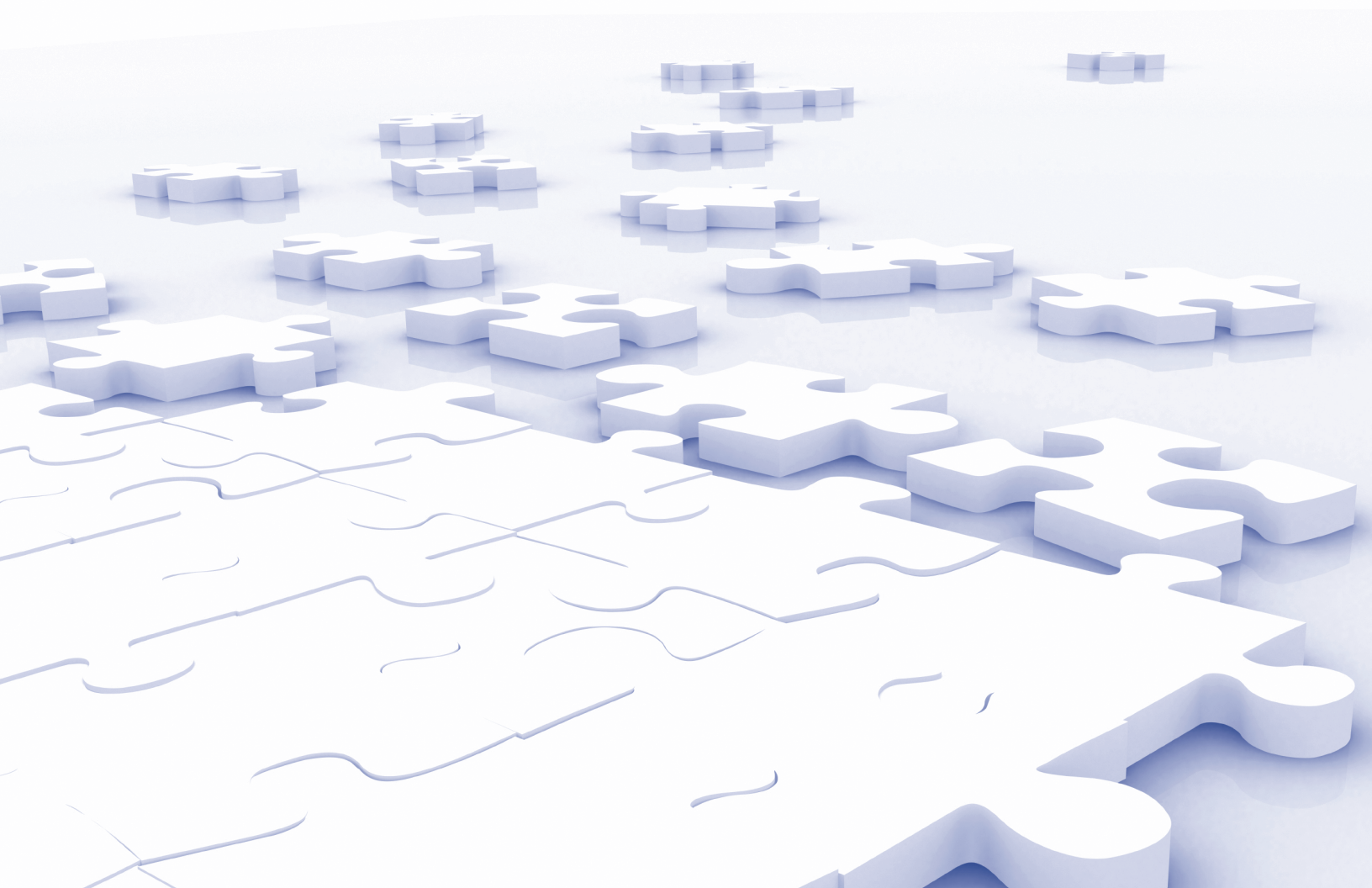


# Autism and Faith: A Journey into Community



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This publication is a collaborative product of The Elizabeth M. Boggs Center on Developmental Disabilities at UMDNJ-Robert Wood Johnson Medical School, Department of Pediatrics and Autism New Jersey, (formerly COSAC). The project and first printing were generously funded by a grant from The Daniel Jordan Fiddle Foundation. The second printing was funded by the New Jersey Department of Human Services, Division of Developmental Disabilities, contract (Contract #07ML11C).

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*A University Center for Excellence  
in Developmental Disabilities Education, Research, and Service*



New Jersey's Autism Resource



## Autism and Faith: A Journey into Community

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## Preface: How this Booklet Came to Be!

At a Sunday service several years ago, as the congregation was chanting an ancient and haunting invocation to the Holy Spirit, I heard a loud and clear and very distinctive voice above the song. I knew immediately there was a child with autism in the church. And my first thought was, "We are not alone." My younger son had been diagnosed with autism just a year before, and I had not told many people in my faith community, and had no idea there were other families of children with autism in the congregation. I had assumed we were the only ones. But that Pentecost morning, as we invoked the Spirit of God who acts in human history and who sustains our life together, I began to realize that this community, like faith communities of all kinds, could and did welcome individuals with autism.

This resource for including individuals with autism in faith communities is written so that others will not feel alone. Parents and families of individuals with autism, congregations struggling to become better at being inclusive, and individuals with autism themselves all need to know that they are not alone.

*"...as we invoked the Spirit of God who acts in human history and who sustains our life together, I began to realize that this community, like faith communities of all kinds, could and did welcome those with autism."*

This booklet has its roots in a panel presentation given at the 2005 annual conference of The New Jersey Center for Outreach and Services for the Autism Community (COSAC) on including individuals with autism in faith communities. The work has been carried on by The Autism and Faith Task Force of The Elizabeth M. Boggs Center on Developmental Disabilities and COSAC. The Task Force's first action was to survey parents, family members, and professionals in faith communities, to determine the most

pressing issues regarding inclusion so that this resource could be as useful as possible. Alice Walsh, during her Traineeship at The Boggs Center, did much of the coordinating and organizing work on the questionnaire and the first versions of this booklet.

Many parents, religious educators, and other religious professionals completed our survey, and we would like to thank them. We especially want to thank all the families who took the time to write down and share their stories; this booklet is much richer for those many varied voices.

We also want to thank all the members of The Autism and Faith Task Force, who have gathered for numerous brainstorming and editorial meetings during the past two years. Thank you also to all of our contributing authors - your words will make a difference in the lives of others. We remain especially grateful to The Daniel Jordan Fiddle Foundation for funding support and for believing in the purpose and value of this resource.

Finally, we'd like to thank all the individuals with autism spectrum disorders whose lives and dignity have inspired all involved. You are not alone.

*Mary Beth Walsh, with Alice Walsh and Bill Gaventa, Editors*



# Open the Door

**Linda Walder Fiddle, Esq.**


In 1993, when my son, Danny, was diagnosed with Pervasive Developmental Disorder (PDD) (that I later learned meant he was autistic), my first thought was not to run to my local synagogue for support. Perhaps this was in part due to my own religious upbringing, which amounted to attending High Holiday services and various life cycle events of friends and family members. Indeed throughout my adult life, I had rarely sought out support or participated in a faith community. Thus, when confronted with Danny's autism, I did what I always did: I organized a plan of action. That plan included finding an appropriate school, therapists and doctors and although I was propelled by my own sense of faith, the plan did not include joining a faith community.

When I reflect back now I realize that the reason I did not look to my faith community for support was that I just couldn't deal with the possibility of rejection. Quite frankly it was challenging enough to navigate the daily routines that required tremendous planning due to Danny's unpredictable and frenetic behaviors and I did not feel at all that he could handle the requirements of religious worship. My defensiveness and protectiveness fueled the notion that if Danny would not be welcomed, the rest of the family would not be welcomed either. And so, our family never joined any faith community of any kind.

There were times, however, that I peered through the peephole of the door to my faith community but always my fears, real or imagined, kept me from opening it. And because I did not open the door, I did not know what was behind it and what I was missing. A caring friend would call me from time to time to invite me in and finally, after many excuses, I joined her for Shabbat dinner and services. Gradually, I realized that I was not dishonoring my son if I sought the comfort and support of my religious community. In fact, through my own involvement and knowledge I could create a path to honor him as well as opportunities to include others who, like me, stood at the door but could not open it.

It is my hope and prayer that whether you are a parent of a child with autism, an adult with autism, a mother, a father, a sister, brother, aunt, uncle or friend of someone with autism that you will read this book and find ways that you can open the door to your faith community. Bring it to your clergy, your lay leaders and your teachers to read so that they can help you open the door. You and they will never know what has been missing until that door is opened.

*Linda Walder Fiddle, Esq., is Executive Director of The Daniel Jordan Fiddle Foundation and a member of the Board of Trustees of COSAC. Ms. Walder Fiddle is a member of the NJ Adults with Autism Task Force and a member of the Board of Trustees of The Barnert Temple in Franklin Lakes, NJ.*



*“When I reflect back now I realize that the reason I did not look to my faith community for support was that I just couldn't deal with the possibility of rejection. My defensiveness and protectiveness fueled the notion that if Danny would not be welcomed, the rest of the family would not be welcomed either.”*

# The Value of Faith for Individuals with Autism Spectrum Disorders

**Linda Meyer, Ed.D, M.P.A.**

*“I sat motionless as my daughter stepped up to the Torah for the first time at her bat mitzvah.”*

- Dad of a 12-year-old daughter with autism

*“This was the first time we were able to attend mass on Christmas Eve as a family.”*

- Mom of a 9-year-old son with autism

The parents quoted above speak of “first times.” Their comments imply there were previous times that were less than successful, or times not attempted perhaps due to fear of rejection or embarrassment, stress, and/or lack of support or energy. It is clear that these parents value their ability to attend worship services and are grateful when their children with autism spectrum disorders can accompany them and they can worship as a family. For many parents, faith goes beyond themselves, and their family. It means being part of a community. Half of people living in the United States attend weekly religious services. Given that faith can play such a significant part in a family’s life, individuals of varying abilities and disabilities should have access.

We can speak of the value of inclusion, not only for individuals, but also for the communities. We look to a future when individuals with special needs are accepted and accommodated naturally and spontaneously in the places where they learn, exercise, live, work, play, and pray. Spiritual training may be considered the highest form of education.

*“Religion is all deeds and all reflection...Who can separate his faith from his actions...? ...And take with you all men: For in adoration you cannot fly higher than their hopes nor humble yourself lower than their despair.” (Kahlil Gibran)*

All of us: parents, religious educators, rabbis, priests, ministers, imams, congregations, behaviorists, lay leaders, administrators, and teachers need to work together to offer opportunities for participation and choice for all individuals with autism spectrum disorders in their congregational lives and worship. How can we level the playing field and open the doors?

First, teach with the end in mind. Employ evidenced-based learning principles to teach attendance and participation in services with the same intensity and consistency used to teach academic, vocational, leisure, or domestic skills. As with any inclusion opportunity, repeated practice and feedback are essential to initially “look the part,” and eventually, truly become a part of the community.

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Second, remember that on a personal level, we are all teachers. Teach each individual with an autism spectrum disorder with:

**Compassion**...to make a difference in the life of an individual with an autism spectrum disorder, you will need to go beyond what is convenient and easy;

**Understanding**...of the spectrum of differences;

**Acceptance**...welcome all and those who accompany them by your positive verbal and nonverbal behavior;

**Respect**... the individual gifts each person brings to his/her relationship with God and the community, and their privacy;

**Support**...until everyone can take advantage of naturally occurring supports;

**Tolerance**...to recognize and allow for deficits;

**Patience**...while skills are repeatedly practiced;

**Willingness**...to hear and learn about challenges, how people learn, and when and how you could respond (or not respond in some cases);

**High expectations**...know that all can learn the necessary skills to become full and contributing members of the community.

Third, all of us seek communities that will welcome and support us. We all know how valuable it is to feel included; but it is even more powerfully rewarding to help someone else feel that they belong.

*“Lord make me an instrument of thy peace...  
Grant that I might not so much seek  
To be consoled as to console;  
To be understood as to understand;  
To be loved as to love.”  
(St. Francis of Assisi)*

Fourth, we would like to believe that individuals with special needs are being increasingly accepted and accommodated naturally and spontaneously in the places where they live, work, play, and worship. Unfortunately, that is not always so. Parents and professionals need to adequately prepare their children and learners to meet the challenges of the real world. Places of worship need to be ready to welcome all. Then inclusion will not only be a possibility, but also a reality.

*“Whether one believes in religion or not, and whether one believes in rebirth or not, there isn’t anyone who does not appreciate kindness and compassion.” (Dalai Lama)*

I observed a Yeshiva program serving preschoolers with autism. One boy struggled each day with *Moreh* (teacher) Lisa to learn that people, places, and objects had names. His parents reinforced his lessons in the evenings. His ability to respond to simple questions was emerging. With lots of practice he was beginning to repeat short prayers. This day, while describing where objects were placed in relation to him and others, he was listing the people and objects in the room. He paused for a second, and his face lit up. With a smile he exclaimed, “God is everywhere!” Good job everyone.

*Linda S. Meyer, Ed.D., M.P.A., is Executive Director of The New Jersey Center for Outreach and Services for the Autism Community (COSAC).*

# What is Autism?

**Peter Gerhardt, Ed.D.**

In recent years, autism, or as it is more commonly referred to today, autism spectrum disorders (ASDs) have been the focus of extensive media attention. Barely a week goes by without some mention of autism in the media: from the epidemic-like increase in diagnosis, to potential genetic or environmental causes, to the discovery of promising interventions, or the news of some court case. But beside soundbite descriptions of autism as “a mysterious disorder,” there is rarely any discussion of what autism is, or for that matter, what it means to be a person with autism.

First identified by Leo Kanner in 1943, autism is a developmental disorder that impacts an individual’s ability to effectively communicate and understand reciprocal social behavior. It is associated with the display of unusual (e.g., body rocking) or ritualistic (e.g., standing up/sitting down three times before taking his seat) behavior, interests or activities. Current prevalence estimates (CDC, 2007) indicate that 1 out every 150 children born will be diagnosed with an ASD and that it is far more commonly diagnosed in boys than in girls. In 1994, the DSM-IV broadened the definition of autism spectrum disorders to include Asperger Syndrome.

Although autism is usually diagnosed before three years of age, it is not uncommon for individuals who have more language to be diagnosed somewhat later in childhood. In addition, there are a number of mildly involved individuals with autism who were misdiagnosed in childhood only to receive an accurate ASD diagnosis in adulthood. While intensive early intervention has proven to be a valuable tool in the development of more age-appropriate skills and abilities, ASDs are often regarded as lifelong conditions.

*“Autism is a developmental disorder that impacts an individual’s ability to effectively communicate and understand reciprocal social behavior.”*

Autism is considered to be a spectrum disorder, ranging from mild to severe, due to the diversity of expression that is associated with the disorder. On one end of the spectrum are individuals diagnosed with more “classic” autism who tend to have limited verbal language and poor social comprehension. On the other end are those individuals labeled as having Asperger Syndrome who are verbally competent

but still have significant challenges with social comprehension. In addition, a percentage of individuals with ASDs may also be diagnosed with an intellectual disability (e.g., mental retardation) while others may have IQs well above the average. It is this diversity of expression that prompted Steven Shore, an adult with Asperger Syndrome, to state that **“If you have met one person with autism, well, you have met one person with autism.”**

No matter where a particular individual may fall on the spectrum, challenges in understanding reciprocal social interaction are central to the diagnosis of, and living with, an ASD. To those of us not on the spectrum, this impairment in social interaction is often the most confusing and challenging part of learning to interact with individuals on the spectrum. While a typically developing child is, in effect, pre-programmed to be fascinated with other children and to learn from other children (and adults), children with an ASD tend to be more fascinated with objects. While a typically developing child will easily make and keep friends, the individual with autism will, in most cases, have limited interest in, or ability to, develop age-appropriate social relationships. For individuals whose autism is less severe, this difficulty in the area of social interaction, particularly as they age, is sometimes misinterpreted by typical peers and unfamiliar adults as being purposeful, rude, or even arrogant. When this happens, it is important to remember that ASD is a brain-based disorder. Thus, the resulting social deficits are neurological in nature, and not a matter of choice, arrogance, or poor parenting.

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Overlapping the social deficits are communication challenges that are common to all individuals on the spectrum. As noted, some individuals may be quite verbal while many others may be non-verbal, have limited speech, or communicate through the use of pictures, sign language, or a specialized, augmentative communication device. Even those individuals who are verbal may be unable to sustain a conversation with another individual, particularly on a topic of little interest. On the other hand, if the topic is of interest, they may monopolize the entire conversation and insist that everyone talk only about that topic. In general, individuals on the spectrum have a very concrete understanding of language and, as such, have difficulty understanding idioms (e.g., “A picture paints a thousand words.”), metaphors (e.g., “All the world’s a stage.”) or euphemisms (e.g., putting “spin” on something to mean, well, lying). Since much typical conversation relies on such communicative flourishes, we can often inadvertently make language much more difficult for the individual with autism to understand than need be.

The final area of challenges common to all individuals with ASDs are restricted, repetitive, and stereotyped patterns of behavior, interests, and activities. The diversity, however, comes in how these patterns are expressed in each individual across the ability spectrum. For one individual, it may mean a near total fascination with the green straws at Starbucks. For another, it may mean knowing, in precise detail, the evolution of the IBM Selectric Typewriter. Individuals may engage in a variety of repetitive actions or movements (body rocking or hand flapping, for example) called stereotypies. While we all engage in stereotypic behavior (twisting your hair when bored or tapping your pencil while you work), learners on the spectrum do so at a much greater frequency and intensity than do typical learners and, unsurprisingly, without an understanding of the social rules governing such behaviors (that is, for most people, those behaviors tend to be private rather than public).

Autism spectrum disorders are challenging developmental disorders that significantly impact individuals, their families, and society-at-large. However, while the deficits and challenges (which are both complex and extensive) of autism are great, they represent only part of the picture. Individuals with an ASD can, and do, continue to grow, learn, and develop new skills and abilities across their lifetimes. They have the capacity for great joy as well as extreme frustration. Individuals with an ASD can be brutally honest by way of stating an obvious fact (“You are quite bald.”) but

*“Autism is considered to be a spectrum disorder, ranging from mild to severe, due to the diversity of expression that is associated with the disorder.”*

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## Mary, a member of her church

It was 5 pm on a hot Friday afternoon. I walked down the hall to reach the waiting area, to greet Mary and her father. Mary has autism, as does her twin sister, Joann.

We made our way to my office and not a minute went by before Mary had pointed with urgency at my desk calendar. She was very distressed that it still was on May 2007, and she visibly calmed when she ripped off that page and the month of June lay flat across my desk.

Up and down the room she paced, reminding us both that it was June 2007. Taking hold of her father’s head, peering into his eyes, she kept repeating “2007?” To which he replied gently, “Yes, 2007.” She had such a strong presence in the room, was someone who knew what she wanted and she pursued that with zest and energy. She stood at the window, peering off at the trains as they passed by while I asked her dad about her progress during the previous months. He spoke of his daughter in a gentle, thoughtful way. His love and respect for her were clear and strong, so palpable in the room.

We spoke of many things, and faith was just one. Mary’s family belongs to a Catholic church, and they all look forward to Sunday mass. Mary needs to make sure they all leave on time and her sister, Joann, starts to sing the hymns in the car on the way there. On arrival, the family takes their seats. The service starts, and Joann settles into the rhythms. Mary looks around checking the dates on

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**Mary** *continued*

the calendars, straightens out the books in the pews and, when distressed about something, will turn to her father, holding his face really close while insisting that he repeat the words she utters. Her father describes the tension between keeping Mary in the church and not wanting to disrupt the mass for others. Short trips outside of the church are necessary for Mary to satisfy her need to repeat and be echoed. But they return, making sure not to miss the best part, the blessing. Mary loves vigorously shaking the hands of her fellow congregants, needing to make sure that no one is left out.

There are those difficult moments, when repeating exactly what is said just is not enough, and Mary's tension rises and begins to show on her face. She will not move from the church bench despite her parents' expert, gentle guiding toward the back door. Her father remembers how relieved he was when fellow congregants next to them helped get her moving on one occasion, reassuring her and repeating what she was saying to soothe her.

During our session, I had the clearest picture of Mary and her family in church, singing and repeating, and being part of the life of the church. I found myself thinking how honored this church was to have this family as part of their community. All were enriched by their presence, respecting and admiring a family whose life journey is different to most, yet so similar in their desire to live out their faith in their chosen religious community.

*Charles Cartwright, M.D., Medical Director,  
The Autism Center, UMDNJ-New Jersey  
Medical School.*

find no satisfaction in gossiping behind your back. They are loved by their families and, in their own idiosyncratic way, love them back. Individuals on the spectrum can make friends but, often times, only with those who make the effort to reach out and become valued to them, as friends. Adults with an ASD can be employed in desirable jobs and live, with the necessary supports, in their own communities and in a manner that supports a positive quality of life. People with an ASD, it seems, are people.

It is easy, with autism spectrum disorders, to focus solely on the challenges and deficits that define the disorders. On a person-by-person basis, however, this focus needs to be broadened beyond what the person **has** to include **who** the person is. This means attending to the strengths, preferences, talents, likes, dislikes, idiosyncrasies and, yes, charms that are part of each and every individual with autism. It will take some effort on your part. It will take some patience on your part. It will take some resilience on your part. But trust me, it will be time well spent.

*Peter F. Gerhardt, Ed.D., is President & Chair of the Scientific Council, Organization for Autism Research (OAR).*

*“Individuals with an ASD can, and do, continue to grow, learn, and develop new skills and abilities across their lifetimes. They have the capacity for great joy as well as extreme frustration. They are loved by their families and, in their own idiosyncratic way, love them back.”*



# Autism Life Cycles and Faith Communities

**Sandra L. Harris, Ph.D.**

People with autism are much like the rest of us. They are male and female, of every age and come in many shapes, sizes and colors. Some are very intelligent and some have intellectual disabilities. Some people have relatively few characteristics while others are profoundly affected by their autism and have many symptoms. They come from every social class, ethnic and racial group, indeed from every identity group including a diversity of religious backgrounds. They do share with one another important challenges that make their lives far more complex than most of us encounter.

There are five disorders on the spectrum of autism. These are Autistic Disorder, Asperger Syndrome, Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS), and two rare conditions, Childhood Disintegrative Disorder and Rett's Disorder. The characteristics tying these individuals together include their difficulties comprehending social interactions and their unusual use of language. Many people on the spectrum also engage in repetitive or stereotyped behaviors. They vary in the severity of these characteristics ranging from some people with Childhood Disintegrative Disorder or Autistic Disorder who may appear oblivious to the feelings or needs of other people, may not speak and are content to flap their fingers or rock for extended periods, to others with a diagnosis of Asperger Syndrome or PDD-NOS who are aware of others, capable of some empathy, have complex but not socially attuned speech, and may be distressed by their failure to grasp the social rules, which are self-evident to most of us. These deficits in understanding social relationships, using speech for meaningful communication, and having rigid behavior patterns have an inevitable impact on siblings, parents and extended family.

*“For the family affected by autism, every life cycle event is fraught with potential challenges for the parent of a child on the autism spectrum and every point of the spectrum has its own demands.”*

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*Sponsor Aunt Connie, father Tim Craig and Clinton Craig with Bishop DaCunha at his confirmation.*

## Living with Autism...

Living with autism and having autism are different. Here are examples why. My son has autism so as he walks briskly tapping his head with each stride, he is unaware that there's a hole in the grocery bag he's carrying to the car for me and that he's dropping food as he goes. Living with it, I only realize the bag has a hole. When hurrying to catch up with him, I notice two men turn and look at my son, then look down at the head of lettuce at their feet and shrug; teens sitting at an outdoor table an arm's length from him point and laugh; a woman and child in front of a movie theater stop to read aloud the label on the cheese he dropped but don't bother to stop him.

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### **Living with Autism** *continued*

He has autism, so he knocks things off a table at Roman Gourmet one day, thinking that I didn't understand what he wanted. He doesn't even realize every startled person in the restaurant is looking at him— even if they are trying not to. Living with it, I am painfully aware of the looks and the whispers in the restaurant as I determine a compromise that won't inadvertently reward his behavior, but still prevent further disruption as I get him out of the place as quickly as possible.

He has autism, so the next day at the same restaurant he's too intent on his pizza to notice tears in my eyes when I apologize for the previous incident and the response is, "Don't worry. We love him. He's been coming here since he was this big," motioning somewhere around knee level.

He has autism, so it doesn't occur to him that the people waiting with us in the long post office line may not be as entertained as he is by his unique way of "singing" to fill time. Living with it, I remember a man on the train yelling at me, "Can't you keep him quiet?" I am prepared for the worst when the woman in front of me at the post office turns around, but she smiles and asks if it's the echo in the room that he likes. The woman behind assures me, "it's okay," when he leans a little too close to look at her. I am prepared for a long, anxious wait in line but then both of these strangers offer to hold my place so I can attend to his needs.

Situations like these arise every day. Although you might not know what it is when you see it, you probably live with

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Some people use the term "Family Life Cycle" to describe the familiar themes in family life that we encounter if we have children. Life cycle events may be happy, such as the birth of a much wanted child, or sad as in the death of a grandparent, but they are all normative events that most people encounter. Parents anticipate and expect milestones such as the first day of kindergarten, getting a driver's license, or going off to college. For the family affected by autism, these events may not occur, and when they do not, their family member's differences are highlighted all over again. Thus every life cycle event is fraught with potential challenges for the parent of a child on the autism spectrum and every point of the spectrum has its own demands.

The characteristics of autism begin in early childhood and often persist into adulthood, making life very difficult for the family. They can also make inclusion in the worship practices of one's faith community quite a challenge. However, the benefits of support for the family and the person with autism demand that a religious leader and congregation make this effort. Having a child with this degree of disability may heighten the need for families to understand their struggles within a religious context. One aspect of their sadness is that parents may recognize that their child might never participate in some of the major ritual blessings of adulthood, especially marriage and the practices surrounding the birth of a child. In spite of the loss of these anticipated moments of joy, parents, grandparents and siblings can take great pride in being present when their loved family member participates in some of the childhood religious rituals that are major developmental markers.

A goal for many is to facilitate their participation to the extent that they can engage in age-appropriate rituals such as a First Holy Communion, Confirmation or Bar/Bat Mitzvah. Achieving this goal requires creativity and know-how on the part of teachers, religious leaders, and other members of the congregation. I have seen this done in ways that were deeply moving for all who were present. We need to do all we can to enable the person on the autism spectrum to be welcomed and participating members in our religious communities. **For everyone, the most important benefit is having a lifelong community and place to belong.**

While we cannot know the extent to which a person will experience the sacred nature of the encounter, we do know that for those who love the individual with autism, this participation can be profoundly moving. We also know that the encounter with a spiritual dimension in one's life is experienced by each of us in our own way. It is not our task to judge the quality of any other person's experience, but rather to point in the direction of our faith community and allow the sacred relationship to evolve.

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Fortunately, the religious education teacher and leader of the congregation are not alone in having to devise methods for helping a person with any of the five types of autism adapt to the religious setting. Educators and parents often know a great deal about how to engage the person with autism. Parents and school teachers can explain the child's learning needs and strengths and can identify trigger points that might cause distress. They can also teach the support people within the religious congregation how to use the appropriate teaching tools to facilitate realistic learning goals.


Raising a child with an autism spectrum disorder is a daunting challenge to which many parents respond with remarkable grace, courage, and love. They educate themselves about the most effective teaching methods, work collaboratively with teachers and medical professionals, advocate vigorously to include their child in the community, and love their child deeply. This work has its rewards. Seeing a child who has been mute begin to speak, watching a child grapple with social challenges and become more adept interpersonally, getting a hug from their child, celebrating all of the youngster's achievements large and small are all very meaningful and not taken for granted in families who recognize how hard the whole family works to accomplish these goals. Many mothers and fathers report a strong sense of effectiveness as parents because they have coped well with unusually hard problems. Being recognized by one's religious community for these accomplishments can be sustaining during hard times and a source of joyous celebration at other times.

*Dr. Sandra Harris is the Executive Director of the Douglass Developmental Disabilities Center in New Brunswick, New Jersey.*

### **Living with Autism** *continued*

autism, too. Perhaps it's the young man next to you at church who calls out unexpectedly, the girl at the pool who is mesmerized by splashing water, or the boy continually opening the automatic door at the grocery store. Autism is all too common: 1 in 150 children born today will have an autism spectrum disorder. How you live with it makes a big difference.

*Therese Ojibway, BCABA  
(Clinton's mother)*



*“The symptoms of autism begin in early childhood and often persist into adulthood, making life very difficult for the family. They can also make inclusion in the worship practices of one’s faith community quite a challenge. However, the benefits of support for the family and the person with autism demand that a religious leader and congregation make this effort.”*

# Communities of Faith and Individuals with Autism: Perfect Together

**Mary Beth Walsh, Ph.D.**

Just as the autism spectrum is remarkably diverse, so, too, the religious landscape of the State of New Jersey is exceptionally varied. One source reports at least 84 different faith traditions, movements or denominations right here in the third smallest state of the union.<sup>1</sup> From the Church of the Nazarene, to the Church of Jesus Christ of Latter Day Saints, from the Greek Orthodox Church to the Evangelical Lutheran Church, from Mennonites to neo-pagans, including representatives of all the major world religions, Buddhism, Hinduism, Judaism, Christianity and Islam, and through new religious movements like Falun Gong and the Mita Movement, New Jersey houses a rich and complex mosaic of religious communities. Yet, there is one thing we can point to that all these faith communities have in common: out of every 150 adherents in each of these traditions, one will have an autism spectrum disorder. And autism never affects one person alone; it involves the whole family, and the whole community.

## **The Mosca Family**

Our son is a part of this community of believers, and they deserve the chance to know him, too. We are not going to hide in the “cry room” anymore!

Communities of faith have a critical role to play in the lives of individuals with autism and their families. Autism often and easily leads to a family’s isolation. Simply leaving the house can be challenging. Malls with escalators, revolving doors and crowds can be hard; movies with their imposing visuals and crushing sounds can be challenging; and restaurants may be impossible for people with restricted diets or food selectivity issues. Even visiting friends or relatives becomes difficult when they don’t understand the family’s challenges or second-guess choices made by the family. When a family member has autism, it is often easier to stay home alone than to venture out into the world.

Communities of faith can mitigate the isolation that autism often brings. They can provide a place of solace and refuge. They can become a haven of acceptance and belonging for individuals with autism and their families. Welcoming, inclusive faith communities can make a powerful difference in the lives of families living with autism. Becoming a welcoming faith community will take some effort, but any such effort is amply justified by many of the central faith claims of diverse religious traditions.

I would like to highlight four Christian beliefs that together build the case for including people with autism in faith communities.<sup>2</sup>

The book of Genesis makes clear from the start that all of creation is of value to God. Genesis 1:31 tells us that God looked at creation and said it is good. One way to actively value the goodness of creation is to assure that our faith communities go out of their way to welcome all of God’s people. Including the ones who are

## **Anonymous**

While sitting in worship with my two young children, an older woman asked me to remove my disruptive toddler. She spoke with a condemning tone, one I would soon become immune to. I took my children to the nursery and cried. A few weeks later, I tried to take my children to worship again, but my son was just as disruptive. When I stood up to leave, the pastor stopped me. In the middle of her sermon, she told me to sit down. She told the rest of the congregation that my son was a member of our church and that it was all of our responsibility to raise him and to teach him the ways of God. The tears I am shedding as I write this story are ones of gratitude, in contrast to those I shed seven years ago in the nursery of my church.

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## The Lewis Family

While I cannot say that my grandson understands all that he hears, I can say that he understands who God is, that we are in God's house for worship, and that God saves us, loves us, and helps us with all things. My grandson recites Psalm 100 with the congregation and participates with the prayers and fellowship. The music captivates him. Initially, I had to bring a pad and pencil for him to doodle on after the music portion of the service was over, as his interest would fade. He has become more and more tuned into the service and I no longer need the pad and pencil.

On February 25, 2005, my grandson was baptized. He has been accepted into the membership and looks forward to attending Sunday worship. Initially he would tear up the donation I gave him to place in the offering plate. He has since not only stopped this behavior, but has been allowed to stand and hold the collection plate.



*Teraye Garry, Baptism Day, February 25, 2005.*

friendless, the ones whose wheelchairs cannot get up our steps, and most especially the ones whose behavior may surprise us or disrupt our services are important ways to honor the goodness of God's creation. It is the job of faithful Christians to figure out how to best include all in their worship. By doing so we are living out our belief in the implicit, radical goodness of all that God created.

In addition to creation, the Hebrew Scriptures speak of the centrality of covenant. God tells the Israelites, "I will be your God and you will be my people." (Lev. 26:12; Jer. 7:23) God extends an unbreakable promise, a covenant to God's own people to not abandon them. While Christians and Jews see the precise nature of the covenant through the lens of their different histories, all believe it tells us something critical about God. God is faithful. God does not abandon God's own people. God is always present for us. Faith communities can demonstrate their belief in the faithfulness of God when they themselves are faithful to those families in their midst who embrace a person with autism. Worship communities reflect the faithfulness of God when they stretch themselves to accommodate people with autism and their families, when they find special educators to offer religious education to children with autism, when they sing alongside the voiceless, or choose not to react to unusual behavior.

Christianity shares with many other faith traditions a deep and abiding theological affirmation of hospitality as a virtue. From Paul's Letter to the Hebrews, "Do not neglect to show hospitality to strangers..." (13:1) through the centrality of the value of hospitality in monasteries, up to the contemporary embrace of hospitality by groups like the Catholic Worker, the religious significance of welcoming others, especially strangers, has long been valued by Christianity as well as other faith traditions.<sup>3</sup> Christian faith communities must be inclusive if we are to honor our core beliefs; we value hospitality when we work for inclusion. We are called to find ways to accommodate those for whom it is difficult to be in church, those for whom the music is too loud, or the crowds too overwhelming. We need to make sure our faith communities welcome people with autism because, most simply, this is what Jesus would do.

Even a cursory familiarity with Jesus' public ministry reveals that he spoke with the outcasts of his social world, with those despised by others, like the tax-collectors, and with those who were sick and those thought to be possessed, with women and children and

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slaves and all those less valued by society. It is these people, those who will never earn their keep, who dwell outside the circles of power and wealth, who dwell on the margins, who were the friends of Jesus, as are all those on the margins today. We know that language remains an elusive goal for many with autism, and as Christians, we are called to speak with and for the voiceless, to recognize that not being able to speak is not the same as having nothing to say, and to include people with autism in a way that allows us to genuinely hear them into speech.

These four core Christian faith claims, reflecting on creation and covenant, and on hospitality and the ministry of Jesus, orient us toward the work and ministry of inclusion. While not always a simple task, communities of faith must find ways to welcome people with autism and their families, not just because those with autism will benefit, but more so because in this way Christians testify to the truth of their faith through their actions.

Although I have spoken here primarily from the perspective of Christian faith, one could make a parallel case for the importance of including people with autism from any of the many different faith traditions in New Jersey. It is critical that faith communities become inclusive given the prevalence of autism in our state. Communities of faith have before them a tremendous opportunity. When the doors of our churches, synagogues, mosques, and temples are opened, along with our hearts, to people with autism and their families, faith communities will experience a gratitude that knows no bounds, as they more authentically live out their beliefs.

#### **Footnotes**

<sup>1</sup> Approximate count from 181 different sources on New Jersey: [www.adherents.com/adhloc/Wh\\_232.html](http://www.adherents.com/adhloc/Wh_232.html). Retrieved March 6, 2007.

<sup>2</sup> Since I am trained as a Christian theologian, it is from and to that tradition that I speak. However, my first two scripture references will be to the Hebrew Scriptures, and I hope that my reflections on them will ring true to all people who hold those texts sacred, Jews, Christians, and Muslims.

<sup>3</sup> Scriptural citations of the importance of hospitality from many religious traditions (Islam, Judaism, Christianity, Hinduism, Jainism, Buddhism, and others) can be found here: [www.unification.net/ws/theme141.htm](http://www.unification.net/ws/theme141.htm).

*Dr. Mary Beth Walsh is a Catholic theologian, Board member of The Association of Science in Autism Treatment, and parent of a child with autism.*

*“Communities of faith can mitigate the isolation that autism often brings. They can provide a place of solace and refuge. They can become a haven of acceptance and belonging for individuals with autism and their families.”*



## Presence is Important: A Hindu Perspective

Bringing up a child with autism is always a great challenge. Taking our son (he is 6-years-old now) to religious functions or other functions that take place in temples was and is a great challenge. Autism is not a common occurrence among earlier generations of Indians. Most do not know much about it. There are certain unique features of most Asian cultures, especially Indians, which actually work to our advantage. Indian families are generally very tolerant of unruly kids. They tolerate screaming and tantrums by their children very well and behave very much the same way when they encounter other children exhibiting difficult behavior. Many of the western classifications of child behavior such as attention deficit syndrome, hyperactivity, etc. (which some use to describe milder versions of the “dreaded” autism spectrum disorders) will be dismissed with contempt.

The Indian viewpoint is: It is OKAY for kids not to be paying attention or hyperactive.... all these will disappear when they grow up. The truth is I have seen enough to accept that this is true from my experience. But kids with ASDs are a different matter. Our son actually likes to attend concerts and watch dancing, singing, etc., which are an integral part of celebrations at Hindu temples. Hindu temples are very social and lively places. There is a lot of talking, chatting, and chanting of Sanskrit incantations. Because of this, our son’s tantrums or screaming to leave the place sometimes are barely noticed. One reason could be he is very well behaved most of the time.... he would sometimes cry and want to be taken away. Those who notice just think of it as some extra sensitive child expressing his dislike of noise and crowds, but nobody seems to express resentment or intolerance.

There was one occasion when the guy sitting next to me at a temple function wanted me to quiet my constantly squirming son. I told him that as he is not making any noise, he should concentrate on the function and not worry about my son’s restlessness. He was upset that I could not keep my son quiet and left with displeasure! Other than that sole incident, the Indian community has been very tolerant and helpful wherever we went with our son. We have had no hesitation in taking our son to temples for attending religious functions or routine visits for worship. We hope that at least this part of Asian culture survives so that parents of children with ASDs do not face additional difficulties in taking care of their children.

*Mekala Ravishankarv is a parent who lives in New Jersey.*

*“Autism is not a common occurrence among earlier generations of Indians. Most do not know much about it.”*

# Autism and the Family

Alice F. Walsh, M.Div.

*The door to the church building creaks open, then closes...opens, then closes. The lights in the fellowship hall flicker on and off, repeatedly, as four-year-old Jason makes his way into the church. From the other side of the room I hear these words, "I see Jason is in church today! Welcome, Jason, and family!" And my harried soul finds sanctuary...*

## Autism's Impact on the Family

Getting ready to go to church on a Sunday morning is difficult for many families...the inevitable lost shoe, the misplaced jacket. However, when one of your children has a disability on the autism spectrum, that transition from home to church can be even more challenging. At times, the temptation may be great to stay home, to not inflict the uncertainty, or even pain, that such a transition may bring. But when you have been regularly worshipping with a particular faith community for many years, it feels natural to continue that affiliation when the autism diagnosis comes. And it *is* natural... except now everything is also changed.

**Autism affects the entire family. A diagnosis of autism for one family member will affect the whole family system.**

What are some of the ways autism affects a family? Adrienne Robertiello, a Roman Catholic parent in Scotch Plains, NJ, speaks of the overwhelming daily tasks and the resulting isolation:

*Simple situations like haircuts, grocery shopping or community gatherings, and religious practice have quite a different outlook for families having members with autism. The minutiae of living encompasses challenges with family balance, demands on family members, depletion of time and energy, enormous strain on finances, ongoing frustrations and self-esteem issues, overburdened schedules with unending appointments, doctor visits, meetings, childcare, educational communications, and logistical coordination. Autism changes daily interactions, safety considerations, recreational activities, expenditures, and priorities. It puts a significant load on all relationships. Autism leaves families fighting to deal with emotional and spiritual confusion. With these tremendous burdens, families do not have the time, energy or confidence to search or ask for the help that they desperately need. These individuals need a source for coping and relating and finding spiritual direction.*

## A Faith Community's Impact on the Family

Our faith communities can play a positive role in the life of the family. Communities of faith are natural places of support for families affected by autism. One mother decided that church might offer a perfect opportunity for inclusion, so she approached her church to find out what might be possible. She was welcomed, and her son was included in Sunday school. After a short time in which the mother sat in the class to be sure everything was going well, the coordinator of Christian Education said to her, "You are here to be participating in worship. We will look after your son." (Note: This was the first time anyone had ever offered to care for her son without pay. This mother later became a member of that church, realizing that she was involved in a community of love.)

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## Anonymous

Going to church can be a real struggle for families with autistic children. We have had several moments in church where the boys are too loud, don't behave appropriately when the children are called to the front of the church, etc. Some of it is typical kid stuff and some of it is the autism. However, I feel that the more people in church understand children with differences, the better the experience is for us all.

## What are some effective ways faith communities minister to families with autism?

First, by being a spiritually welcoming community for ALL of God's children. Along with this hospitality comes a commitment and resolve to do whatever it takes for successful inclusion. Increased awareness leads to attitudes of acceptance and understanding, resulting in a willingness to relate to individuals with autism and their families. This works wonders in minimizing the isolation that can be so prevalent.

Second, out of that welcome and resolve come creative ways to deal with extra challenges, such as:

- Being attentive to the needs of the other siblings in the family.
- Providing an hour of hands-on respite care so that weary parents may worship together, sing in the choir, or attend religious education classes as a couple.
- Listening to the cares and needs of a family.
- Providing "sanctuary" (in the truest sense of the word)—a safe place for families to ask all of their hard questions.

I have witnessed, as both pastor and parent, the positive difference that a loving and accepting congregation can make in the life of a family who is hurting or struggling with this diagnosis. A congregation can help enrich a family's faith. A faith community can be an advocate. My journey with autism has taught me that every person's relationship with God is both individual and communal. In community we learn the importance of celebrating the uniqueness of the human family as well as the diversity of each human individual. Together, in community, we can have life.

*Rev. Alice F. Walsh is a United Methodist pastor/chaplain and a parent of a child on the autism spectrum.*

## The Higginbottom Family

Bringing our son Robbie into our church family has been difficult and is not complete. When Robbie was about 6, I inquired into how he could become part of the congregation. I was told that another church in our conference had two children in an autistic class.. I went to visit the class but it was not a fit for Robbie. Robbie did not have the skills the other two children had. He couldn't sit still, etc. They were higher functioning. Our minister realized that we were upset. Many people in my family attend the church. We met with our minister and I basically told him that I was baptized, confirmed, married, etc., in this church. He asked what I wanted. I told him basically a classroom. Robbie and I lie on the floor and read books (Christian books). We do crafts also. His older cousin joins us at times as do other family members. He knows some basics. He is not a religious scholar. Another hurdle has been coffee hour. It is now after about 3 years of coming to church that people make an effort to engage with him. There have been times when I have left church hurt or angry, but things are getting better.



*Robbie in Sunday School*



# The Hallways of My Church

**Maria Abinader**

I've always loved going to church  
Because it felt like a place of welcome, a place where I belong.

That all changed when I started bringing my little boy to church.  
You see, my little boy has AUTISM and he gets sensory overload.  
He becomes echolalic, he repeats everything he hears  
and laughs inappropriately.

I immediately start getting weird looks from people around me  
So I get up and go out to the hallways.

Walking through those hallways makes me very sad.  
I don't want to be in the hallways,  
I want to be inside.  
I came to hear God's words and I can't do it from outside.

While walking the hallways, I've met some really nice moms.  
We've cultivated friendships and we're always kind.

Then I realize that I have a choice to make  
Do I stay inside and feel that I'm bothering everyone  
Or do I walk the hallways and look at everyone inside?

When you give a mom a weird look: in a minute you forget;  
But there's little waves a-flowing, and there's ripples circling yet,  
And perhaps in some sad heart a mighty wave of tears you've stirred,  
You've made some people sad that just wanted to come to church.

People with developmental disabilities  
Lack the opportunities and supports.

Please understand that in the hallways we don't feel like we belong!

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The words you read above were written three years ago. Today I can say that we discovered that the mutual support and acceptance of the faith community was and is of great importance, the union, the optimism and the mutual hope feeds the spirit and the soul. They were and still are an amazing source of strength.

I don't know what would have happened if we were alone, isolated, with no support. We thought we were in a tunnel of the unknown flooded by emotions.

Faith became our anchor, our strength, our compass with a defined objective that leads us to defend our child's rights with all our might, to improve his quality of life and our family's as a whole. Our little boy with autism and our faith, without intent, became our north, our compass of steel, to sail in this open sea called life.

*Maria Theresa Abinader is a parent, member of the New Jersey Council on Developmental Disabilities, cultural advocate and broker, and founder of a Spanish website on autism: [www.manitasporautismo.com](http://www.manitasporautismo.com).*

*“Faith became our anchor, our strength, our compass with a defined objective that leads us to defend our child's rights with all our might, to improve his quality of life and our family's as a whole.”*

### **Anonymous**

Although the teachers are not trained in autism, one of the reasons our son with Asperger syndrome has been able to participate in Sunday school with some success is because two of the three teachers are family friends. They know our son well and know to find me if he is having an “autism moment.”

One day when our son was upset, the teacher came down to find me in the Sanctuary. Of course, I could hear him well before they found me so I left the Sanctuary to see what was going on. My son was upset because someone had “laughed at him.” He was loud and wanted to get “revenge.” You can imagine the scene. A mom and 9-year-old boy are in the hallways of church and he is steaming mad and has no clue what he is saying, how he is saying it or where he is saying it. I was quietly talking to him and felt confident that he would settle down quickly.

However, someone from church came by and decided to intervene. Rather than speak to me, he spoke to my son and reprimanded him for shouting “in God's house.” I know the man was well-intended, but he was not helpful. It may have been helpful to ask me if everything was okay, but to bypass me and address the child without any idea of what was going on can really escalate an “autism moment.” On top of trying to settle my son, I then had to direct my attention to this man and try and get him to move on without making the matter worse.

The difficulty with autism is that many times people do not know that the child has it. This man didn't read the situation as a mom talking to a child with a disability. All he saw was a young boy being disrespectful in church.

# Inclusive Faith Practices for Children with Autism

Anne Masters, M.A.

A central tenet of the “Abrahamic religions,” Judaism, Christianity, and Islam, is that each person is created by God and therefore part of one human family. However, when a person is marginalized because of autism or any other disability, that marginalization seems to deny this gift from God and our shared human dignity. This has significant implications for the person with autism, his or her family, and the faith community. For these families, the pain of rejection by others can be overwhelming, particularly when that rejection comes from their faith community, a place where we gather to celebrate and draw strength from God’s presence in our lives.

Inclusion of children with autism in the religious education and communal prayer life of a community is the focus of this discussion. However, the process could easily be applied to teenagers and adults, because the human need for inclusion lasts a lifetime. I am writing out of the Catholic tradition, but am grateful for the review of this article by Jane Eisen-Abesh, M.S., OTRL, Special Needs Coordinator for Congregation M’kor Shalom and Maysaa S. Bazna, Ed.D., who specializes in the area of learning disabilities and Islam.

When we exclude people from our faith communities because their needs or behaviors are “too different,” we must ask ourselves what we are teaching our children about the validity of those central tenets of faith that form moral behavior. Most likely, what they will learn is, “Follow those teachings... when it is easy.” Is that the message we really wish to teach? Our religious education settings have the opportunity to be apprenticeships of faith that allow for the development of behavior informed by faith. For this to be really effective, children need to see this behavior modeled by the adults in the community. The saying, “Children will do as we do, not as we say,” applies just as easily to the faith community as to the family. Is the public prayer life of a community professing welcome for all?

So how does a faith community welcome and educate people with autism into its life and mission? The long answer to this question is to make use of the resources recommended in this booklet and talk to communities who already do so successfully. However, the short answer is, “**Welcome one.**” Instead of worrying about starting an entire program to welcome people with autism and their families, begin by welcoming one. Many faith communities that have successful programs for inclusive religious education began by determining the needs of the *one* child first presented to them.

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## Imhof Family

When my son was younger, around 7-years-old, I contacted the CCD department of this parish requesting a viewing of the Special Needs class conducted Wednesday afternoons. After a lot of phone tag, I finally conferred with the sister in charge at the time for CCD. I explained my situation and she felt that they were not equipped to handle my son. Though she said she would get back to me with a possible Special Ed teacher that could come to the home, that never happened and we pretty much gave up on the matter. Matter of fact, we do not attend at all nor contribute to this parish. I guess you can say they lost parishioners because of this blunder.



*Is there ever a wonder why  
we lose faith?*

Then, child-by-child, they learned how to respond to the needs, and after a period of time, they had a “program.”

Families and teachers of children with autism can be the best source of information and ideas for religious educators and congregational leaders. In learning the needs of the child before you, begin with inquiries about his or her interests and gifts, what makes him or her unique, and then proceed to the particular needs for support. (**See Guidelines for Clergy and Religious Educators for Conversations with Parents, p. 23**). We are all people first. Particularly in a faith community, different abilities and disabilities do not determine our personhood, though they do influence what each person is able to do. In this conversation, demonstrate an attitude of openness and support. Assure the parent(s) that your questions are motivated by a sincere desire to provide the most supportive environment for the child and that privacy will be respected. The information will be shared only with whomever the parent and child allow, which should at least include the people working directly with the child. This will help to explain different behaviors, leading to awareness and improved understanding.

### **Our Lady of Mercy**

Twin boys were preparing to receive the Sacrament of First Eucharist. One boy was autistic and his twin was not. In our parish, each child makes a banner that hangs on the pew for their sacrament day. Seeing all of the preparations, the mother came to me with tears in her eyes. I asked her what was wrong, to which she replied, “There is nothing wrong at all! For the first time my two sons are doing something together. They usually go to their separate school and activities and today they are side by side.”

After you have a good understanding of the child, determine what the parent(s) want and the level of inclusion they hope for. There are many possibilities, such as being incorporated into a “mainstream” religious education group with appropriate support in place, spending some time with children in “mainstream” groups and some time in a more specialized setting, or in a totally separate group. However, even when religious education occurs in a separate environment, the goal is always connection with the larger community in some way, as often as possible.

Further, the strategies and goals of religious education should reflect the particular needs of the person and the values and traditions of your faith community. One of the basic tenets in the autism community is that *when you have met one person with autism, you have met one person with autism* (Stephen Shore). Another is that they often have difficulty applying and using what they learned in one situation to another, even if the two are nearly identical. For example, being familiar with worship in one location may not translate to worship in another. In Catholicism, participation in the Mass is very important, so it is important to include

comfort and familiarity with the church space, as well as comfort with the actions, words and rhythm of the Mass. In addition, if a child with autism is in a “special religious education program,” there also needs to be a strategy for participation in the worship of the community.

Some families are able to bring their son or daughter with autism to worship. Other families may need more support from their congregation. Again, the child’s teachers in school could be very helpful. Because teaching specific behaviors is typically part of the education of a child with autism, some teachers will include behaviors for successful participation in the family’s faith community as part of a child’s education plan, because this experience, together as a family, is so important. If that is not possible, he or she may still be willing to guide you in the process, or you may be able to find a special educator or behavioral consultant who is happy to assist. If we accept that all people have a right to be welcomed into faith communities because we are all created by God, then we are morally bound to support the education that leads to participation in the full life of the community. In fact, you might envision learning how to participate in the worship life of the community as the beginning curriculum.

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While parents have valuable insight into their child(ren)'s needs, they should not be expected *to be* the solution. Be sensitive to the parents' need for support, affirmation, and spiritual growth as well as their children. Do not expect them to design and run the program. There are always exceptions. Some parents may take on a lead role, but do not require it. There may, in fact, be other places in the faith community where they would like to participate or their gifts could be shared.

When parishes are not welcoming, it is usually not from a lack of desire, but from a lack of understanding or knowing what to do. Good information can empower effective caring and action, leading to quick results. Religious educators in particular have a unique opportunity to embrace a family and model effective inclusion for the whole community.

The more challenging situations are those in which hearts and minds are closed to what we are called to be as children of God. Information alone is not enough. To open hearts and minds, we must remember the theological foundations of our calling as created in the image of God. We must be willing to recognize new possibilities for celebrating God in our world, the gifts that God has given to each person, and the ways that the whole community can benefit from being open to including and receiving gifts that might come in unexpected and atypical packages.

*Anne Masters, M.A., is Director, Pastoral Ministry with Persons with Disabilities of the Roman Catholic Archdiocese of Newark.*

**Rabbi Jennifer Clayman,  
Temple Emanu-El, Westfield, NJ**

“We believe that every Jew has a right to a Jewish education in the least restrictive environment,” Rabbi Clayman added. “This effort will not just enhance the learning experience of students with special needs, but their whole synagogue experience as well.”

**Anonymous**

How could we work with our church to develop a way for our family to be in worship...to grow in our faith...while living with the realities of autism in our daily lives? The first commitment/covenant we made, as a church and family together, was that we would come to worship on Sunday mornings...and we each made preparations in order for that to happen.

As Jason's mother, I spent time each day during the week preparing him for our Sunday morning trip to church. I wrote social stories for him outlining every aspect of worship/Christian education for that week. The church was faithful in letting me know of any changes to the morning that would affect Jason's need for routine. (Communion Sunday, a special luncheon, a visit from our clown ministry.) Together, Jason and I made a “Jason Goes to Church” book, which contained pictures of meaningful areas in our worship center and the people he would encounter there, including a picture of Jason dressed in his “Sunday” clothes (one particular outfit that was comfortable enough for him to wear with his sensory sensitivities). And we would read that book together every day, in preparation for going to church.

The church also made preparations for our coming. The religious education department brainstormed ways to present consistent, predictable lessons in a very concrete manner to Jason. They cued into his love of light switches and helped him to learn that Christ was the light of the world. They understood Jason's need for a predictable routine so they tuned into tradition, presenting the Bible stories in a way that showed their continuity through the ages, from the Bible times to today. Jason learned that he could depend on those Bible stories...and ultimately learned that he could depend on the God who was faithful in each of those stories.

By this time the church was more aware of our family's needs (for Jason's siblings to have time with friends their own ages in their classrooms, for my husband and me to worship or study together, or even to sing in the choir together). So the education department made sure that there was someone present in Jason's classroom when we arrived at church who would then take him under their wings for the next hour or so. That was such a gift to us... Those persons grew to know and love Jason in deep and meaningful ways, and we still maintain contact across the miles today. They became his advocate...his cheerleader...and most of all they demonstrated to Jason what it means to live in Christian community.



## Guidelines for Clergy and Religious Educators for Conversations with Parents

- **Present an overall attitude of openness and a desire to be supportive.**
  
- **Ask the parent(s) what they are hoping for.**
  - Specifically, are they hoping for inclusion in a ‘mainstream’ religious education group with his/her peers? Potential possibilities are inclusion with the appropriate supports, within a group for children with special needs, one-on-one religious education or some combination.
  
- **What are his/her special interests?**
  
- **What are his/her special gifts?**
  
- **Let the parent(s) know that in order to provide as positive an experience as possible, certain information will be helpful.**
  - How would they describe his/her social relationships?
  - What methods of communication are used?
  - What have been effective learning strategies?
  - Are there any aggressive or inappropriate behaviors?
  - What are possible triggers of inappropriate behavior?
  - What is helpful for holding his/her attention?
  - Are they willing to share a copy of his/her IEP, or at least what the requirements of it are?
    - It is important to recognize and respect the confidential nature of such a document.
    - Again, let them know that the reason for requesting it is to improve the quality of the experience for their child.
  - Does she/he have any dietary or environmental issues?
  - Does she/he have any medical issues you need to be aware of?
  
- **As you do with any new family, it is good to get a sense of the role that faith plays in their life.**
  - Also remember that if they have not been able to attend worship regularly, it may be because they are very de-energized from dealing with disability in their family. A welcoming community can go a long way to helping them participate more.

## Shannon Family

My son Tom started out at the Children's Center, a specialized placement for children with autism. They used a method called "backward chaining" for many of the skills the children needed to learn. With this method, the child is taught to perform the very last part of a skill first and work his way backward. For example, in learning to make a bed, first the child learns the very last step – perhaps smoothing the bedspread over the pillow – and gradually works his way back to the step before until he has learned the whole "chain" sequence for the skill. We decided to use this method to teach him to sit quietly in church. I began by taking him for just the last five minutes of Mass, with an appropriate quiet book or snack, and elaborate praise for sitting quietly until it was time to leave. We gradually started coming earlier and earlier, until he could sit through a service without disruption.

I was a little worried when it came time for First Communion, which takes place in second grade. Tom had some sensory issues with eating unfamiliar foods, and it could have been disastrous if the first time he was presented with a Host was at the First Communion ceremony. But the teacher was very accommodating and allowed me to have as many unconsecrated hosts as I wanted, so Tom could take his time and become comfortable with it before the ceremony. I was also present at all practices to help redirect him when necessary if things got too confusing. He managed the ceremony beautifully (although we had to remove him quickly at the end when the picture-taking session went on a little too long for his comfort).

Then in third grade, he heard the announcement for training for altar servers and wanted to join. Once again I wrote to the pastor and the woman who trained the servers, asking for them to just give him a chance, and promising that I would be there to help. I also had to once again ask for unconsecrated hosts for practice, because previously he had learned to take the Host in his hand and put it in his mouth. But in our church, altar servers are expected to have the patens in their hands already when served Communion, and must take the Host on their tongues. The trainer was very accommodating and he learned that

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## One Task, Many Roles

The one task is inclusive religious education, yet there are many ways that people in your community can contribute. It is possible for people with a wide variety of skills, time availability and/or interest to contribute to the task. Not everyone needs to be a religious educator. As for any role involved in religious education, training is required to support the level of interaction of the task.

1. **Religious Educator** – Religious educator with skills as an educator, particularly special education, although does not necessarily need to be professionally trained. Sense of humor and flexibility are huge assets.
2. **Aides/Assistants** - Caring adults who can be present in groups to be extra eyes, hands, legs and hearts. Sense of humor and flexibility are huge assets.
3. **Teen Aides** - Caring teens who can be present in groups to be extra eyes, hands, legs and hearts. Sense of humor and flexibility are huge assets.
4. **Buddies** – Someone who will support one child in particular in a larger group, in a non-invasive way. Buddies will also be very helpful for modeling/teaching particular behaviors for worship. Sense of humor and flexibility are huge assets.
5. **Inclusion Consultants** – People with special education background who can serve as consultant/support for religious educators.
6. **Hall 'Monitors'** – Some facilities have many entrances and exits. It's good to have extra people around for the restroom and keeping in those who belong inside and keeping out those who belong outside.
7. **Crafters**
  - A. Some materials/activities may require extra preparation for children with limited fine motor skills. It can be a huge help to religious educators if someone else can prepare the material once he/she has determined what is needed.

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### **Shannon Family** *(continued)*

part easily. Because of his excellent memory, once he got the sequence of events down, Tom became a reliable and enthusiastic server, always eager to jump in when we attended a Mass where a server didn't show up. He even learned how to serve by himself when the other assigned server didn't come. In the beginning, I would be in the front pew and he would watch me for hand signals when he got confused. But it wasn't long before I was able to just sit back and relax. In the end they even assigned new servers when Tom was serving so they could watch him and learn.

### **One Task, Many Roles** *(continued)*

- B. For people with limited or no ability to read, it is beneficial to adapt the materials used. For example, make books interactive to allow for matching or selection of important items in a picture; create story boards for storytelling.
  - C. People with computer skills and graphic design talents, such as Boardmaker, to make picture schedules or social stories, and/or can use a digital camera for the same purpose or to make a "tour" of your community's worship space.
8. **Audio Recorders** – Someone with a good speaking voice to record prayers, songs, and other catechetical material. This is especially for children with visual impairments or who are blind, but also helpful for others, particularly children with attention issues.

Remember, people with autism and/or other disabilities are also called to serve and love to contribute. They can do some of the tasks above, or others in the life of the congregation. Let their gifts and your creativity guide you.

## **“Faith at Home” Work\* - Some Tips for Parents**

- Say basic prayers every night with your child.
- Listen to religious songs with your child.
- Play a matching game with pictures of people important to your faith community.
- Take photographs of important elements and places in your house of worship. Make flash cards out of them or a “tour.”
- Have the child match the picture to the actual object in your house of worship.
- Visit your house of worship with your child when no one is around.
- Tell him/her how long the service will be.
- Incorporate the rituals, practices and expressions of faith into your home and family life as much as possible.

\* A PRAISE Resource - *Persons Recognized Accepted Included in Spirit-filled Education*. Roman Catholic Archdiocese of Newark.

## Ivie Family

Our church, West Side Presbyterian Church of Ridgewood, New Jersey, has had a Special Needs Sunday School program for more than five years. Subsequent to its founding, Travis joined the class. His experience has been excellent.

For example, he very much enjoys attending Sunday School and church services, grabbing his Bible out of the car and marching in. The lead teacher works with Travis on Bible reading, something he enjoys, as well as on weekly projects, such as crafts. The class currently has 4-5 regular students, with a very experienced, talented, and loving adult leading the program and two mature and committed high school youth members helping out.

The class always includes 15 minutes in Chapel, which involves guitar-based children's songs lead by West Side's "singing nun" of sorts. About one month ago, after four years of listening and enjoying the music, Travis suddenly exploded in enthusiastic singing, to each and every song, having memorized the music, and is now very engaged in group singing. It created a bit of a sensation among the teachers and students.

Travis also enjoys Church services, having memorized the order of worship and The Lord's Prayer. West Side has been good about accepting into service young children in general and special needs children in particular. We are fortunate that Travis is behaved and listens to me when I ask him to be quiet, notably during prayers. That said, it could still be uncomfortable for parents of special needs kids to attend with their children. However, I have always felt very much welcome with Travis as well as with the rest of my family.



## Some Strategy Suggestions

- **Attend to communication – Receptive/Expressive/Communication**
  - Is it happening? What are her/his capabilities?
  - Avoid speaking in the negative
  - Visualize sequenced directions
  - Use shorter phrases
  - Wait before repeating yourself
  - Avoid misunderstandings
  
- **Preparation for Transitions – Advance Warning Systems**
  - Verbal countdown
  - Concrete language
  - Picture or word schedule
  
- **Using Visuals to Reinforce What We Say**
  
- **Writing Stories to Help Anticipate New Situations\***
  
- **Thinking Alongside the Person\***
  
- **Behavior Supports**
  - Schedules (Promote Independence; Provide Predictability; Allow for Self-Management)
  - Making Routines Comfortable\*
  - Task Analysis
  - Shaping
  - Prompt and Fade
  
- **“Faith at Home” work**

*\*Barbara J. Newman. Autism and Your Church: Nurturing the Spiritual Growth of People with Autism Spectrum Disorders. Grand Rapids, MI: Faith Alive Christian Resources, 2006.*

*Travis during Music Chapel at West Side Presbyterian Church, Ridgewood, New Jersey.*

# A Vibrant Spiritual Life: Suggestions for Congregations on How to Support Adolescents with Autism

Lois Spitzer, Ph.D.

We often don't give adolescents, especially those with special needs, enough credit when it comes to spirituality. Because an adolescent has a physical, neurological, or intellectual disability, and can't communicate in our way, we assume a lack of depth or sophistication. A disability, however, does not mean there are limitations in the ability to have a spiritual life. In my years of knowing individuals with autism, I have made some observations on how congregations can better support adolescents with special needs within their congregations.

*“Adolescents need to feel that they are a valuable addition to small group settings, and be encouraged to participate.”*

Everyone needs to be given the freedom and encouragement to worship without feeling self-conscious. We assume that adolescents are very self-conscious. To be sure, some are. However, mine is not. I sat next to my 22-year-old autistic son, Joshua, recently in church and watched him out of the corner of my eye. He always sings with gusto, in his monotone voice, even when he doesn't always look at the words in the hymnal. He sings from his heart like he believes that God is listening and is pleased. I almost always catch people glancing at him and smiling. Even though I think he is singing too loud and off-key,

they are obviously enjoying it. No one sitting close to him could accuse him of not worshipping in church! When it came time to pray, Joshua bowed his head and I noticed he was mouthing words. What was he saying? When it came time to take communion, he very deliberately looked up at the cross at the front of the church as though he were having an internal conversation with God. What was he communicating to God? How wonderful it must be to feel the kind of freedom that he obviously feels.

Participation and attendance in the service needs to be encouraged and affirmed. Ever since Joshua was a little boy, he has loved going to church. While he wouldn't sit quietly anywhere else, in church he instantly would become transfixed. Baptist sanctuaries tend to be functional and thus devoid of visual religious stimuli, and so, Joshua's attention was not being commandeered by icons or paintings. When he was an infant, he went to the nursery. When he became old enough to sit through service, I remember at first sitting in the back of the church not trusting him to remain still or quiet. Soon, I discovered that this wasn't a problem. He would participate in service in a very mature manner. Why don't we bring all of our children and adolescents into the service (or as much as they can tolerate) to experience worship among the family of God?

Adolescents need to feel that they are a valuable addition to small group settings, and be encouraged to participate. Often, the comments and prayers of individuals with special needs are very profound and profoundly expressed. It would be a shame to deprive others of the experience of praying out loud with Joshua! As a teenager, Joshua loved accompanying his father (who is a pastor) whenever he would visit people in their homes and hospitals. Once, when he was visiting a dear elderly friend who was about to have surgery, Joshua offered a very simple prayer: “God, please heal Bob's heart.” Bob was so touched, he began to cry. He said that prayer had more meaning to him than many other more articulate prayers that he had heard. Joshua's prayers have power and simplicity, and people feel it.

If there's a job to do, let or encourage adolescents with special needs to volunteer. If we are aware of an individual's strengths and limitations, often we can anticipate the areas in which a person can serve. Sometimes, we might be surprised by what can really be accomplished! Joshua loves to do everything from cleaning the kitchen and refilling the soda vending machines to restocking the office photocopiers and printers with paper. He is such a hard and careful worker and people appreciate his assistance,

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but more important, they recognize his willingness to help and his unfailingly positive attitude. He loves any church building and appreciates that churches are special places where God's presence may be felt.

Offer adolescents support and comfort in the form of friendship and fellowship. I believe Joshua views church as a good and safe place where he can always encounter people who will love and accept him. It is one of those comfort zones for him. Even when we visit a church where we don't know anyone, he is always excited to enter and very politely extends his hand to greet people when appropriate. He has been raised in the church and knows it is part of our family's routine. He also identifies himself as a Christian and acknowledges that he has a personal relationship with Jesus Christ.

Don't assume that because an adolescent isn't looking at the person in the pulpit, or is seemingly not paying attention, that she/he isn't. We never have to tell Joshua to be quiet, sit still, or pay attention during a religious service. He intuitively knows he should. Even though he often thumbs through a book that we have let him bring, the hymnal, prayer book, missal, or Bible, if you ask him what went on while he was seemingly not paying attention to anything else happening around him, Joshua knows and can recount everything with unexpected accuracy.

Joshua wouldn't be where he is spiritually if it weren't for the support of many close fellow Christians and members of the congregations of churches we have attended. If I could distill my experience as a parent into a single suggestion, it would be to encourage congregations to allow adolescents with special needs to serve in whatever capacity is possible and appropriate. There also has to be a level of trust and confidence felt by the adolescent if she/he is to feel secure in the calling of service. We all need to feel useful and then to live out that calling among friends who believe in us. There is no greater way to feel God's love and blessing than to serve Him fully and to our utmost ability. We all need to feel that we are in full service of the Lord.

*Dr. Lois Spitzer is an English as a Second Language educator, married to the executive minister of American Baptist Churches of NJ, Rev. Dr. Lee Spitzer, and the parent of Joshua, an adult son with autism.*

*Hannah Herbert, on the occasion of her bat mitzvah*



### **Miriam Herbert**

We've had mostly wonderful experiences in our congregation. We have a 14-year-old daughter with PDD-NOS. Perhaps in the beginning years, people stared at us, until our daughter acclimated herself to religious services, as it took many years for her to be able to sit still for services or to sit for our Rabbi's stories, but now she can. She can actively follow along and read Hebrew prayers along with the congregation. She may recite them louder than most, causing others who do not know us to look, but it's all right with them.

The Temple clergy and religious school director were very supportive of our daughter's religious school education, enabling her to stay in a homeroom until the fifth grade, providing a 1:1 shadow for her in her classroom from the first through the seventh grades. She completed the last two and a half years of her religious school education in a special education religious school class on site.

Our daughter had a near-typical bat mitzvah service. It was a team effort in achieving her successful bat mitzvah, with each of us, from her 1:1 shadow to Hannah, dedicated to that purpose. There was much rehearsing, plus the Hebrew prayers were enlarged and highlighted to keep her focused. Our friends and others in the congregation were so proud of her.

When our daughter was asked to read from the bema this past autumn, along with other recently bar/bat mitzvah students, she did very well and many congregants made sure to tell us so. We feel grateful to have had such heartwarming experiences; I know some of our friends with special needs children have not been so lucky.



*Joshua Spitzer being baptized in the Jordan River by his father, Rev. Dr. Lee Spitzer*

## My Story

### Joshua W. Spitzer

When I was young, I went to Lincoln Public Schools. The teachers really helped me. They were my friends. One teacher gave me an Apple computer to use for a whole summer. The principals were also my friends. I liked their offices! I did not like homework. When I graduated Lincoln South East High School, I was very proud. I have a picture in my room of it. In New Jersey, I took a class at Burlington Community College. We did computer graphic design.

I love computers. My mom and dad gave me my first one when I was three-years-old. I used to play Chips Challenge – that was my first game – on my Gateway computer. When I was in fifth grade, my dad and I visited the headquarters at Gateway in South Dakota, and I got

to act like a worker on the factory floor.

I like to play computer games and surf the Internet. I have a book of every college in the United States and I visit their websites. I like the NASA website and weather websites. I also like to collect the HTML codes of web pages. I save them in alphabetical order.

I have a great dog named Peanut. I really love animals. Peanut understands me and likes to play with me. I buy her bones from work as presents because she is a good girl. My mom and dad walk her every day. I like to ride my three wheel bike in front of them.

I work at ShopRite in Bordentown as a bagger. My job is fun and I like everybody. I do a good job, talk to customers and sometimes I get tips. I have lots of friends at ShopRite and I know everyone's name. I like to chat with them online from my home computer. I work on Sunday, Tuesday, Wednesday, Thursday, and Saturday. I make a lot of money because I work hard!

My checks go to the Commerce bank server. I have a checking account and a savings account. I like to swoosh my Commerce card when I buy things. Each time the bank's computer adds a line to my account. I like to eat at McDonalds and buy computer programs online. Quicken tells me how much money I have left.

I have a neat sister named Larisa. I like to call her Larisa Loser Labadie and Tiny Snail Brain! She goes to Montclair State University. I go to see her perform on the violin. Sometimes Larisa and her boyfriend pick me up from work and take me out. He's a nice guy.

My dad takes me to San Francisco to the MacWorld Computer Conference every year. We stay at a nice hotel. We stay at a different hotel each time. It has to have wireless internet. There is a big, two story Apple store and I like to go there every day. I love to travel! This summer, I am going to Long Island, Maine, and Nebraska. I also like to take the NJT to NYC and go to museums and the new Apple Store at Central Park.

I go to First Baptist Church, Mt. Holly. My pastor's name is Bob Ingram. I work in the sound booth and I record the services. I love church and I love to sing. My favorite song is "Amazing Grace." I like to give my money in the offering plate. I also like to work at my dad's region office. I help with mailings, put paper in the machines, keep the internet connection, and go to churches with my dad.

In 2001, I went to Israel with my friends from First Baptist Church, Lincoln. My dad baptized me in the Jordan River. That was my favorite experience. I am really happy because I know God loves me and so does my family.

*Joshua Spitzer is a young adult who works for ShopRite and as a volunteer in the offices of the American Baptist Churches of New Jersey. In November 2007, he received a Self Advocacy Award from the New Jersey Coalition for Inclusive Ministries.*

## Becoming a Member

On Palm Sunday—it seems an eternity ago already—I was trying to occupy myself, to make it less obvious that I could not find a way to participate in the socializing going on around me. I turned, as I do, to words on paper. I read the bulletin board. The entire bulletin board, from left to right. And toward the end of my reading, I discovered the minutes of the vestry meeting. And a single sentence leapt out at me: “Cal Montgomery has been welcomed as a new member of Good Shepherd.” I turned and walked away. I came back and looked again. “Cal Montgomery has been welcomed as a new member of Good Shepherd.” It was still there. Not “except,” but “member.” I looked again. And again. And willed my hands to stop their joyful flapping and my body to slow its excited rocking, lest someone notice and intrude on the moment. I feel like a member. I am treated like a member. I am a member. It says in the words on the paper that I am a member. I can have a home within the church. Thank You, thank you.

*Cal Montgomery, Thanksgiving/Easter 1998. Journal of Religion, Disability, and Health. III.1. Binghamton, NY: Haworth Press. pp. 11-12.*

## A Mennonite Story

### Christine Guth, AdNet

“A young adult with autism serves as treasurer for children and youth Sunday School offerings. With great commitment, he collects the money and keeps track of the amounts. He is also responsible for coming in on Mondays to compile attendance data gathered the previous Sunday. Pastors value this information for helping to keep track of members and attendees.”

## “Of Course” – Ministry and Service by Adults with Autism

**Bill Gaventa, M.Div.**

Of course “It is more blessed to give than receive,” but it takes intention!

A number of years ago, a friend asked me via e-mail if a young woman with autism could correspond with me about her faith journey. “Of course.” Whereupon we began a series of e-mails about her journey and her current congregation, where she had finally found a spiritual home that listened to her, accommodated her needs (e.g., printing a sermon beforehand so she could follow the text, letting her sit on the floor with her back to a wall where she felt more secure, and more). Then she asked me if she could send me a prayer she had written. “Of course.” Expecting a one page e-mail, I got a twelve page spiritual autobiography, entitled “Thanksgiving/Easter, 1998.” It was one of the most moving moments in my ministry. In a format based on a psalm, she talked about her life experience of “the kingdom of God being open to all...except her.” She had come into her current church looking for that “except you” experience once again, but it never happened. Hence the Thanksgiving.

If your congregation is welcoming an adult with autism who has not had a faith home in his or her childhood or teenage years, be prepared for the testing, and find ways to receive and listen to the pain of that journey. Be also prepared for the incredible gift of that welcome and membership to the individual and his/her family.

If someone with autism has grown up in your congregation, or another, and moved into adult years, the challenge may be finding new roles and ways for participation and inclusion that are age-appropriate. The children’s special needs ministry may not be the appropriate place anymore.

How do we make that shift? Hopefully, it has begun to happen in the teenage years as it does for everyone. But there are some key strategies:

- Assume ability and competence. People may communicate very differently, as well as be at very different places on the spectrum of autism, but do not assume that a person is not understanding, intellectually and emotionally, what he or she experiences. Finding ways to hear their perspective, such as through computers and writing, may provide a rich and new perspective of the life of faith.

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- People with autism may be socially awkward, but often are keenly aware of their sensory environment. Again, can we be open to the ways that people experience the world and communicate that experience in different ways? They may not be the only ones uncomfortable in coffee hours!
- Predictability and routines are often very important for safety, security, and a sense of control. Hence the value of ritual and liturgy and congregational traditions that are shared with everyone, and, once mastered, an important source of stability. If changes are going to happen, help adults know about them, so they can plan ahead.
- Develop a circle of support for an individual and family, a small group known and trusted, and hopefully chosen, by the adult with autism, to help him/her find new ways to be included, work together on problems, be the ones that the person can ask for help, and help interpret issues or questions to the wider faith community. If the adult is living in or served by an adult services agency, develop relationships with the agency, and ask the individual if he/she could participate in program planning meetings within the agency.
- Finally, work together to find ways that the adult member(s) with autism can use his or her interests and gifts in service to others and the life of the congregation. Help find ways for them to contribute, serve, and respond to God's call in their lives. Look for capacity and talents. Giving them the opportunity to do just that may just be the greatest blessing they will receive, and the rest of the congregation as well. You might notice, of course, those strategies might work for everyone. That's when hospitality, welcome, inclusion and service to and with others become a matter "of course."

*Bill Gaventa, M.Div., is Associate Professor, Director, Community and Congregational Supports, The Elizabeth M. Boggs Center on Developmental Disabilities, UMDNJ-Robert Wood Johnson Medical School.*

*"If someone with autism has grown up in your congregation, or another, and moved into adult years, the challenge may be finding new roles and ways for participation and inclusion that are age-appropriate."*



### Sblendorio Family

When I look at faith I think of a congregation of people coming together to help each other out in times of need. I think of kindness, support, understanding, tolerance, not judgment and alienation. It saddens me that families who have real issues in life to deal with and turn to faith cannot receive support, especially a family like ours who does everything in their power to help others around us. Let's hope that in the future this changes. That people in our area choose to think of others and not just themselves and realize that faith in whatever denomination has a different meaning than just showing up to mass each week. Children with autism deserve the chance to be included, loved, and most definitely respected. Luckily, we finally found a parish that embraces our son and situation.



*Val Sblendorio at his communion*

commanded to imitate God's attributes of love and kindness. After all what else can it mean to "walk in God's ways?" Creating an atmosphere where parents of children with autism can gather in safety and honesty will enable the synagogue/church to successfully put into practice its noble calling and, as a result, present an opportunity to add value and meaning to the lives of its congregants well beyond the group.

## Creating Sanctuary: A Clergy's Guide

**Rabbi Geoffrey Haber**

The diagnosis of a child with autism can engender a crisis of faith that causes parents to withdraw from participation in their faith community and particularly their house of worship, which is a symbol of religious expression and God's presence in their lives. These parents need to give and receive support from one another, explore their faith-based assumptions, and find a place of acceptance within their faith community in order to better cope with their life situation and retain their connection to the organized religious community. Here are ways in which pastors and rabbis can make their congregations more accessible:

1. **"You shall be holy, for I, the Lord Your God, am holy."** (Leviticus 19:2): The first step requires transforming the congregation into a sacred community. Schwarz defines a sacred community as one that provides its members with a sense of acceptance and love, warmth and belonging.<sup>4</sup> To create a sacred community people cannot be strangers – cold and indifferent – to one another. They must make the effort to reach out and get to know the wonderful families and individuals who make up their special faith community and by welcoming those with differences into their hearts and homes. Here the pastor/rabbi can teach the value of welcoming through sermons, classes and by example. Creating an environment that welcomes families that have children with disabilities is perhaps the biggest hurdle of all. Setting a tone of welcoming will go a long way to overcoming that obstacle.
2. **"God said: 'Let us make humankind in our image, after our likeness.'"** (Genesis 1:27): All people are unique, and that difference in each person makes sense not only psychologically but theologically as well. The Hebrew Bible states that all human beings are made b'tzelem Elohim, "in the image of God." If God is infinite, then every creature made in God's image will reflect a different, finite, aspect of that infinite Source of life. The fact that each new person presents a new aspect of God's image is a consequence of God's creative energy. Aware of this reality, the house of worship—as a religious and spiritual institution—and its members must respect each individual for his or her special qualities and are, therefore,

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## Christ Lutheran Church, Bridgeton

First, it took an alert ministry professional (Vicar Sue Riley, now pastor of Christ Lutheran) to discover the disability hidden from view: She noted that either Wade or Pam Sjogren attended every week with their children, but never came together. Inquiring about this, she learned that one parent stayed home each week with Christopher, who has autism.

3. **“Let them make Me a sanctuary that I may dwell among them”** (Exodus 25:8): God commands the Israelites to make a sanctuary (mishkan) in the midst of their camp that will be the symbolic dwelling place of God during their desert wanderings and encampments: God does not dwell “in it,” that is to say, in the sanctuary, but rather “among them,” or as the Hebrew betokham may be translated, “in them,” meaning in the hearts, minds and spirits of the Israelites. Likewise, the house of worship must be a sanctuary for parents of children with autism so that God’s presence may dwell “in” and “among” them. Thus, the house of worship must become a place for parents of children with autism to get together in a supportive group environment to explore their spirituality and theology in the face of the challenges brought about by having to cope with the reality of a child disabled with autism.

4. **“Know before Whom you stand.”** (Babylonian Talmud, Brakhot 25b): In the context of Jewish religious teaching, this phrase refers to God and our knowing that at all times we stand in the presence of the Holy Blessed One and should act accordingly.

For the pastor/rabbi in this context, “knowing before whom you stand” means not prejudging the abilities of the child who stands before you. **Let the child demonstrate his/her capabilities** and reveal them over time. Set long-term goals and break them down into manageable short-term objectives. Use receptive prayer, repetition, modified rituals or worship services to shape an appropriate ceremony that will be meaningful, ritually legitimate and successful for the child. As the child masters one form or element, add another and another until the child achieves the goals agreed upon by parents and clergy. Utilize parents as teachers, aids and liaisons to ensure success, involvement and lasting appreciation for their church/synagogue and pastor/rabbi.

5. **“You shall not ... place a stumbling block before the blind.”** (Leviticus 19:14): Obstacles have two forms: those that are there and which must be removed, and those that we place in the way of others either intentionally or unintentionally. In each case, it is incumbent upon the pastor/rabbi who wishes to make his/her house of worship also a house of welcoming to remove both kinds of obstacles. When it comes to the former, it may mean adapting the environment to accommodate the disability, such as large print prayer books for the people with visual impairments or a ramp for people who use wheelchairs. For a child with autism, it may be teaching that roaming around, hand-flapping or screeches are part of this child’s nature and we

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## Very Rev. John R. O’Connell, V.F., Roman Catholic Church of the Nativity, Midland Park, NJ

Upon learning that families of children with special needs typically avoid Christmas Mass because of the crowds, I agreed to add a Christmas Mass for people who are “differently-abled.” This wasn’t to shun the families affected, but to encourage them to attend Mass together as a family, without worrying that their children’s behavior would disturb other parishioners. I see this as a religious obligation. If Jesus did anything, he welcomed all types of people, and I think these people who are differently-abled have been pushed to the fringes of society for too long.

So each month we have an additional Mass for people who are differently-abled, and the goal is to make everyone comfortable. If a kid jumps up and screams, it’s not a problem with me. This is not my house – this is God’s house and I’m just the custodian. There are families now attending “regular” Sunday Mass, because they feel welcomed in their need and also fed by their church. They became comfortable enough to join the general assembly. This has been a wonderful experience for me. I get more out of it than they do.

must see them as his/her way of communicating with God (after all, it's not that much different than speaking in "tongues" or calling out "hallelujah"). It may mean that the pastor/rabbi must teach a child according to his/her level and physical ability (e.g., using a voice box or picture communication system if the child is non-verbal), but that teaching should be viewed as legitimate and each step of progress should be acknowledged and celebrated with pride.

6. **"We are all responsible for one another."** (Babylonian Talmud, Shavuot 19a): Perhaps one of the biggest stumbling blocks of all is congregational ignorance, prejudice or intolerance. Perhaps the role of the clergy person here is to educate the community to be sensitive to and unafraid of individuals with disabilities. Sensitivity training for clergy, teachers, children, parents and the community as a whole will go a long way in making the faith community a welcoming one.

### **St. Joseph Church, Maplewood**

A boy with autism playing the role of shepherd in the Christmas Story at his parish is spinning happily on the stage. This was not a scheduled part of the play, but there had been unexpected changes he was not prepared for, and he misunderstood his mother's hand signals to move to the other side of the stage. However, there is no problem. The pastor whispers into the mother's ear, "I'm sure there were some shepherds that were that happy on that night."

The Hebrew word for the ancient Jerusalem Temple, Beit Miqdash, literally means "House of Holiness," or more commonly, "Sanctuary." The Hebrew word for synagogue, beit kneset, literally means "House of Gathering," and the word "church" comes from the Greek *kriakos*, meaning "of the Lord." These definitions teach us that our houses of worship, whether synagogues or churches, must be a sanctuary to all who wish to gather in assembly under its roof in praise of God. They must be places of gathering for all, including those with special needs and their families. By their very presence within the house of worship, parents and families of children with autism can be sources of education about disabilities, promoters of advocacy on behalf of those who cannot speak for themselves and creators of a culture of caring and compassion for all of God's vulnerable children. And that, alone, gives importance and relevance to their presence within our houses of worship.

<sup>4</sup> Schwarz, Sidney, *Finding a Spiritual Home: How a New Generation of Jews Can Transform the American Synagogue*. (San Francisco: Jossey-Bass, 2000).

*Rabbi Dr. Geoffrey Haber served Temple Emanu-El in Closter, NJ for 11 years before becoming the spiritual leader of Congregation Mishkan Tefila, Chestnut Hill, MA in 2007 and is a parent of a child with autism.*

*"Creating an atmosphere where parents of children with autism can gather in safety and honesty will enable the synagogue/ church to successfully put into practice its noble calling and, as a result, present an opportunity to add value and meaning to the lives of its congregants well beyond the group."*



## Finding Sanctuary: A Parent's Story

**Madeleine Goldfarb, M.S.W.**

I am often asked to talk about my second son, Jonathan. Jon, as he prefers to be called, is a typical thirteen-year-old in many ways. He is very concerned about what his friends think. He wants only Abercrombie and Fitch shirts, Levi jeans, and unlimited rap songs on his iPod. His many accomplishments are exceptional in all ways, because Jon is autistic. The past ten years have been a journey. A journey, if I had the choice, I would have rather not taken. Given that I did not have the choice, I have chosen to face it and fight it head on.

The fight began one year before Jon's diagnosis, as we sought help for the two-and-one-half-year-old toddler, who was drifting away from us. He stopped developing language and his focus on the world was fleeting. Day by day, his very soul seemed to be seeping away and we were powerless to stop it.

After what seemed an eternity, we finally heard the word that would influence our lives in ways that few words could. Autism drove us from our home to find a school. Autism depleted our bank accounts and tested our will. Autism shaped our son's development and progress. Autism turned our world into an obsessive race to get Jon therapy and reverse the path of disability he was traveling. Autism was an avalanche and we were standing at a precipice trying to hold it back.

Autism tested everything from our marriage, our commitments, to our faith.

Religion and even faith was something I did, yet, was not something I necessarily felt. My husband would hold his hands to the sky and cry out, "Eloheeme, why me?" Eloheem is one term to refer to the judgmental G-d. I was far more pragmatic. It was not a case of why G-d had done anything to impose this challenge upon us, but, more of the fact that this challenge was upon us. How will I face it and conquer it? As I said, religion was something I did more than felt. I wanted my children to always have a sense of their religion and I considered my upbringing to be an observant one. In keeping with the traditions of my faith, my family lights candles every Sabbath and recites prayers of thanksgiving for all we have been given.

That is a constant and has never changed. I have never had a crisis of faith until it was time for preparation for Jon's bar mitzvah. The bar mitzvah is a rite of passage in the Jewish faith, when a Jewish boy becomes a Jewish man. The transition takes place at the event of the young man's thirteenth birthday. This event is remarkable in that according to the Jewish faith a young man after his thirteenth birthday is then able to take on the responsibilities of a Jewish male adult. Partially, that obligation of adulthood includes his ability to participate in the daily prayers and being called to read from the Torah (the five books of Moses). This event is typically heralded in by the young man being called up to read from the Torah and giving a speech.

We made the decision to join a reform temple, though we considered ourselves more of a conservative family. In the United States, organized Jewish religion can be divided into different groups, the main ones being orthodox, conservative, and reform. The reform movement has a looser structure toward the service than the other two and we felt for my son it would be a better fit. Given Jon's struggle with learning English, we did not send him to Hebrew School. Every word Jon learned came with a great effort. Once he learned a word he never forgot it, yet every word was learned by rote. We met with the Rabbi and arranged how to get Jon prepared for his bar mitzvah. This was about two years before his thirteenth birthday. We felt comfortable with the decision we had made. Unfortunately, shortly thereafter, the Rabbi took another pulpit out of state. There was a search, and a new Rabbi was selected. We did not think anything would change in reference to Jon. Oh, how wrong we were.

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We were called into the Rabbi's study as the time approached to start my son's tutoring to get him prepared. This was over a year before his thirteenth birthday. A meeting I thought was to begin the scheduling for Jon's preparation turned into something very different. This new Rabbi did not intend to honor the arrangements we had made for Jon. Instead, he accused us of trying to usurp our obligation to send my son to their Hebrew school. He told us, "We don't just bar mitzvah anybody. You never sent your son to the Hebrew program and we would not consider giving him a bar mitzvah just like that."

My husband and I were dumbfounded. We left the study with our mouths hung open and our hearts heavy. I felt as though I had been punched in the stomach. This person, in the presence of the Hebrew school principal, had turned his back on my family and more importantly refused to help my son. My husband stood in the lobby and said, "I will never step foot into this place again. Find a place for Jonathan."

Ok, I was on it. Where could we go? I called a number of friends and started the search. I began looking for a place to welcome us as a family, a family of imperfection and difficulty. As I considered what had happened, I began to get angry. I was angry at being reminded that autism had once again framed my world in a way that was ugly and intolerant. I again never questioned my faith, as it was always something I did, not felt. Nevertheless, I felt a deep anger and sadness that we had been singled out and refused help in a place I thought we had the right to expect welcome, tolerance, and understanding.

I suppose the lesson in the end is that sometimes it is necessary to go through the bad thing to find the really great thing. Not only find a great thing, but also have the understanding that it is a thing of great value. For, if the Rabbi had reluctantly agreed to bar mitzvah my son, I believe he would have done so with indifference at best, and more likely with a level of acrimony. More importantly, we never would have found the synagogue we belong to today. We were referred to a Rabbi who is both wise and patient. He agreed to take us on. He spent the entire year meeting weekly with my son and teaching him with such kindness and conviction it was awesome. My son adored this man and rose to the challenge. At one point the Rabbi said, "I really do not want Jon to read from a piece of paper when he is called to the Torah. (Jon does not know how to read Hebrew, so he learned his portion by transliteration.) The only thing is for Jon to memorize his entire section. I know he can do it." I was skeptical, but the Rabbi had faith that Jon would prevail. I guess I needed a lesson in faith. Jon did memorize his portion and as the day neared, he proved himself ready. The long story short is that Jon had his bar mitzvah exactly on time and exceeded all expectation. He made us proud in a way that I cannot fully express. He made us proud as parents of a young man being called up to the Torah and taking on the responsibilities of a Jewish adult.

For once, he was just a kid having his bar mitzvah, with his proud family around him. He was not a kid with autism that day, and I was just a mom filled with pride at the accomplishment her son had made. He was not her son with autism this day. That was the greatest gift of all. As the day wound down to a close, I gave thanks for the day and thanks for all those things in life. For the first time perhaps since the birth of each of my sons, faith was something I felt...not just something I did.

*B. Madeleine Goldfarb, M.A., is Director of Outreach and Education of The Autism Center of UMDNJ-New Jersey Medical School, Newark.*

*"I was angry at being reminded that autism had once again framed my world in a way that was ugly and intolerant... I felt a deep anger and sadness that we had been singled out and refused help in a place I thought we had the right to expect welcome, tolerance, and understanding."*

## “Am I My Brother’s Keeper?”

John H. Harris, M.Div., D.Min.

As I write from an African American clergy perspective, let me begin by saying that in the Black church – be it Methodist, Church of God in Christ, Baptist, etc., – we are and always have been very tolerant and accepting of persons that differ, whether they are called autistic, schizophrenic, bipolar or any of the names or phrases used for people with mental or physical disabilities. Some of our willingness to work with persons we entitle “special” could have derived from our own experience of deprivation in the Black community, such as lack of education, knowledge, and resources. We are a family-oriented people. We are private with our family issues and we have never been able to afford or believe that institutions would provide the proper care for our loved ones. We also believe that God will work it out and “it is just our cross to bear.” In my experience, I have not heard the term “autism” used very often, nor encountered the behaviors associated with it, in the Black church and among acquaintances. But, without a doubt, I am sure it exists in the community, because I have observed it in other venues and around the world.

I have taken a long look back at my own life, from my youth through my current role as Pastor, and I don’t recall ever hearing the word “autism” in my churches. But on the other hand, because of strange behaviors, I do remember hearing “Aw, you know they just crazy,” “not quite right in the head,” “their elevator doesn’t go all the way to the top,” or “he/she is just short of a dozen.”

It is sometimes assumed that Black folks always thought, both then and now, that if a person’s behavior was different, then he or she must be demon-possessed. That did sometimes happen, but I also think we must have known the difference between being biblically demon-possessed and having mental instability. Another false belief was that autism was not found in the Black community, but of course we now know differently. In this modern day, there seems to be a wealth of information regarding autism, but it is obvious that we in the Black community continue to lack accurate or comprehensive knowledge and resources.

*“I do strongly believe that there were many dedicated mothers and fathers who simply did not go to church. They did not want to bring their children who exhibited atypical behaviors we may now call ‘autistic.’ They simply stayed at home.”*

As a Pastor, I have looked into the eyes of caring mothers who appear worn and fragile, while meticulously doing their best to understand the child and his/her behavior, and both seen and heard their frustrated questions: “What have I done to deserve this?” or “What did I do to bring this on my child?” Historically, because of the lack of both secular and biblical education, some African Americans (as well as white Americans) whispered answers to those questions and behaviors on the assumption of demon possession. We as a people had no information or basis on which to attribute these unusual behaviors to anything beyond the realm of what we thought we knew, and what we knew was the Bible.

I do strongly believe that there were many dedicated mothers and fathers who simply did not go to church. They did not want to bring their children who exhibited atypical behaviors we may now call “autistic.” They simply stayed at home. I must admit that there are many undiagnosed or misdiagnosed developmental disorders in the Black community due to the fact that very little information is targeted toward Black communities and presented in a venue like the church where it is “safe” to receive or even believe it. We now know that much is needed in the Black community to assist parents who have had to stop living their lives to provide day to day care of a child with special needs. These parents not only center their lives on the present needs of their child but also live in fear of what will happen to the child in the event of their death. Remember the movie “Radio,” in which the character’s mother died? That reality was dramatized, with a positive outcome, but we know that life does not always have a

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happy ending. The earlier we can help people with autism and families get the support they need, the better. I often wonder how many people in the Black community have not been afforded a psychiatric or psychological evaluation until it is too late, (e.g., before or during a trial related to a criminal offense, or when they are failing in school, or are disruptive)? Is this because no one dared raise the possibility of a mental disorder?

But it also makes me ask the age-old question, “Am I my brother’s keeper?” As we move into this time of new beginnings, let us continue to break the bonds of ignorance and use the venues that we have to support the people in the community. That venue for me, an African American Pastor, is the pulpit. We have to light the way by using the words, dispelling the myths with knowledge, and helping people get good information and support, both from our congregations, and also from service systems that are sometimes unresponsive, difficult to understand, and hard to access. These are also barriers that we can, and shall, overcome.

*The Rev. Dr. John H. Harris is Pastor of Galilee Baptist Church, Trenton, New Jersey.*

Our journey is through the path less traveled. Yet it is the path with the greatest discoveries about ourselves, and our relationship with the maker. We believe that each one of our children is “fearfully and wonderfully made.” (Psalm 139:14).

...My church family started praying with us and for us.

...Our church community was ever supportive. We spoke about the diagnosis at every opportunity we could with different individuals. We asked people to pray for us as we went through the various avenues to seek help for Nicholas. We have left no stone unturned. We have changed his diet, sought biomedical and educational interventions and all have allowed us to see how “awesome” this journey has been.

Sharing our story with the church community has allowed us to advocate for many parents who feel “cheated,” desolate, and sad about what do with a special needs child. Nicholas is loved by each person, as they get to know him and realize how special he is. He is part of the youth of the church and does not receive any less attention than any other child.

While Nicholas is non-verbal, he is the most adorable and engaging child. We praise God as he promised in Malachi 4:2 that “But for you who revere my name, the sun of righteousness will rise with healing in its wings. And you will go out and leap like calves released from the stall.”

We praise God for all his benefits, especially for being to chosen to parent a child who is “awe-tistic,” fearfully and wonderfully made.

*Robert and Genevieve Kumapley, parents of Nicholas, age 5, Protestant, Ghana.*



# The Person in the Pew

**Cynthia Chiarello, L.S.W.**

We assume you are reading this booklet because you would like to know how you, too, could support a person on the autism spectrum or a family with a child on the autism spectrum. Maybe your church already offers special classes or assistance for people with autism. However, if our churches stay at the level of cheerful volunteerism through engaged programming, it is still possible to avoid genuine relationship. Your desire to seek a relationship is a blessing in itself and the place to begin.

It is normal to feel helpless or nervous about interacting with a person with autism. Families do not expect you to be an expert, they sometimes need a friend or just a little help and for this, you need only two skills: being a listener and being available.

People choose to refer to the autism spectrum in different ways. You may hear someone discuss their family member's diagnosis as PDD-NOS, autism, autism spectrum, Asperger's, or autistic. By listening for the terminology that the family chooses to use when referring to the diagnosis, and following the lead of the adult and the parent, you will demonstrate sensitivity and lay the foundation for trust and relationship.

Say hello to the individual who has autism. Wait that extra few beats for them to respond. Be understanding when he or she does not or cannot reply, and one day he or she might surprise you. Children with autism learn, grow, and change like all children.

Families of children with autism have made an enormous effort to attend worship. There is often tension in doing so, which can interfere with their ability to socialize after services with other families. A kind word acknowledging their efforts will provide encouragement and strength to persevere. Perhaps you could also offer to call them during the week at a time that would be better for them, and when you do call, consider offering to pray for or with them.

## **CC, Fanwood, NJ**

"We attend a large church. Our child has been supported from the first day with a 'shadow' during Sunday school classes. Getting to know other families in the church, however, has been hard. Because our child experiences sensory overload, we head straight for the car and often are not able to mingle in the halls like other families. However, one family has gone out of its way to show love and support to our family. When our other child was injured and hospitalized, Bev, who works full-time, offered to baby-sit as we went back and forth to the hospital. Most significantly, our autistic child has been invited to their child's birthday parties for the last four years. We feel so blessed that our daughter has the opportunity to attend a 'neurotypical' party, and have witnessed her progress socially as each year has served as practice for the next."

*"Valuing the participation of the child over the 'performance' may require you to welcome the unexpected, but can provide a memorable experience that truly communicates 'sanctuary' to the larger community."*

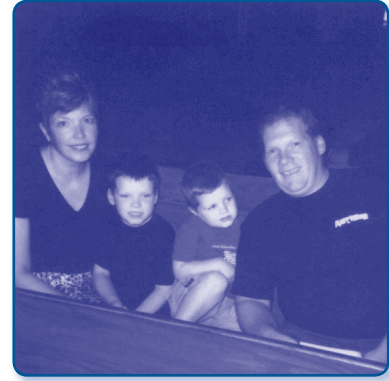
Involve individuals and their families in the functions of the church. They also feel blessed in giving and participating. Include the child in special events and programs, and discuss with the parents how this can be achieved. Valuing the participation of the child over the 'performance' may require you to welcome the unexpected, but can provide a memorable experience that truly communicates 'sanctuary' to the larger community.

All modern families juggle many activities in their schedule. Families with an autistic child often are also dealing with speech, occupational therapy appointments, tutoring, doctor's appointments, special education meetings, and filling out insurance and other paperwork. Perhaps there is

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## Lynn Family

Our family began attending mass at the beginning of July 2006. We introduced ourselves to the ushers and lectors at mass, our pastor and the director of religious education for the parish. We especially took the time to introduce our children, Eoin and Colin. Colin, our 4-year-old, has autism. Our priest and the religious education director made us feel very welcome, in every way, and asked us if there was anything at all they could do to assist with making Colin feel comfortable and to please let us know.



*Marianne, Gerry, Eoin  
and Colin Lynn.*

Unfortunately, not all of the parishioners were as welcoming as the parish staff. We were attending an 11:30 am mass and sat in the back, like we usually do, in case we needed to give Colin a break. He was pretty quiet, however, drank his juice, ate cheerios and played with his matchbox cars. He did move around a bit and was a little restless, but not overly distracting to any one around us. Or so we thought! During the mass when it came time for the sign of peace greeting, I reached out my hand in a sign of peace and the woman sitting next to me refused to shake my hand. She said while pointing at our son Colin – after I had offered “Peace be with you” – “I don’t think so...” “He doesn’t belong here – he is not ready for mass.” I explained he had autism and said I was sorry she felt that way. She replied, “I know all about you.” I told her, “God made him the way he is” and she said, “Don’t give me that.” I then said to her, “Shame on you.” At that point we received communion and rather than return to my seat next to that woman, I stayed at the back of the church with Colin. When mass was over, she pursued an exchange of words with my husband.

She explained she was a teacher for forty years, and in her judgment Colin did not belong at mass with us – he wasn’t ready. She recommended we sit in the “cry room.” I explained that did not work for our family. She clearly did not want to compromise. My husband asked if she could display some patience and tolerance as a fellow Christian, that that was all we wanted from her. She responded, “that is not what you want, you want my pity!” At that point I asked my husband to leave and I told her that we would like to take up our concerns with the pastor for him to decide.

a concrete way you can help: drop off/pick up dry cleaning, bring a meal, or offer to look after siblings while the parent brings the autistic child to therapy appointments. This may seem to be a small thing to you, but when people have had the experience of rejection, acts, signs, and symbols of welcome and support are very powerful.

As you develop your relationship with the child or adult with autism, you will be rewarded. As you share in the ups and downs of life with these families, you will begin to see the world in a different light. Small steps, which most would overlook, are the source of much joy, and you will witness God’s grace afresh.

*Cynthia Chiariello, LSW, is the parent of a child on the autism spectrum, a social worker for the Morris School District and a former COSAC Support Group Facilitator.*

## The Grant Family

Some months later Calvary Chapel Old Bridge started the Beyond Limits Ministry for children and families with special needs. If warranted, the children are in a self-contained class where they are taught in appropriate terms and they are assigned Best Buddies to help them remain engaged. Both my sons have now attended church for five years and love it. The servants have seen the best and the worst of my kids and as they continue to teach my children about Jesus, they show His love, His grace and His patience. The ministry has also grown in the years and they now bless several families that are affected by disabilities. The many practical things that they have done include:

- Scheduling date nights, where they baby-sit the children at church while they either take the parents out to dinner or give them a gift certificate for dinner.
- Issuing special parking permits to families that allow us to park in handicapped spots at church.
- Assigning Best Buddies during church picnics, etc.

They have helped other churches start ministries for persons with disabilities and have put together a booklet for this purpose.

I thank God for this ministry and the servants who God uses to bless our families.



**Dilshad D. Ali, from “Because of Autism,” reprinted with the permission of [www:BeliefNet.com](http://www.BeliefNet.com)**

“Living a life full of therapy and without a larger sense of purpose was draining me. And I needed to be a whole person, connected with my faith, so that I could be the mother my children needed me to be.” In January of 2005, Ali and her husband went for Hajj, the “once-in-a-lifetime pilgrimage” to Mecca and Medina that all Muslims are required to do: “I came away from that experience with the feeling that when you finally accept your fate, you can embrace your life. And then you can actually celebrate and thank God for giving that fate to you. And that’s the golden ticket, I believe, to being happy and strong. An autistic child is not a loss, I realized, but a sort of gift that can be managed through faith.”

**Janet Grillo, “What Is It Every New Mother Fears?”  
Huffington Post (11/2/2006)**

“As if by helium, he lifted away from us, from our family, from our world and inwards towards a remote and private one. The doctors called it “autism.” I did not know what to call it. I still don’t. It is too big for words to organize...

Faith is what taught me that what I want is not necessarily what I need, that love is not what I prefer but what is required, that rising to the challenge of what is required enlarges the heart and fills it with more love than I ever knew was possible. That love is the fuel of faith, that by loving my son as he was in our struggle to restore what was not, faith found me. Faith found me through the urgency of living. Fear had to wait.”

**Lisa Gwinner, “Greetings from Autismland”  
(11/27/2006)**

<http://lisa-jedi.blogspot.com/2006/11/autism-sermon-part-2.html>

“At every turn, we and Brendan have been accepted and continued to feel welcome in this church community. Brendan has found friends here of all ages, understanding Sunday School teachers, mentors, and peers who treat him as a person of worth and dignity, no matter how difficult it may sometimes be for him to participate in class or other aspects of church life. This has been a great blessing for all three of us. There are not many places in public these days that Brendan feels comfortable. Church, school and our sailing club are

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## Autism: Presence & Justice

**Kristina Chew, Ph.D., and Jim Fisher, Ph.D.**

The presence of persons with autism in communities – including communities of worship/religious congregations – is a starting point for any discussion of autism and social justice grounded in religious and ethical traditions. Though it is unknown when the condition of autism as currently understood first appeared on the spectrum of human cognitive experience, it is clear that for most of the twentieth century, if not earlier, the presence of autistic persons in religious settings – like the presence of other persons with demonstrable cognitive differences – was nearly always treated as problematic because of those differences.

Communities of faith rarely, if ever, challenged the dominant paradigms of autism handed down from the psychiatric establishment, most notably the “refrigerator mother” theory associated first with psychiatrist Leo Kanner in the 1940s and 1950s, then popularized by Bruno Bettelheim in the 1960s. The abuses against children with autism later uncovered at Bettelheim’s Orthogenic School helped shape the legacy of autism’s “dark ages.” While such active hostility toward autistic persons and their families is less evident today than in the recent past, everyone that loves, cares for and/or works with persons on the autism spectrum has experienced frustration at times in seeking greater acceptance and understanding. Many persons with autism have grown increasingly outspoken in a variety of ways as they directly experience a sense of disapproval or rejection by those unfamiliar or unsympathetic with the daily challenges of life on the spectrum.

The autism community has promoted ways of coping with the inevitable frustrations of navigating the medical and educational systems: professionals in these fields have done their part to break down barriers that arose during the long decades of mutual contentiousness and distrust. Since the processes of public advocacy and self-advocacy remain exhausting if often rewarding, families and individuals generally wish to avoid a replay of these struggles within communities of faith and worship and other voluntary communities that historically provide respite and spiritual renewal. Though “inclusion” is

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part of the legal repertoire now enjoyed by persons with autism in educational settings, much work remains to be done in communal settings with their own (often ancient) traditions and rituals of participation and belonging. Persons with autism are becoming increasingly present in communal spaces that were once marked by their absence even when this absence went unacknowledged. The presence of persons with autism might at times be construed as “disruptive” to the values of order and decorum, but this response should be balanced by the recognition of a legacy of exclusion, which rendered human communities of all kinds incomplete.

The “difference” of autism is indeed different and need not be dismissed or minimized, but just as differences of gender, ethnicity, or human sexuality are recognized as elements of human identity not composing the whole person, so too does the difference of autism not compose the whole autistic person. The difference a cognitively “disabled” person represents simply by her or his presence is an occasion for mutual understanding and perhaps an occasion of grace as understood in some faith traditions.

Justice grounded in any faith surely demands that the person in community is to be known in and for oneself and as a member of community. Rabbi Geoffrey Haber has spoken often of his son’s bar mitzvah experience as an exemplar of Judaism’s traditional injunction to know that person who stands before you. The experience of autism may offer an opportunity for deeper engagement with the questions: how are we to know and be known? How do we know the person who stands before us and who is the person who stands before us?

Persons with autism are required to change and to constantly adapt to sensory environments they may find uncongenial. Persons with autism may be especially challenged to adapt to the reverential tone and sensory environment of worship spaces, yet experience shows that many autistic persons do adapt, often as part of an educational process that enhances their freedom and human dignity by empowering them to surmount some of their sensory/behavioral challenges. At the same time, the value of mutuality that is integral to so many spiritual traditions calls us to consider ways we might adapt to the presence of autistic persons; such adaptations may in fact enrich the faith foundation of communities for helping us understand our traditions, our liturgies as living not static.

Many persons with autism have testified they do not wish to “recover” from a human condition they see as intrinsic if not God-given. On the other hand, family members, caregivers and loved ones often do hope and pray for profound change within the autistic persons in their lives. A primary challenge and opportunity for faith communities is to find ways to honor these potentially

### **Greetings from Autismland** *continued*

about the only places where we can go and socialize with friends, meet new people, work for social justice, do the work of the community and still bring Brendan along for the work and the fun without worrying too much that the behaviors he sometimes exhibits will cause misunderstanding. Being actively involved in this community as a family has kept us open to the world and aware that we have a lot to give this world, and not just to our son. From playing computer games with other kids in the lounge to playing with homeless kids while dad helps make dinner for Interfaith Hospitality Network families, Brendan gets the chance to experience the wider world through our involvement at church.”

### **Kassiane Alexandra Sibley, Autism and Advocacy conference (October 27, 2006)**

[www.fordham.edu/cs/media](http://www.fordham.edu/cs/media)


“I’m not broke and don’t need fixing.” By this simple declaration, Ms. Sibley not only revealed a self-perception but suggested—in an act of autism self-advocacy—that even the most earnest expressions of solidarity are problematic when rendered unilaterally. We sometimes proclaim our “broken” condition as an element of our common humanity with all those that suffer, but in so doing we may subtly, unintentionally discount the ways solidarity is sometimes proffered on our terms. Ms. Sibley’s invitation to examine our language, our images and our theological assumptions is but one example of mutuality in action, a model for engagement that will enrich the experience of all persons in community.

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conflicting convictions by promoting supports that serve the whole person and the family. From this engagement will develop a theology of autism/cognitive disability grounded in the mutual encounter of persons in community. Whether we understand our religious convictions in terms of “faith seeking understanding” or a “faith that does justice” or in wholly other ways, all persons of faith should find common ground in proclaiming the human rights of autistic persons to an appropriate and effective education across the life span. This conviction is grounded in the belief that all persons are endowed with the potential for lifelong growth and development as human beings; however we differ cognitively, we are the same in our endowment of human dignity and our capacity for fulfillment in community.

From this discernment grows certain fundamental convictions: the inequality of educational opportunity for persons with autism is not simply a matter of public policy, but social justice. This disparity closely mirrors inequalities of economic status, which in turn are often grounded in legacies of racial inequality and de facto residential segregation that relegates persons who are cognitively disabled and poor to substandard educational programs. Everyone in the autism community knows just how unequally distributed are these vital and indispensable educational services, from early intervention to classroom teaching to vocational training. These inequalities are further evident from delayed diagnoses to inadequate services that can lead to physical harm done to autistic persons or members of their families. The fundamental inequality of autism services—and the demeaning competitive scramble into which most families are driven—call for action grounded in moral and religious convictions on the dignity of all human persons.

*Kristina Chew, Ph.D., is Assistant Professor of Classics at St. Peter's College in Jersey City and Jim Fisher, Ph.D., is Professor of Theology at Fordham University in New York City. They are the parents of a son with autism.*

A decorative graphic on the left side of the page, consisting of a light blue, stylized vine with leaves and small flowers, curving upwards and to the right.

*“The difference a cognitively ‘disabled’ person represents simply by her or his presence is an occasion for mutual understanding and perhaps an occasion of grace as understood in some faith traditions.*

*Justice grounded in any faith surely demands that the person in community is to be known in and for oneself and as a member of community.”*



# Inclusion in Faith Communities: Some Tips for Parents to Get Started

**Bill Gaventa, M.Div., and Mary Beth Walsh, Ph.D.**

1. Introduce yourself and your child to your religious leader before you attend, if possible. Ask if there are other children or adults with autism in the congregation. Explain what autism is, and your child's limitations and potential. But first, let them know how important participation in a religious community is to your family, and that this is an area of concern for many families.
2. Offer to help provide information, educational opportunities, or people who can assist religious educators to include your child. Professionals may be quite willing to give guidance to religious educators and to help figure out how to adapt a curriculum. There may be other ways that you as a parent can volunteer in the religious education program to help overall teaching and staffing resources. There are also online resources and materials.
3. Find a family-oriented worship service where a little noise is not uncommon.
4. If your child is too young to pay attention to the service, bring books or other engaging toys to occupy him or her.
5. If the expectations are for children to sit in a religious service for 45-60 minutes or more, make sure the child is able to do this at home first, or has an opportunity to practice.
6. Figure out a way to come to the sanctuary with your child and go through the steps of the service so it is familiar space. Practice can happen outside the service and at home. Video modeling, a video of what happens in the service and what people do, can be a way of helping a child learn visually.
7. Use concrete language and visual aides when instructing your child.
8. Use a digital camera to make a picture book of your worship service and space, important parts of the service, key people, etc. You can use the pictures to help a child learn the names of the places, actions, and people. Practice at home, and reward the child when he/she labels them in public.
9. Find something in the worship service that your child enjoys and can participate in and succeed at to make attending services fun for your child.
10. Learn how to use a motivational system and then make it as discrete as possible.
11. Use this booklet as a resource and provide it to your congregation and other parents and families.
12. Use the resources in the next sections. There are some excellent ones for congregations.

# Resources

## Organizations and Resource Networks in New Jersey

### **The New Jersey Center for Outreach and Services for the Autism Community (COSAC)**

1450 Parkside Avenue, Suite 22  
Ewing, NJ 08638  
609.883.8100; 1.800.4.AUTISM  
Fax: 609.883.5509  
information@njcosac.org  
www.njcosac.org

### **The Elizabeth M. Boggs Center on Developmental Disabilities**

UMDNJ-Robert Wood Johnson Medical School  
P.O. Box 2688  
335 George Street  
New Brunswick, New Jersey 08903  
732.235.9300  
Fax: 732.235.9330  
<http://rwjms.umdnj.edu/boggscenter/>

### **The Arc of NJ**

Education Advocacy  
985 Livingston Ave.  
North Brunswick, NJ 08902  
732.246.2525 ext. 20  
Fax: 732.214.1834  
www.arcnj.org

### **Asperger Syndrome Education Network (ASPEN)**

9 Aspen Circle  
Edison, NJ 08820  
732.321.0880  
info@aspennj.org  
www.aspennj.org

### **Family Support Center of NJ**

Lions Head Office Park  
35 Beaverson Blvd., Suite 8A  
Brick, NJ 08723  
732.262.8020  
www.familysupportnj.com

### **NJ Protection and Advocacy**

210 South Broad Street, 3rd Floor  
Trenton, NJ 08608  
800.922.7233  
www.njpanda.org

### **Statewide Parent Advocacy Network (SPAN)**

35 Halsey Street  
Newark, NJ 07102  
800.654.7726  
www.spannj.org

## New Jersey State Government Offices

### **NJ Department of Education - Office of Special Education**

609.292.0147  
www.state.nj.us/education/specialed

### **NJ Division of Developmental Disabilities (DDD)**

800.832.9173  
www.state.nj.us/humanservices/ddd

### **NJ Early Intervention Offices**

888.NJ.EI.INFO  
888.653.4463  
www.njeis.org

Also see the New Jersey Resource Guide from The Daniel Jordan Fiddle Foundation. 92 pp. PDF file at [www.j-add.com/The%20Daniel%20Jordan%20Fiddle%20Foundation%20-%20Homepage\\_files/Resource\\_Guide.pdf](http://www.j-add.com/The%20Daniel%20Jordan%20Fiddle%20Foundation%20-%20Homepage_files/Resource_Guide.pdf)

## Speakers

Speakers: Many of these organizations, as well as members of the Autism and Faith Task Force and authors of articles in this booklet, are sources for speakers for congregations.

## Interfaith Resources

Join the New Jersey Coalition for Inclusive Ministries to network with other congregations, families, clergy, and organizations who are working together to strengthen congregational supports. To join, send an e-mail to [NJCIM-online-subscribe@yahoo.com](mailto:NJCIM-online-subscribe@yahoo.com).

## Books on Autism

Any list of books on autism may be out of date as soon as it is published. Thus, we recommend checking with a few key organizations or publishers for recent publications.

**www.thegraycenter.org:** The Gray Center has a number of resources with first-person accounts, audio visual resources and more, including *Reflections of Self*, *Diagnosis Asperger DVD*, and *ASD to Z*.

**www.woodbinehouse.com:** Woodbine House Press has a number of books on autism oriented towards families, friends and the community, including some good books about autism for children and siblings, ones that would be useful in working with children in religious education settings.

**www.brookespublishing.com:** Resources focused toward professionals and families, including Paula Kluth. (2003) *"You're Going to Love This Kid!" Teaching Students with Autism in the Inclusive Classroom*. Baltimore, London, Sydney: Brookes Publishing Company.

## Others particularly useful for congregations

Ellen Sabin. (2006) *The Autism Acceptance Book: Being a Friend to Someone with Autism*. Watering Can Press.

Daniel Gottlieb. (2006) *Letters to Sam: A Grandfather's Lessons on Love, Loss, and the Gifts of Life*. Sterling Publishing. 17 letters from Dan Gottlieb to his grandson, Sam, who has autism.

Cindy Ariel and Robert A. Naseef, Editors. (2006) *Voices From the Spectrum: Parents, Grandparents, Siblings, People with Autism, and Professionals Share their Wisdom*. Philadelphia: Jessica Kingsley Publishers. This book contains 60 personal stories on the joys and struggles of autism from the perspective of parents, grandparents, siblings, professionals as well as people with autism.

Haddon, Mark. (2004) *The Curious Incident of the Dog in the Night-Time*. Vintage Press. Murder mystery told through the eyes of a young man with autism who is the detective. Excellent for awareness building.

## Books on Ministry, Religion, and Autism

These come from different faith traditions, but note that good resources and strategies can be adapted across religious and denominational boundaries. A more complete list of books, articles, and videos on autism and faith is available from The Boggs Center at <http://rwjms.umdj.edu/boggscenter/> as well as an online bibliography of resources for inclusive ministries with people with developmental disabilities and their families called *Dimensions of Faith and Congregational Ministries with Persons With Developmental Disabilities and Their Families 2005 Edition*. 180 pp. (Print copy also available.)

### Religious Education

**CCFH Ministries:** [www.ccfh.org](http://www.ccfh.org)

Jim Pierson. (2002) *Exceptional Teaching: A Comprehensive Guide for Including Students with Disabilities*. Cincinnati: Standard Publishing. This site also has an online training program for religious education teachers.

**Friendship Ministries:** [www.friendship.org](http://www.friendship.org)

Barbara Newman. (2006) *Autism and Your Church: Nurturing the Spiritual Growth of People with Autism Spectrum Disorders*.

Barbara Newman. (2001) *Helping Kids Include Kids with Disabilities*.

**Labosh Publishing:** [www.laboshpublishing.com](http://www.laboshpublishing.com)

Kathy Labosh. (2007) *The Child with Autism Learns the Faith: Bible Lessons From the Garden of Eden to the Parting of the Red Sea*. A Catholic mother and parent, but the tips and these lessons obviously can be used in many settings.

**Network for Inclusive Catholic Education:** [www.udayton.edu/~ipi/nice.htm](http://www.udayton.edu/~ipi/nice.htm)

Resources include Sacraments: *Gifts for All. Confirmation, Eucharist, and Reconciliation Welcome One, Welcome All: Inclusive Religious Education Resource Binder*.

**Silver Burdett Ginn Religion:** [www.sbgreligion.com](http://www.sbgreligion.com) or 800.552.2259

*Rose Fitzgerald Kennedy Program to Improve Catholic Religious Education for Children and Adults with Mental Retardation*. (2003) Silver Burdett Ginn also distributes a number of other resources from the Archdiocese of Pittsburgh, which had one of the first autism task forces.

**Jewish Family and Children's Services of Minneapolis:** [www.jfcsmpls.org/inclusionresources.html](http://www.jfcsmpls.org/inclusionresources.html).

Jewish Inclusion Resources from many different organizations and publishers as well as a newly published *Jewish Community Guide to Inclusion of People with Disabilities*. (See below).

### Inclusive Ministries

Kathleen Dyer Bolduc. (2001) *A Place Called Acceptance: Ministry with Families of Children with Disabilities* and (1999) *His Name is Joel: Searching for God in a Son's Disability*. Congregational Ministries Publishing, Presbyterian Church, USA Presbyterian Publishing Corporation, 100 Witherspoon Street, Louisville, KY 40206; Phone: 502.569.5096. (Joel is her son with autism.)

Erik Carter. (2007) *Including People with Disabilities in Faith Communities: A Guide for Service Providers, Families, & Congregations*. Baltimore: Brookes Publishing Company. Many strategies and tips.

Ginny Thornburgh and Ann Rose Davie. (1993) *That All May Worship: An Interfaith Welcome to People with Disabilities*. Washington, D.C.: National Organization on Disability.

Shelly Christensen. (2007) *The Jewish Community Guide to Inclusion of People with Disabilities*. Minneapolis: Jewish Family and Children's Services.

## Videos

### Excellent videos (DVD's) on attitudes and inclusive ministries

- *Ten Commandments for Communicating with Persons with Disabilities*. Program Development Associates. 25 minutes. Uses humor and vignettes for ten guidelines.
- *Believing, Belonging, Becoming*. Wisconsin Developmental Disabilities Council, [www.wcdd.org](http://www.wcdd.org), 11-minute video, four stories of congregational inclusion, two focused on children, two on adults.
- *Family Journeys into Faith, Autism, and Communities*. Video made from interviews with New Jersey families by the Autism Center at UMDNJ-New Jersey Medical School in Newark. Contact B. Madeleine Goldfarb at [goldfabm@umdnj.edu](mailto:goldfabm@umdnj.edu).

### For more videos on autism and disability, go to:

Program Development Associates: [www.DisabilityTraining.com](http://www.DisabilityTraining.com)

Fanlight Productions: [www.fanlight.com](http://www.fanlight.com)

## National Websites

### Autism sites: There are many, but these are good places to start.

Association for Science in Autism Treatment (ASAT): [www.asatonline.org](http://www.asatonline.org)

Autism Speaks: [www.autismspeaks.org](http://www.autismspeaks.org)

Organization for Autism Research (OAR): [www.researchautism.org](http://www.researchautism.org)

### Faith-based sites:

Community Connections: [www.communityconnections.umd.edu/news/spiritualnewsletter](http://www.communityconnections.umd.edu/news/spiritualnewsletter). Building spiritual connections with Tip Sheets for including children with disabilities.

National Organization on Disability: [www.nod.org](http://www.nod.org). Go to the Religion and Disability Program section of the website for information on the Accessible Congregations Campaign and more.

[www.ncpd.org](http://www.ncpd.org): National Catholic Partnership on Disability

[www.naiflm.org](http://www.naiflm.org): National Apostolate for Inclusion Ministry

[www.jfcsmpls.org/inclusionresources.html](http://www.jfcsmpls.org/inclusionresources.html): Jewish Inclusion Resources











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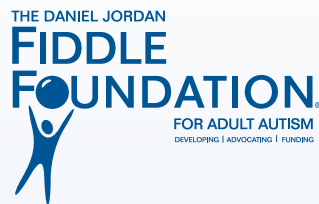
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