

Lost and Found: An Integration Story

Milton Tyree

He was lost. Or so his parents believed. Searching anxiously, they ultimately found him exchanging spiritual truths. No. I'm not recounting the story about Mary and Joseph's search in Jerusalem for 12-year-old Jesus. You'll recall how Jesus was discovered missing from the group during their return to Nazareth following the family's annual Jerusalem pilgrimage for the Feast of the Passover. "*After three days they found him in the temple courts, sitting among the teachers, listening to them and asking them questions. Everyone who heard him was amazed at his understanding and his answers.*" (Luke 2:46-47)

Mine is a different story. You can decide if or how they're related. This story is much more recent. The missing one is older. And, thankfully, the duration of his absence shorter. This time, the one believed to be lost was a young man with Down syndrome. Just so happened that he'd been one of the ushers assigned to the morning worship service. Additionally, it just so happened that two people who had not been to church in a while had come to worship that day with recent news that their newly born grandchild had Down syndrome. Questions cluttered their minds: Why? What does this mean? Will our grandchild be able to learn and go to school? Might he be "a vegetable"? (They'd heard this possibility but had no idea what it meant!) Will he be dependent on his parents forever? Will he have friends? When he grows up, will he be able to have a job? What kind of life will he have?

And then, they saw Bryan: distributing bulletins just like the other ushers, collecting the offering just like the other ushers, being a congregational member – just like the others. Bryan's presence was reassuring. His words were comforting. They'd raced to him following the service and asked one question after another about his life. And so he was late meeting his parents in the parking lot. You see; Bryan was not lost either. On that day everyone found what was needed.

Now if Bryan was the right person in the right place at the right time for this couple, then how might things have been different if he'd been absent from the sanctuary? What if expectations surrounding Bryan had been low? What if he'd not been included as an active congregational member? Or what if he'd been at church that day, but instead of having involvement in the regular worship service, he'd attended *special* worship for people with disabilities?

Social integration is an interesting concept. It's something that people living with a socially valued status take for granted. We get so accustomed to being invited to life's parties that we don't even notice the invitations. Not true for people who are socially devalued – that is, those who have some negatively perceived characteristic that causes them to be known as fundamentally different. For Bryan it's Down syndrome. The huge risk for him is that this *one* characteristic will consume his *entire* identity. In the eyes of others, he becomes "the Downs guy." Then all sorts of decisions about what he does, where he goes and the people he knows are based on having Down syndrome *without* regard for the many other dimensions of Bryan. Fortunately for Bryan and others, he and his fellow congregational members have avoided this trap.

So what are some things that might be learned from this one Sunday morning snapshot of Bryan's congregational membership?

- **Role Exchange & Unpredicted Teachers:** Mutuality, give and take, reciprocity: such is the stuff of balanced relationships. Bryan had something very ordinary, yet something very important to offer the visiting couple. What a relief for the one who's taking, not to always be the taker! What a blessing for the giver, to experience the dignity of giving! God isn't keeping score, as long as everyone gets to play.

Do you know people in your congregation who *always* find themselves on the receiving end of relationships? What are their gifts and talents? How can these be shared for the benefit of others? How can they contribute to their church's ministries?

- **Exponential Hospitality:** When Bryan is welcomed and included in the full life of the church, his family is welcomed and included. The opposite is also true. Parents of children with disabilities are excluded when their children are *not* welcomed. Their lives frequently become consumed with care and advocacy for their children. They encounter the parental brand of isolation and segregation. Time and again they're invisible. Quietly rejected. It doesn't have to be this way.

The whole family hungers for a place to belong. Could there be a better, more natural entity than the church to offer hospitality, to welcome the stranger, to accept the rejected, to invite the outsider, to promote authentic, heartfelt involvement?

- **Modeling with and for the Larger Community** – One of the primary ways that people learn is through modeling others. Placed in a new situation, we strive to surround ourselves with others who know what to do. All of us want to fit in! So it makes sense for Bryan to learn the role of congregational member, as well as the many sub-roles (confirmation class member, Presbyterian Youth Connection participant, usher, corporate worshiper, etc.), from others who are already established and competent in these roles.

The same applies to the church serving as a model of integration for the community. How often do we hear, "the church has lost its relevance"? Do we have a relevance issue for you! More and more churches are seeing a generation of people with disabilities and their parents who've grown-up having or seeking social integration with non-disabled people in school, work, neighborhoods, and communities of faith.

Why not share what we know *and* learn from others? Good intentions are not enough. We need to know what we're doing! A significant body of knowledge has been developed, especially over the last 30 years, about ways to support social integration of people with disabilities in everyday aspects of life. While we don't want to define people by their disabilities, it's just as wounding to ignore people's disabilities. Our congregations have the fabulous opportunity to model social integration for others, *and* learn from and with community schools, employers, YMCAs, other churches...

How can your church mentor individuals with disabilities if they need support to learn the ways of your congregation? How can you partner with others in the community to model and support genuine involvement of people with disabilities in schools, jobs, swim teams, civic organizations, as well as other communities of faith?

- **The Power of the Preposition:** The quality of the invitation has much to do with the shape of Bryan's participation in church life. Not *to*, or *for*, but *with*. Integration respects the needs of those integrated and the integrators. Bryan has likely grown up with many opportunities to be involved in typical aspects of church life. For someone *without* these experiences, integration may require additional consideration. On the one hand, we don't want to impose integration. But on the other hand, we don't want to deny its benefits to one who may have been socialized into ways of separateness.

Where is your congregation now when it comes to knowing and involving people with disabilities in the everyday life of the church? Who can devote the time to know these people, or perhaps know them in new ways? How can you encourage people with disabilities to discover new possibilities for themselves? Darcy Elks developed this things-to-know list to get the ball rolling: *a) Person's age? b) History? c) Functional impact of disability? d) Societal barriers including negative stereotypes? e) Interests? f) Abilities/skills/gifts? g) Who are the people in this person's life? h) How are the people involved? i) Who else would you like to see involved? j) What would they do? k) What does this person or others want for the future?*

- **Awakening a Vision for Justice:** Bryan can stir our broader social justice sensibilities, opening our eyes to things that become so much a part of our social landscape that they dodge our scrutiny. For example, on the last day of 2006, a Louisville *Courier Journal* headline on page 3 reads: "Down Syndrome Testing to Change." The three paragraph article matter-of-factly informs, "Tests far less invasive than the long-used amniocentesis are now widely available, some that can tell in the first trimester the risk of a fetus having Down syndrome..." The upshot of this story is a recommendation for an increase in prenatal testing for "every pregnant woman, regardless of age."

This article caused me to think about Bryan in his Sunday morning usher role. How would fellow congregational members respond to this sterile story and its alarming insinuation about people "like Bryan"? There's no mention in the *Courier* about the gravity of this issue, nor is there a reference to a recent medical study estimating pregnancy termination rates of 80% to 90% when prenatal screening reveals the possibility of Down syndrome. Good people of faith may disagree on theological, spiritual and social implications of abortion. But what about the escalating targeting of people who just happen to have an extra 21st chromosome? Given this intensification, what is the connotation for others in our world who are thought to be less? A good social outrage equity test might be this: Try filling in the blank with another socially devalued group. "The ACOG is heightening its prenatal testing recommendations for the risk of a fetus having/being/becoming _____."

How can Bryan help us see oft-unrecognized dynamics of social devaluation?

So this thing of inviting, including, and integrating people with disabilities transcends “being nice.” It can impact the very integrity of our church, of our lives. Families and communities are affected by the church’s response to children, youth and adults with disabilities. How can Bryan help us open our hearts and minds to unsuspected teachers? How can he help us strengthen ties within our community? How can he help us move from worldly valuation of people to heavenly valuation? What’s the cost of welcoming and including people like Bryan? What’s the cost of not?

The lost usher is based on a true story that happened at a Catholic parish in New Jersey. Bryan is a pseudonym.

Milton Tyree, PDC Consultant for Developmental Disabilities

Aspergers Syndrome by a Fifth Grader

I would like the people in the church to know that there is something different about me. I am a normal person, but I have a disorder called Aspergers Syndrome. It is an autism-spectrum disorder, sometimes called high-functioning autism. I was born with it, and it is not something a person can catch from me.

Aspergers Syndrome affects the way my mind works. Sometimes I escape into my own little world, and it is hard for me to pay attention to what is happening around me. I don't always notice how other people are feeling, and I have trouble reading their body language. Being in a crowd makes me feel tired. I can't remember all those people's names, and who they are.

Sometimes I may act really weird, and do things without knowing I am doing them. If you see me doing strange things with my hands, or running around, it is because I'm thinking about things that interest me. It means that I am either interested, happy or excited.

I can focus on things I like. Some of the things that interest me are robots, computers, electronic games, computer programming, and karate. Things I don't focus on well are writing, other people, and sometimes the sounds around me.

Some famous people, such as Albert Einstein and Thomas Edison are thought to have had Aspergers Syndrome. Bill Gates has said that he has it.

People can help me by making me feel normal and by understanding me. I just want to fit in, and I like being part of the church.

This article was printed in the newsletter of his church in Minnesota

Friendship Group
Valley Community Presbyterian Church
Golden Valley, Minnesota

by: Linda Wold

Valley Community Presbyterian Church has a class for developmentally disabled adults called "The Friendship Group". It is a group that offers adult education on Sunday mornings.

I first became familiar with the Friendship Group when I was asked to teach their Sunday Educational program. I had been advocating for children with learning disabilities for many years prior and so putting my skills to work with the Friendship Group seemed a natural fit.

The educational program for the Friendship Group is varied and many resources are used. Since the group members are all non-readers, and some have physical disabilities, all their senses are called upon to teach each lesson. Each lesson and each period of the year is taught in a different manner. Many curriculums have been used and adapted. Lessons from the various age groups, tools and methods of teaching are all utilized by the Friendship Group. For example, the manipulatives from the pre-school "Kingdom Kids" program, were used to tell the exodus story. The table-sized sandbox represented the desert and all the many characters in that Bible story were represented by wooden figures dressed in appropriate clothing. The Friendship Group were able to listen to the story and move the "players" through the desert while sharing their own thoughts about what it must have been like to travel through that terrain. I taught that particular lesson more than 2 years ago and the Friendship Group still talk about it to this day which tells me they certainly internalized that experience.

The Friendship Group, including guests they invite to join them, are fully a part of the activities at our church. They attend worship, participate in communion, attend the fellowship activities such as the coffee hour after worship, Christmas pageants, annual meeting dinner, Christmas dinner, Fall Festival auction/dinner. Not only do they attend and fully participate, they help with set-up and clean-up right alongside all the other church members.

Their various gifts and abilities are appreciated and they are an integral part of our church. They have a pure faith in the Lord and never waiver in their beliefs! Their patience with me and others is amazing and noteworthy. Their honesty, depth of loyalty and trust are remarkable. And their sense of humor is the icing on the cake. We love and cherish the Friendship Group at Valley Community Presbyterian Church and are so fortunate to be a part of their circle of friends in Christ!

Tips for Church School Teachers

Working With Children Who Have High Energy and/or Have Challenges With Focusing and Staying on Task

Knowing that each child in our church school classes is unique and brings his or her special “gifts” to the class, the following “teacher tips” are intended to provide a smorgasbord of options that may be helpful for assisting each child to be successfully included. No one suggestion will work for all children or all situations. A child’s age and developmental level may direct variations of the ideas suggested. Likewise the following suggestions are not presented in order of importance or intended to be a complete list but rather a starting point from which more ideas may emerge. They should be available to all the children in a class.

1. Design routines to allow children to get through transitions or tasks so the experience will be positive. Children may benefit from routines (i.e. during arrival, greeting friends, getting out or putting away supplies). Routines need to be brief, fun and consistent (once established children will expect you to follow them). Lists and charts can help everyone remember the routine. They take away the need for adults to “tell kids what to do” (you might use photos or hand drawn pictures for young children). Class activities may need to have frequent breaks. Some children attend better or make transitions go more smoothly if directions are sung (create a little song). Some children respond well to routine and predictability of “first we do this, then_____”. When a change in schedule or instructions for an activity must occur, prepare the child by having extra support for dealing with the transition. Make the change in small steps.

2. Start a class session with a highly motivating activity. Include multi-sensory activities. Vary sit-down activities with activities that are movement-based. (movement songs, movement games related to the lesson, heavy work using many muscle groups at the same time such as lifting objects, moving furniture, cleaning up or passing out materials). Movement helps some children to divert excess energy. When unable to remain calm in a

classroom, the child might go outside or in a hallway and run back and forth between two points as many times as possible in a 3-5 minute period or jump up and down for a few minutes before attempting to relax and be attentive.

3. Explore different ways to structure a lesson such as teacher-directed or activity centers/stations. Children may benefit from a prescribed format of changing stations on a certain signal or free roaming at his or her own pace (for some children this is less threatening and they feel they have more control, but for a child who flits from one learning space/activity to another, it is less effective). Minimize verbal directions. Supplement with pictures or charts. Speak in slow, even tones.
4. For children who have high energy and need to “wind-down” to becoming calm, try activities that have a slow rhythmic movement or oral activity such as (with parent permission) chewing gum, sucking or licking a lollipop. Snacks might include healthy chewy food such as celery, carrots, fruit leather, or beef jerky. Create calming routines. Some children may benefit by sitting at the edge of a group of children vs. in the middle of other children where they might feel threatened by others brushing against their back or coming up beside them from behind.
5. If children appear to be stressed or have disruptive behavior, explore what is the behavior trying to say: “I’m tired. I need more or less sensory input. I don’t understand. There was a sudden change that overwhelmed me. I’m bored. I’m afraid. I’m too excited. Pay attention to me. Stop the noise.” Some children may just need more time for a task/activity.
6. Physical Environment: Create a storage system for class materials so children can be independent in getting out and putting away materials (label containers and keep near where they will be used when possible). Reduce sensory stimulation and lesson distraction by resisting the temptation to cover every wall with posters and art work. Some children may benefit with different types of seating. Some may need a sturdy chair or one with rubber bottoms on chair or table legs. Others may attend better in a beanbag chair. If sitting on the floor, consider using carpet squares or other designated item to sit on which defines a

child's place in space. Seating a child away from a window or the door may reduce excess stimulation from outside noise, movement and minimizing sights.

7. For children with additional challenges of regulating sensory input (touch, taste, smell, feel, hear, see): try using choices of tactile materials during art projects. Use a glue stick vs. glue or paste. A child may benefit from holding old a "fidget toy" during long period of listening. For some children who are 'skiddish' because every stimulus is threatening, reduce noise and strong odors, offer choices of food/drink, and lower the amount of light.
8. Explore additional support and resources from other church educators, public (or private) school educators, and children's parents who know them well. Build a support system for yourself.

THANK YOU for including and appreciating the "gifts" each child brings.

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