

April 7, 2013

On the Spectrum

Worship Leader: Rev. Barbara F. Meyers

Homily: Monica Arce

Worship Associate: Drew Wilson

Music: Pat Rodgers

Call to Worship

Robert French Leavens ¹

“Holy and beautiful the custom which brings us together,
In the presence of the Most High:

To face our ideals, to remember our loved ones in absence,
To give thanks, to make confession,
To offer forgiveness,
To be enlightened, and to be strengthened.

Through this quiet hour breathes
The worship of ages,
The cathedral music of history.

Three unseen guests attend:
Faith, Hope, and Love;
Let all our hearts prepare them a place.”

¹ #416 in *Singing the Living Tradition*

Meditation

Let us pray for the vision impaired...
Who can only see differences in people...
Not who that person is inside...

Let us pray for the speech impaired...
Who can only speak with harsh and hurtful words,
Instead of kindness and understanding....

Let us pray for the mentally disturbed...
Who cannot seem to care for anyone that is any different from
themselves,
Instead of at least trying to love everyone,
"Different" or not....

Let us pray for the hearing impaired...
Who can only hear the unspoken words,
Instead of listening for what someone is trying to tell them...

Please...
Help these people who truly have DISabilities
So that this world can become a better place
For ALL of your children.....

Amen!

- Tina Yows, ² adapted

² *disABILITY Prayer*, by Tina Yows, Web. 29 Dec 2012
www.oafccd.com/lanark/poems/prayer.html

On the Spectrum Sermon

Open with anecdote from Carly Fleischmann ³

“At the age of two, Carly Fleischmann was diagnosed with severe autism and an oral motor condition that prevented her from speaking. Doctors predicted that she would never intellectually develop beyond the abilities of a small child. Although she made some progress after years of intensive behavioral and communication therapy, she remained largely unreachable. Then, at the age of ten, she had a breakthrough.

“While working with her devoted therapists Carly reached over to their laptop and typed in ‘HELP TEETH HURT,’ much to everyone's astonishment. This was the beginning of Carly's journey toward self-realization.”

By typing, she became articulate and able to express what she was thinking and feeling. She eventually went from being in special education classes to being in the advanced college prep high school classes. She now has a popular Blog and she hopes to attend UCLA. She remains non-verbal. She is helping others understand what it is like to have autism.

Here is an example: Show video - Carly's Cafe – Experience Autism Through Carly's eyes:

<http://www.youtube.com/watch?v=KmDGvquzn2k>⁴

³ Description of Carly Fleischmann comes from *Carly's Voice – Breaking Through Autism* by Arthur Fleischmann and Carly Fleischmann

⁴ <http://www.youtube.com/watch?v=KmDGvquzn2k> *Carly's Cafe Experience*

She says: “Autism feels hard. It’s like being in a room with the stereo on full blast. It feels like my legs are on fire and over a million ants are climbing up my arms. It’s hard to be autistic because no one understands me. People just look at me and assume that I am dumb because I can’t talk or because I act differently than them. I think people get scared with things that look or seem different than them. It feels hard.”⁵

Definition and Dramatic Rise of Autism

In the 1943 Leo Kanner, a doctor at Johns Hopkins wrote a paper identifying 11 children with something he called “infantile autism.”

As Temple Grandin, probably the most well-known person with autism, a woman with autism who has achieved a PhD explains, “Autism is a very big continuum that goes from very severe -- the child remains non-verbal -- all the way up to brilliant scientists and engineers. It's a continuum of traits. When does a nerd turn into Asperger, which is just mild autism? I mean, Einstein and Mozart and Tesla would all be probably diagnosed as autistic spectrum today.”⁶ The term “autism spectrum disorders” or ASD is used to denote this wide continuum. ASD has several disorders in addition to autistic disorder as shown here: Childhood Disintegrative Disorder, Rett’s Disorder, Asperger’s disorder and Pervasive Developmental Disorder, Not Otherwise Specified or PDD-NOS, each of which has a set of characteristics of severe deficits in

⁵ From *Carly’s Voice – Breaking Through Autism* by Arthur Fleischmann and Carly Fleischmann

⁶ Temple Grandin – Ted Talk *The World Needs All Kinds of Minds*,

http://www.ted.com/talks/temple_grandin_the_world_needs_all_kinds_of_minds.html I should mention that her characterization of Asperger’s is not agreed upon by everyone and some find it offensive.

many areas of development. Speculations by some⁷ include Adolf Hitler, James Joyce, Andy Warhol, Charles Darwin among others who were probably were autistic. Lately it has become a more wide ranging practice to speculate that anyone who is socially awkward like Mitt Romney, or nerdy like Bill Gates or Mark Zuckerberg must have Asperger's. There is stereotyping either way – “retarded” or “genius.”

When I discussed these kinds of speculations by Grandin and others with an autism therapist he said that all of these examples are based on public personas and not on any kind of evaluation. He explained that to be autistic requires a full range of symptoms, not just social awkwardness. He also told me that there is currently a big political battle regarding tightening of criteria for autism in the soon to be published version of the Diagnostic and Statistical Manual, called the DSM 5, and that any of this tightened criteria would not include any of these public figures.

There is a wide variability of Autism's expression in human beings. The aspects that are most characteristic are:

- **Social Skills.** People with autism often lack the intuition about others that many people take for granted. Temple Grandin described her inability to understand the social communication of what she called “neuro-typicals”, or people with normal neural development, as leaving her feeling "like an anthropologist on Mars"⁸. Children with high-functioning autism, sometimes Asperger's Disorder, suffer from more intense and frequent loneliness compared to non-autistic peers, despite the

⁷ Michael Fitzgerald, of the Department of Child Psychiatry at Trinity College, Dublin, has written numerous articles on the subject, as well as at least four books: *The Genesis of Artistic Creativity*, *Unstoppable Brilliance*, *Autism and Creativity* and *Genius Genes*. He has identified over thirty individuals as potential ASD sufferers, including Adolf Hitler, James Joyce, Andy Warhol, and Charles Darwin.

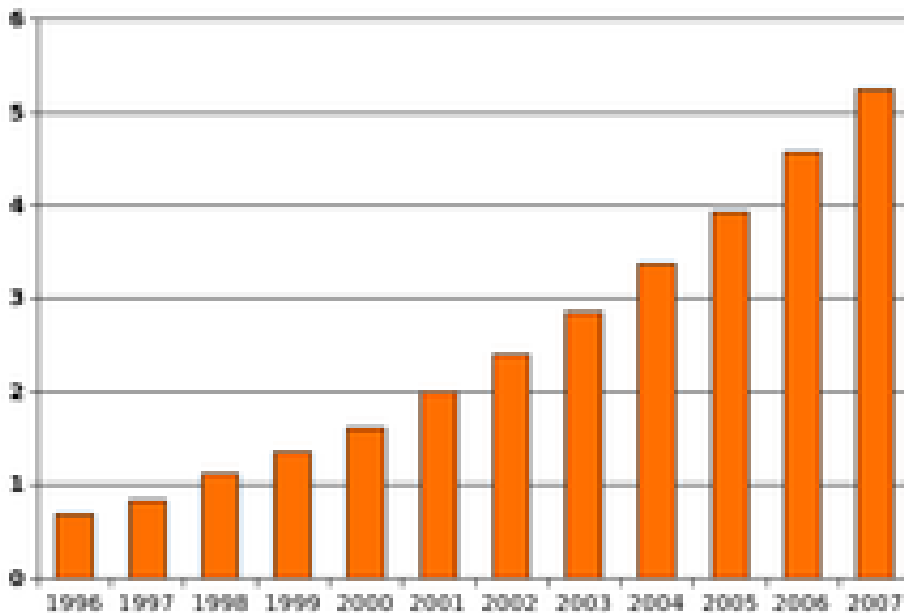
⁸ *An Anthropologist on Mars – Seven Paradoxical Tales*. by Oliver Sacks, Vintage, 1996 has a profile of Temple Grandin.

common belief that children with autism prefer to be alone.

Making and maintaining friendships often proves to be difficult for those with autism.

- Language difficulties – delayed speech or inability to speak at all
- Behavior characteristics: repetitive movements, rituals, sensitivity to light, sound or touch

In 2008 it was estimated that 11 per 1000 children in the United States have an autism spectrum diagnosis. This has been climbing dramatically since the 1990s. Here is a chart for autism itself:



Reports of autism cases per 1,000 children grew dramatically in the US from 1996 to 2007. In 2009 England's National Health Service did the first ever census of autistic adults and found roughly one in 100 adults are on the autism spectrum.⁹ It is not known how much of the growth came from autism's prevalence and how much from better or different diagnosis or availability of services only if you are labeled autistic,

⁹ *For the First Time, a Census of Autistic Adults*, Time Magazine, October 3, 2009. On line at: <http://www.time.com/time/printout/0,8816,1927415,00.html> .

although the English study identifying autistic adults suggest that we are doing a better job of identifying people who are on the autism spectrum. Part of the political issue in changing autistic criteria in the DSM 5 is that many fear they will lose their diagnosis and education and social supports with the new criteria. Some studies suggest that the majority of people diagnosed under DSM 4 would continue to qualify under DSM 5 proposed changes. At this point it's probably "too soon to tell."

One highly-political aspect of the proposed change in the DSM is that what are presently unique mileposts under DSM 4 will be folded into one diagnosis of "autism spectrum disorder." Many neurodiversity advocates embrace "Asperger's syndrome" as a unique identity and are reluctant to give up that identity.

The causes are not known, other than that there is some component of genetics, particularly from older fathers, or older grandfathers. The belief that it is caused by vaccinations has been disproven. Dr. Tony Attwood, in his book *The Complete Guide to Asperger's Syndrome*¹⁰ states "Recent research has indicated that 46 percent of the first-degree relatives of a child with Asperger's syndrome have a similar profile of abilities and behavior, although usually to a degree that is sub-clinical, i.e. more a description of personality than a syndrome or disorder." Lending credence to the role that heredity can play.

It seems these days like you see it everywhere. One of the sons of a friend of mine from graduate school has Asperger's, children of some of our MPUUC members are on the spectrum. There is a lot of endless speculation about who might have it, or have a touch of it. As we see

¹⁰ Attwood cites the study on page 21 in his book *The Complete Guide to Asperger's Syndrome*, by Jessica Kingsley Publishers, 2007. The study he cites is Volkmar, F., Klin, A. and Pauls, D. (1998), "Nosological and genetic aspects of Asperger syndrome." *Journal of Autism and Developmental Disorders* 28, 457-453.

more and more of this, one can understand why the late producer and playwright Nora Ephron pondered about the Autism Spectrum: "Is every man in America somewhere on it? Is every producer on it? Is every 8-year-old boy who is obsessed with statistics on it?"¹¹ Am I on it?

In a feature article in New York Magazine, Benjamin Wallace states: "There is speculation that every generation has its defining psychiatric malady, confidently diagnosed from afar by armchair non-psychiatrists." In the recent past it has been narcissism, or obsessive compulsive disorder. Maybe this decade it is Autism Spectrum Disorders, because "nerd titans hold the high ground once occupied by square-jawed captains of industry." And maybe this 'who must be on the spectrum' speculation is a "tool to soothe our cultural anxiety about the ongoing power shift from humanists to technologists."¹²

A friend of mine Dr. Bobby Newman who is a psychologist and Behavior Analyst who works with people who are autistic reminds me that it is important to mention just how serious this disorder can be for people and their families. There are many autistic people who, unlike Carly Fleischmann, never learn to communicate by any means, who need intensive teaching just for simple skills like toileting or dressing. Some are dependent on those around them for even the most basic daily functions, those who self-injure severely enough to require stitches, those who give themselves broken bones, those who are aggressive towards others, and so on. This all takes a toll on people who are autistic, their families and care givers.

¹¹ *Are You On It? If so, you're in good company. From Asperger's to "Asperger's," how the spectrum became quite so all-inclusive.* by Benjamin Wallace, New York Magazine, October 28, 2012. <http://nymag.com/news/features/autism-spectrum-2012-11/>

¹² *ibid* adapted.

How is it treated?

Treatments for autism vary depending on the needs of the individual. In general, treatments fall into three categories:

- Behavioral and communication and social skill development. Addressing these areas requires close coordination between parents, teachers, special education professionals, and mental health professionals. This is the only form of therapy that has empirically validated research backing it up, according to governmental reports.
- Medical and dietary therapy
- Complementary therapy (music or art therapy, for example)
- There is anecdotal support for a wide variety of treatments, and unfortunately the field is rife with charlatans who offer to cure autism with various kinds of means, including telepathy, and take advantage of desperate parents trying to get help for their children.

Neurodiversity

Neurodiversity¹³ is a concept suggesting that neurological differences be recognized and respected as a social category on a par with gender, ethnicity, class, or disability. For some, neuro-diversity is viewed not just as a concept but as a social movement.

This movement understands neuro-diversity as a variation of human wiring, rather than a disease. These activists reject the idea that neurological differences need to be “cured” as they believe them to be authentic forms of communication, self-expression and being. Some don’t believe in behavioral therapy to change “unusual” behaviors. They

¹³ Definition from Wikipedia.

promote support-systems that allow those who are neurologically different to live their lives as they are, rather than attempting to conform to a clinical ideal because, to quote Temple Grandin “the world needs all kinds of minds.”

The world Needs all kinds of Minds – Temple Grandin¹⁴

Temple Grandin knows that it is important for people to learn how to get along in the world, but she also knows that the worlds needs all kinds of minds. This is in effect a balance of Neurodiversity and conforming to the world without losing her unique talents and self. She describes herself as “ different, not less.”

Here are some excerpts from a Ted talk she gave in 2010:

“We've got to think about all these different kinds of minds, and we've got to absolutely work with these kind of minds, because we absolutely are going to need these kind of people in the future.”

“So, what is thinking in pictures? It's literally movies in your head. My mind works like Google for images. Now, when I was a young kid I didn't know my thinking was different. I thought everybody thought in pictures. And then when I did my book, *Thinking In Pictures*, I start interviewing people about how they think. And I was shocked to find out that my thinking was quite different. Like if I say, "Think about a church steeple" most people get this sort of generalized generic one. ... I see only specific pictures. They flash up into my memory, just like Google for pictures.”

¹⁴ From Ted Talk by Temple Grandin, “*The World Needs all Kinds of Minds*” 2010.

“What can visual thinkers do when they grow up? They can do graphic design, all kinds of stuff with computers, photography, industrial design. The pattern thinkers, they're the ones that are going to be your mathematicians, your software engineers, your computer programmers, all of those kinds of jobs. And then you've got the word minds. They make great journalists, and they also make really, really good stage actors. Because the thing about being autistic is, I had to learn social skills like being in a play. It's just kind of -- you just have to learn it.”

“Another thing that can be very, very, very successful is there is a lot of people that may have retired from working in the software industry, and they can teach your kid. And it doesn't matter if what they teach them is old, because what you're doing is you're lighting the spark. You're getting that kid turned on. And you get him turned on, then he'll learn all the new stuff. Mentors are just essential. I cannot emphasize enough what my science teacher did for me. And we've got to mentor them, hire them.”

"If by some magic, autism had been eradicated from the face of the Earth, then men would still be socializing in front of a wood fire at the entrance to a cave. Because who do you think made the first stone spears? The Asperger guy. And if you were to get rid of all the autism genetics there would be no more Silicon Valley, and the energy crisis would not be solved.” She may be stretching the point in these examples, but her point is that autistic people bring value to the world.

Hospitality

What does all of this mean theologically and what does it mean to a congregation? In a sermon about hospitality, Sally Patton¹⁵ tells us of a Christian tradition dating from the 5th century. “In his book *The Rule*, St. Benedict talked about hospitality. He asks that we see the divine in every single person that we encounter. His hospitality is not about social graces, it is about mutual reverence. In our faith communities it is about accepting those who are different. Acceptance is not about judging or condoning behavior. It is about embracing. We do not have to like a person’s behavior in order to embrace and accept the person. Welcoming all people into our faith communities is an act of radical hospitality.”

How do congregations go about doing this important work?

Sally Patton advises that “One of the ways we can become more accepting of the people we label is to find ways to see the world through that person’s eyes. Connecting with a person who is struggling can be simple, it does not necessarily mean making every one your best friend. It means listening to people’s stories. Listening is one of the ways we see the world through the eyes of another. Listening is one of the ways we see the Divine in each person.”

This sounds like the sermon message that Rev. Jeremy gave us on March 10 on Listening, really listening, and what a gift that is to the other person. It works for all kinds of people, even and especially those who have difficulty communicating.

My behavior analyst friend Dr. Bobby Newman has written a book¹⁶ about how to encourage the full participation of all people in our

¹⁵ From UUA worship web site Sermons : “*God Makes No Mistakes: Creating Beloved Community for All Our Children*” by Sally Patton, adapted.

¹⁶ *The Inherent Worth and Dignity of ALL Individuals: Encouraging Full Participation in our Unitarian Universalist Congregations*, by Bobby Newman, Ph.d., B.C.B.A, 2008.

congregations. The book applies to situations of inclusion more broadly than for autism alone. Here are some of his guidelines, , expressed as congregational rights:

- Every person has the right to attend services and worship as he or she chooses, as long as he or she does not interfere with the equal right of others to do the same.
- I have the right to be myself, but I have to consider the limits of my freedom if some aspect of my behavior makes it difficult or impossible for others to freely worship.
- I have the right to privacy.
- I have the right to be considered a responsible individual
- If my right to freely worship is somehow being compromised, I have the right to bring this to the attention of the proper people without being called intolerant.
- I have the right to be informed if any of my behavior is interfering with the free worship of any other members of the congregation.
- I have the right to expect that the congregation will help me to develop the skills to be a fully autonomous, fully included member of the greater society.
- If conflicts arise in the congregation, I have the right to a frank and open discussion of this conflict. We should seek out solutions that will allow everyone to worship and attend services in comfort.

Sally Patton again: “As a congregation we can embrace the opportunity that each person who crosses the threshold into our church provides us to be in a community that sees differences as gifts and opportunities for meaningful interaction and spiritual connection.”

We are all here as unique, spiritual beings in physical and mental bodies having a variety of different experiences. None of us is a mistake. It is

my belief that we are all created, cherished and loved by God just as we are. The world needs all of us. Practicing radical inclusion with compassion is our sacred responsibility.

May it be so.

Amen.

Benediction:

by Lauralyn Bellamy ¹⁷

If, here, you have found freedom,
Take it with you into the world.

If you have found comfort,
Go and share it with others.

If you have dreamed dreams,
Help one another,
That they may come true.

If you have known love,
Give some back
To a bruised and hurting world.

Go in peace.
Return in Love

¹⁷ #692 in *Singing the Living Tradition*