<input type="checkbox"/> \$200	<input type="checkbox"/> \$230	<input type="checkbox"/> \$250	<input type="checkbox"/> \$280	<input type="checkbox"/> \$300	<input type="checkbox"/> \$330

One Day Pass	Early Bird (by Sept. 1)		Regular (Sept. 2-Nov. 1)		Late (Nov. 2-Onsite)	
	Member	Non-Member	Member	Non-Member	Member	Non-Member
Includes admission to one day of the TASH Conference	<input type="checkbox"/> \$125	<input type="checkbox"/> \$155	<input type="checkbox"/> \$150	<input type="checkbox"/> \$180	<input type="checkbox"/> \$175	<input type="checkbox"/> \$205
	Select day	<input type="checkbox"/> Wednesday (November 28) <input type="checkbox"/> Thursday (November 29) <input type="checkbox"/> Friday (November 30)				

Post-Conference (Dec. 1)	Early Bird (by Sept. 1)	Regular (Sept. 2-Nov. 1)	Late (Nov. 2-Onsite)
Advocate	<input type="checkbox"/> \$60	<input type="checkbox"/> \$65	<input type="checkbox"/> \$75
Professional	<input type="checkbox"/> \$100	<input type="checkbox"/> \$125	<input type="checkbox"/> \$150
Student	<input type="checkbox"/> \$70	<input type="checkbox"/> \$75	<input type="checkbox"/> \$85

Please note: the purchase of a non-member conference registration or one day pass includes Basic TASH membership. You may discontinue this membership by contacting TASH at info@tash.org. **Membership details are on the following page.**

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 a first time TASH Conference attendee? ☐ Yes ☐ No

Would you like to participate in the TASH Conference mentorship program? ☐ Yes, as a mentor ☐ Yes, as a mentee ☐ No

-Continued on Next Page-

Accommodations Information *(optional)*

Will you need simultaneous translation? ☐ Yes ☐ No If yes, for what language? _____

Do you require a personal assistant? ☐ Yes ☐ No

Do you need any reasonable accommodations? _____

Do you have any dietary restrictions? _____

TASH Membership *(current members please skip - required for non-member registrations)*

Conference registration for non-members includes **Basic Membership** by default. To upgrade to another membership type, you must pay the cost difference. Please select from the following membership types. Benefits vary by membership type. *(A complete description of member benefits is available at www.tash.org/membership)*

	Basic \$0 <i>(regular \$30)</i>	Standard \$45 <i>(regular \$75)</i>	Premium \$120 <i>(regular \$150)</i>	Student \$15 <i>(regular \$45)</i>	Sm. Org \$220 <i>(regular \$250)</i>	Lg. Org \$320 <i>(regular \$350)</i>
<i>Research and Practice for Persons with Severe Disabilities</i> , the official TASH research journal (print copy)			X		1 COPY	1 COPY
<i>Research and Practice for Persons with Severe Disabilities</i> , (online access to current and archived issues)		X	X	X	X	X
<i>Connections</i> , 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	<input type="checkbox"/> Select	<input type="checkbox"/> Select	<input type="checkbox"/> Select	<input type="checkbox"/> Select	<input type="checkbox"/> Select

☐ Select to opt out of TASH membership *(non-member registration rate applies)*

Payment Information

Credit Card *(select card type)*

☐ American Express ☐ Visa
☐ MasterCard ☐ Discover

☐ **Check** *(make payable to TASH)*

☐ **Purchase Order**

P.O. #: _____

(send copy of purchase order with registration)

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 conference registration total plus membership balance and donation, if applicable)* \$: _____

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

TASH

1001 Connecticut Ave, NW, Suite 235
Washington, DC 20036

Fax (202) 540-9019

E-mail conference@tash.org

Registration Policies

Registration will not be accepted without full payment online or by check, credit card or official purchase order. All checks must be in US dollars and made payable to TASH.

Registration Type

Advocate: person with a disability, family member, direct support staff or other individual not employed in the disability field.

Professional: person employed in the disability field or related field.

Student: part-time or full-time student in a disability-related academic program.

Presenter registration

All conference presenters must register and pay the registration fee for the conference. If presenters wish to attend only on the day they present, they may register for a one-day pass. If all presenters listed on a presentation are not registered by September 15, 2012, the presentation will not be included in the conference.

Cancellation

A 15% service charge will be assessed for processing refunds. All cancellations must be requested in writing (fax and e-mail are acceptable) and must be received (not postmarked) in the TASH office by 5 p.m. ET on November 2, 2012. No refunds after November 2. All requests for refunds should state the registrant's name and the amount of payment. "No shows" at the conference will be billed the full registration fee. We regret that we cannot offer refunds for "no shows," however, substitutes are welcome.

Registrant substitution

Substitutions for a registrant who can no longer attend the conference can be made at any time. If the substituted registrant does not fit into the same registration category, they will be responsible for payment of the difference in conference registration fees.

Personal assistants

Personal assistants are not expected to pay a conference registration fee. However, personal assistants are expected to register and attend sessions with the individual they are supporting. If you plan to bring a personal assistant, identify that you will bring a personal assistant during registration and complete your registration. Once this is complete, please contact the TASH office at conference@tash.org or (202) 540-9015 so we can register the personal assistant directly.

Reasonable accommodations and dietary restrictions

Individuals with disabilities requesting reasonable accommodations and/or dietary modifications at the conference should indicate necessary accommodations during the registration process. We cannot guarantee accommodations and/or dietary modifications for requests received after November 2, 2012.

Mentorship Program

The TASH Conference Mentorship Program offers the chance for attendees to link up with an experienced TASH Conference attendee before heading to the 2012 conference. If you have specific questions about the TASH Conference experience, or you just want to know someone familiar before heading to conference-wide events and receptions, this is a great way to connect. We encourage anyone who is interested to participate as a mentor or mentee. Matches will take place several months prior to the conference.

Association News

TASH Members Making a Difference on Capitol Hill

On June 26, 2012, the TASH Board of Directors and several additional TASH members gathered on Capitol Hill for a day of advocacy. Each participant had worked for weeks in advance to line up meetings with their Senate and House offices throughout that day to promote TASH's public policy agenda, which included:

1. Protecting youth with significant disabilities from abuse by establishing federal restrictions on the restraint and seclusion practices in schools.
2. Promoting stronger accountability and inclusive education requirements for all students.
3. Supporting the view that all people with significant disabilities can work and participate in competitive, integrated employment.
4. Ensuring Medicaid supports help people to live, work and achieve optimal self-sufficiency in the community.

In total, more than 60 meeting were held with Senate and House offices! Thanks so much to everyone who participated in this day of advocacy, including TASH Board Members: Bill Smith, Gail



Board member Gail Fanjoy (left) and Debbie Gilmer meet with Congressman Mike Michaud, a co-sponsor of the TEAM legislation in the House.

Fanjoy, Emily Titon, Micah Fialka-Feldman, Terri Ward, Pat Amos, Carol Quirk, David Westling, Nila Benito, Diane Ryndak, Charles Dukes, Jean Trainor, Mary Morningstar, Lisa Mills, Michael Callahan, Lewis Jackson, and Shirley Rodriguez. They were joined by TASH supporters Debbie Taub, Debbie Gilmer, Kym Grosso, Kayleen Symmonds, Nancy Molfenter, and Hope DeBevoise.



Board member Emily Titon meets with Rep. Jack Reed of Rhode Island.



Board members Nila Benito (left) and Diane Ryndak prepare to enter Rep. Kathy Castor's office.

Remembering Dr. Hank Bersani Jr.

TASH remembers Hank Bersani Jr., professor of special education at Western Oregon University, who died from injuries sustained



during a traffic accident on Saturday, March 31. Bersani, a former TASH member, was a respected and highly influential leader in the field of special education. He also contributed knowledge and expertise to the Forgotten People Foundation, which supports children and adults with disabilities in Vietnam. View a tribute wall for thoughts and memories at WOU's website. (http://wounews.wordpress.com/2012/03/31/hank_bersani/)

TASH Report: What is 'The Cost of Waiting' for Legislation that Protects Kids from Abuse?

TASH has released the second edition of The Cost of Waiting,



which comes two years after the U.S. House of Representatives passed legislation to restrict restraint and seclusion in schools. Such legislation never

reached the Senate floor, and subsequent attempts have yet to yield real protections from abuse for our students. The Cost of Waiting chronicles the implications of inaction, as children across the country continue to be subjected to abusive practices that result in serious emotional trauma, physical pain and injury, and even death. Please view, download and share this report with your networks. (<http://tash.org/tash-shows-%E2%80%98the-cost-of-waiting%E2%80%99-to-end-restraint-seclusion/>)

DOE Releases '15 Principles' on Restraint, Seclusion: APRAIS Responds

The U.S. Department of Education issued 15 principles regarding the use of restraint and seclusion in schools. This represents the most formal position taken by federal authorities to date, although the principles are not enforceable and stop short of what the Department could have done on the matter. In response, the Alliance to Prevent Restraint, Aversive Interventions and Seclusion—a TASH-led coalition—has thanked the Department for calling attention to this critical issue and for taking a firm stance against the use of prone, chemical and mechanical restraints. However, APRAIS believes the Department should do more to promote positive and safe learning environments, as outlined in IDEA and ESEA. We hope this public stance can lead to continued change at the federal level, including the passage of Senate and House bills to prevent restraint and seclusion in schools. Find the 15 principles and view the full APRAIS response here (<http://tash.org/departement-of-education-issues-%E2%80%9815-principles%E2%80%99-stops-short-on-restraint-seclusion/>).

TASH Signs Letter of Protest Against Dr. Phil Show for Euthanasia Segment

TASH has signed on to a letter protesting an episode of the Dr. Phil Show, which presented the idea that parents should be able to euthanize their children who have intellectual disabilities. The show, which aired April 13, 2012, featured a largely biased discussion that began with Annette Corriveau, a woman with two adult children with a progressive genetic condition known as Sanfilippo syndrome. By not providing clear and balanced arguments against this abhorrent practice, the program conveyed social acceptance of euthanasia for people with disabilities by their family members, and further promoted violence against people with disabilities. You can read the full letter on the TASH Blog (<http://tash.org/tash-signs-letter-of-protest-against-dr-phil-show-for-euthanasia-segment/>).

Members Speak Out at National Transition Conference

The Office of Special Education and Rehabilitative Services drew more than 800 researchers, educators, rehabilitation counselors, self-advocates and other stakeholders to three days of discussions on transition to college and careers for youth with disabilities. Barb Trader, TASH's Executive Director, presented with Norciva Shumpert on policy reform that supports expanded

availability of customized employment strategies for individuals with significant impact of disability. In a second panel, Barb and Madeleine Will shared recommendations from a recent roundtable on improving education accountability for transition-age youth, which was hosted by the Collaboration to Promote Self Determination, which Barb and Madeleine Co-Chair. Policy reform is a continued priority for TASH, particularly in the area of improving education and transition practices toward better life outcomes for the people for whom we advocate. Promising systems change work is underway in 12 states and with TASH member involvement as a result of grant programs funded through the Office of Disability Employment Programs and the Administration on Intellectual and Developmental Disabilities. A third grant program, PROMISE, is expected to be launched in 2013 by the Office of Special Education and Rehabilitative Services.

One very prominent theme of the National Transition Conference was the presence of an implementation gap between best practice and current practice in states. With increased pressure for improved employment outcomes expected from many federal partners, TASH members have leverage to influence changes in states. More information will be shared in webinars on this topic throughout the summer months. Please watch TASH in Action for more information. Also, 2012 National Transition Conference presentations will be available on the TASH website by June 15. Program information on the 2012 National Transition Conference is available at www.transition2012.org.

Wanted: TASH Night Out Hosts!

Consider hosting a TASH Night Out (<http://tash.org/conferences-events/tash-night-out/>) event—it's a great way to get involved locally while supporting TASH. A TASH Night Out is a party, celebration, or any way you want to bring together your friends, coworkers, neighbors and others for fun, with a goal to raise funds for TASH. Members and chapters have hosted pool parties, wine and cheese parties, movie nights, happy hours, garden parties, cook-outs, lobster bakes, pot-luck and other events and outings. Also, your birthday, wedding or anniversary can be a TASH Night Out—just ask your guests to make a contribution to TASH in lieu of gifts.

To give you some examples: Gail Fanjoy is planning a summer Lobster Bake in Maine. PennTASH has a pool party scheduled for September. Jean Trainor is having her Third Annual Jimmy Buffett TASH Night Out this August! There are so many great ideas. And, each event helps to raise funds for TASH while bringing together friends, family and neighbors and raising awareness about issues impacting the disability community. If you would like to host an event, please contact Michelle Gentry at mgentry@tash.org or (703) 303-0293.

TASH Gratefully Acknowledges the Following Donations of Time and Money

Martin Agran	Cohen	Haley Kimmet	Barbara Ransom	Emily Titon
Patrick Allen	Charles Dukes	Barbara Loescher	Jonathan and Darlene	Jean Trainor
Elizabeth Altieri	Gail Fanjoy	Sharon Lohrmann	Reithmaier	Terri Ward & Hope
Pat Amos	Amy Feinberg	Serena Lowe	Shirley Rodriguez	DeBevios
Nila Benito	Micah Fialka-Feldman	Lisa Mills	Jeanne Rodriguez	David Westling
Marina Berthiame	Nancy Franklin	Mary Morningstar	Mary Romer	Joe Wykowski
Michelle Bonati	Donna Gilles	Andrea O'Brien	Lyle Romer	Community Vision,
Lou Brown	Sue Henshaw	Valerie Parker-Hunter	Diane Ryndak	INC
Cherri Cary	Bryna Helfer	Kathryn Peckham-	Bill Smith	HSC Foundation
Brandy Clark	Pamela Hunt	Hardin	Lisa Swanson	Jay Nolan Community
Jeffrey and Arlene	Lewis Jackson	Carol Quirk	Colleen Thoma	Service

Chapter News

Cal-TASH Celebrates Its 30th Anniversary

Cal-TASH hosted its annual conference and 30th Anniversary celebration on March 2-3 in Oakland, California. By all accounts, the conference was a tremendous success. The conference offered 49 sessions and two keynote presentations featuring Rob Horner, Darlene Hanson and Rishab Thapar. Attendees also rocked out to The Ian Fays at the Cal-TASH Bash!

All past board members were invited to share in a celebration with the Cal-TASH Chapter. Mary Falvey, one of the chapter founders, shared memories of the early days. Kathy Gee and Jacki Anderson also shared stories of Cal-TASH's past work in the state. It was a fun-filled reunion. Barb Trader, TASH executive director, and Sharon Lohrmann, TASH board member, were also in attendance to support the conference and share in the festivities. Congratulations to the Cal-TASH Board of Directors and a great group of volunteers for all their hard work to pull this conference together.

AZWINS Inclusion Practice Training Series Continues in Arizona TASH

Arizona TASH, as part of the ongoing AZWINS Inclusive Practice Training Series, offered a training session, Linking IEP Goals to the General Education Curriculum: Teaching Students with Significant Disabilities in Inclusive Settings on March 9 in Phoenix, Arizona. AZ TASH offers several trainings, throughout the year, on inclusion and supports for parents and educators of children with significant disabilities. For more information about AZ TASH and AZWINS, contact Sherry Mulholland, mulhollandmatsutakeout@yahoo.com or Andrea O'Brien, andrea.m.obrien@cox.net.

Kentucky TASH Offers an Inclusion Tour and Co-Hosts a Conference with the ARC of Kentucky

Kentucky TASH proudly sponsored an inclusive education tour featuring Michael Remus. The event was held Saturday, March 10, in Prestonburg, Kentucky. Michael Remus is a national consultant and author of *More than Shared Classroom*. The free training provided parents and special educators with information on evidence-based practices that lead to success in education, employment and independent living.

Kentucky TASH and the ARC of Kentucky hosted a joint conference on Keeping the Dream Alive April 27-28 in Hurstbourne, Kentucky. David Braddock from the Coleman Center for Cognitive Disabilities provided the keynote address and other guest speakers, including: Michael Remus, Patty Cassidy, Stephen Hall, Eric Friedlander and Serena Lowe. Attendees chose from 21 breakout sessions in addition to the planned keynote and guest speakers. The conference also included an Exhibit Information Extravaganza and a silent auction.

Cheryl Jorgensen Visits Ohio TASH for Two Special Events

Ohio TASH, in collaboration with the Otterbein University Courtright Memorial Library and friends, presented the Erin McKenzie Virtual Welcoming Space Event on April 12, Westerville, Ohio, featuring Cheryl Jorgensen. Cheryl used the theme and text of the book, *A Place Where Everyone Belongs: the Story of Pedro's Whale*, to describe the values and practices that make schools places where everyone belongs and no one is left behind.

Ohio TASH also sponsored a day-long mini-conference—Civic Engagement and Meaning Based Learning Conference—featuring Cheryl Jorgensen on Friday, April 13, at the College of Mount St. Joseph in Cincinnati, Ohio. Cheryl presented her paper, Inquiry Based Instruction that Accommodates Student Diversity, describing a model for teachers to develop lessons for diverse classrooms.

Welcome to the Newest TASH Chapter, Florida TASH!

TASH is pleased to announce that the Florida chapter is now up and running! Florida TASH will support TASH members living in Florida and will work hard this year to recruit new members

and to uphold the mission and values that improve access, equity, inclusion and opportunity for people with disabilities. Congratulations, Florida TASH!

Don't see a chapter near you? There may be one forming in your region.

TASH Chapters are growing all over the country in 2012! Be a part of the grassroots movement to promote TASH values and advocate for systems change in your community.

[Visit the TASH website](#) for more information about chapters and how you can start one where you live.



Chapters are the heart of TASH!

The TASH chapter network has a burst of energy stemming from the 2011 TASH Conference in Atlanta. Plans are now underway for new chapter initiatives in several states, as well as chapters in three countries. Stay tuned for developments as we grow!

Is there a TASH Chapter in Your Area?

If you'd like to learn more about starting a TASH Chapter, please contact Amy Feinberg at afeinberg@tash.org or call (202) 540-9014.



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
<i>Research and Practice for Persons with Severe Disabilities</i> , the official TASH research journal (print copy)			X		1 COPY	1 COPY
<i>Research and Practice for Persons with Severe Disabilities</i> , (online access to current and archived issues)		X	X	X	X	X
<i>Connections</i> , 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	<input type="checkbox"/> Select	<input type="checkbox"/> Select	<input type="checkbox"/> Select	<input type="checkbox"/> Select	<input type="checkbox"/> Select

*Student members are required to identify university: _____

-Continued on Next Page-

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 20036

Fax (202) 540-9019

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





TASHConnections

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