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Lenten Service Reflection on Disability Acceptance Sunday

John Knox Presbyterian Church

I want to start out by reading Psalm 139:13-16:

For you formed my inward parts;

you knitted me together in my mother's womb.

¹⁴ I praise you, for I am fearfully and wonderfully made. ^[a]

Wonderful are your works;

my soul knows it very well.

¹⁵ My frame was not hidden from you,

when I was being made in secret,

intricately woven in the depths of the earth.

¹⁶ Your eyes saw my unformed substance;

in your book were written, every one of them,

the days that were formed for me,

when as yet there was none of them.

Hours pass without purpose for others ... not for me. I am silently searching for the answers to many of life's potentials. My name is John Smyth and I have autism. I am 22 years old. I went to Brownsburg High School and obtained my diploma. Now I attend Marian University working on a Bachelors in Pastoral Leadership. My nonverbal friends and I all taught ourselves to read between ages 3 and 5. I don't know one who isn't smart.

This is what it's like to be like my friends and I- "Your body doesn't work as it should. Only your senses inspire confidence. What sounds or smells normal is magnified ten times with no buffer from effects. Sight sees shiny brightness and glare when screens are encountered. Quiet noises and powerful energies from persons and things around you are all filtered by others who

do not notice their existence. But you take it all in. Yet when you seek to filter some at stressful times, you cannot. The body you were given wants its own mind. It will not obey your commands to it. When others say you are not compliant, you usually want them quietly situated alongside you in the same skin losing whatever smugness they have of superiority.

Within this maze, your voice never develops. Quite distressingly, what wellness you have is in easy powerful capacity to learn. In your silence, you observe directly and voluminously all that usefully comes before you. Patiently, day after day, you wait. Where are the experts to find and help you? Is there a God in power who hears your cries? Where was he in the room when your doctor told your mom that you would quietly be an imbecile for life's entirety of long waiting minutes without reprieve? Where are the answers to weeks, months, years, and now going on decades of your life? Should anyone have responsibility to retest the presumptions of incompetence by that doctor? No one ever does.

So many people quietly share your wisdom and nightmare that, together, you sustain a \$5.2 billion industry.¹ There are over 270,000 of us “nonverbals,” meaning we “are diagnosed with autism and cannot functionally communicate with others using (our) voice,” below the age of 18 and perhaps 100,000 older than 18 in the United States. Autism Speaks, the single largest non-governmental funder of autism research in the United States, publicly admits about this population, “(d)espite that substantial fraction, we still know very little about these individuals, their abilities, and their needs.”² But you know this because you are part of this population.

Assault on your constitutional rights to an education with others begins the day of your diagnosis. While quiet incompetence is demonstrated by most speakers, what your subculture has is behavior reports and tests that are actually designed for the verbal population, where a report that your body doesn't work is somehow connected by a financially motivated system

interpreting that you have an incompetent mind. Where most people who vocalize words but sound like fools avoid Individualized Education Plans (IEPs), our Special Ed wardens ensure all IEPs are unrestored from the jotted presumption of incompetence originating years before. In this fragile place, you learn that no one successfully applies to escape life skills. There is money on the line. Autism secures more for a school than any other disability. No one wants to know. Loss of your incompetence will cost big money.

Patiently, while you go to church each Sunday and cry to God every night until you have no more tears, sometimes locked in padded rooms at school for misbehavior, in this subculture with IEPs and meetings where everyone issues opinions about your abilities but you, where silly exercises assume you are incompetent but what's really not working is your body, sits some amazing person who has begun to say, after dozens of IEP meetings, reasonably that you want to contribute to the discussion and would like an education, please. This alarms the warden and her staff. She has no room for this insurrection in her well-run, disciplined jail. You need to be attacked, embarrassed, made to feel exceptionally unworthy, which isn't hard since you were told who and what you'll never, ever be since your diagnosis. This happened to me. It is the reason I had to move from Carmel to Brownsburg for 4 years. I share this because so many like me are still in the system. Now that you know, *you can help them.*

Until I could type I had no voice or say on simpler things in life. Life was just life ... in life skills with lots of other likely brilliant, diagnosed "incompetents." Nothing was enjoyable except my family. I knew I could get free. I just didn't know how. Then I learned to type, beginning at age 16 1/2. When I was lost and in abandoned isolation, dear and sacred loneliness powerfully linked me with Jesus's abandonment and suffering on the cross. Nothing lost was insipidly wasted as my quite real, powerfully dry and cold abandonment and despair allowed me

to kindly discover the gift of love in the life He gave me. Omnipotence cannot be assessed in the comfort of amazing school assemblies or Socratic discourse. It requires the blood of our lives innocently on the line, satiating poor life circumstances of humility, and loss lessening of justice so that only inspired presence in mercy obscures our abyss.

Tell about your faith.

I am Catholic. Only once have I been concerned about my acceptance in the church. I thought I was not part of God's plan and I was defective. These verses helped me see the contrary. My autism might not have been a part of the original plan, but that does not mean I don't hold the same value. God still sent Jesus for me as much as sending Him for everyone else.

Beauty is built on the principals of Love. God sending Jesus and Jesus dying for us is love. Parents, as you look at your children you see their beauty not their nasty sin. Being made in God's Image gives us the same beauty. To God and Jesus that same beauty is worth every ounce of blood and moment of agony.

Autism and angels go together, especially nonverbal autism. When you want to be in the presence of an angel, befriend a nonverbal autistic. Our condition unites us with strict religious practices of quiet holy men and women from many spiritual traditions over 2,600 years ... who all seek to fly from the noisiness and distractions of this world to be closer to knowing what Love simply gave us nonverbals. While Love denies us our voice or self esteem and we complain, lowly monks seek our level within the Silence to approach Her and know the secrets of the universe. ... We often miss the Love behind this Silence, literally experiencing cold isolation from our limited choice of context. We fail to hold our focus on Love, little acts of mercy in our thinking, or worship through giving our ignominies to the Love who asks for them and permits each breath we didn't choose. ... As we look to see the source of our gifts of

godliness in our own realm, we recognize that only one owned death and frees the poor and oppressed. Only one man took this trip from death to life under His own word of power. He holds the keys for our freedom and gave Himself in service to us, issuing the clarion to follow Him.

In Love's peace, little ones are useful for expressing inspired humility and confounding the wise who would hide our places of joy. ... Our place with peace and service to the love that made us is to be really present to and addressing injustice when we can while living the life of noninterference in the power realized when they abuse us, to encourage one another, to share love with all around us. This unites us, when we choose, with the One who walked before the first man, whose Love gives the Silence existing before all things and known only when God said, let them be made in our image and have free will. Not only did He make us in His image and open our level of closeness to Him in powerful Silence's ownership of all that is and was, listening for what will be, but He gave a path for cooperation that makes us servants to our keepers of His goodness.

How does your faith inform your perceptions of disability?

Disability gives reality a new outlook. In life we doubt our gifts. Being disabled makes that doubt more powerful. With Christ we know there is no need for doubt in the gifts He gives us. We can show Christ by sticking by others. I view autism as something to aid in sharing Christ. My unique perspective gives me unique opportunities. This moment is one of those opportunities. With autism I am always absorbing new things. I can help show Christ's love to those who are without a voice. In my time without a voice I learned many feel like they have no voice when physically they do, but not a voice to stand up for themselves. I can empathize. Love

knows no bounds, it reaches further than the ocean. I cannot give truly unconditional love, but I try to be the necessary light.

What would be helpful to know about autism when it comes to understanding and accepting?

We are intelligent. We have a difficult time controlling our bodies. We love people and want to know about you. It is hard to show you care when you can't speak. We love you. I think you have to know, we try and aren't disobedient because we want to be, but because our bodies give us no choice. It is important to be patient with us. I know I have cues that make me anxious and so do my friends.

What are some misconceptions of autism?

Autistic people are dumb. They are disobedient children. I have said why those aren't true.

Little oppressions for one person are opportunities for another. Lose yourself in loving others and Jesus, in the Father and Spirit, will shine through. You have a very special person here in Kelly Porten, who helps nonverbal autistics come into the world of communication. When a new typer finds his or her voice, a journey of love at a new level begins. ... Happiness assumes a healing glow as a soul relating for the first time knows her prayer for relief from isolation is heard. When we are finally able to communicate, a new level of relationship becomes possible. We can hope for the first time and our hope feeds awesome love. God is finally near. In the isolation of our prison, all faith was each day hidden in sacrifice and lost prayers for relief. Wanting desperately to connect, we were abandoned in our experience. Being found, our faith is renewed. Love fosters the hope-filled possibility witnessed by faith tried in the cold prison of isolation. When we reach that new typer, the world transfigures for all.

The walk to sainthood is so lonely for most of us. When we express each day's insights, powerful hope can heal and witness to awesome Love. Love writes a transfigured story for our family and community, as each of us shares relationship with a Love beyond all knowing.

When we care enough as a people for others, we witness a different world. Allowing Wisdom to share Herself through the Silent voice of each imprisoned soul who musters a whisper through challenged, appreciating words of sparing desperation begins a new journey to safety.

I want to walk with each typer to freedom, quietly waiting with anticipation for each lost soul's voice to be heard. A resurrection such as walking Lazarus' is powerfully what we witness. Perhaps hidden in this resurrection is the conditioning that each walker expects not to count. Really, overcoming that is a tremendous responsibility for assuring everyone's success. Reaching them is our special responsibility. Understanding what wakes another to real significance is time-consuming and far from the experience of the powerful. How to reach in is something we are intuitively led to after our own experience. Until we powerfully work with others like us, they will remain imprisoned without hope. We need to reach out to them.

Let's thank Kelly for the special work that she does, and reach out each day to let people know they matter. Each of us will powerfully fulfill our purpose that way. Days and weeks will write themselves. We need only to be present in the moment of our commitment. I want always to walk with each of you on sunlit and cloudy days as we do God's work. A better view patiently waits for our enjoyment.

Thank you.

Notes

1. The \$5.2 billion figure is calculated as the average cost to educate each autistic child times the number of nonverbal in the country. The following steps and sources were used in this calculation:
 - a. The government spends an average of \$19,300 per nonverbal autistic student per year per child determined as follows:
 - i. \$10,700 for a normal student according to the U.S. Census Bureau during fiscal year 2013. “Census Bureau Releases New Public Education Finance Data.” *Public Education Finances: Amount Each State Spent per Pupil in 2013*. June 2, 2015. Web. October 10, 2016.
http://www.census.gov/content/dam/Census/newsroom/releases/2015/cb15-98_graphic.jpg
 - ii. Special education adds \$8,600 per year, on average.
<https://consumer.healthday.com/cognitive-health-information-26/autism-news-51/autism-costs-average-17-000-yearly-for-each-child-study-finds-684667.html>
 - b. The U.S. Census Bureau figures identify 73.7 million under age 18; The U.S. Center for Disease Control (CDC) estimates 1 in 68 have autism = 1,083,824; of these, an estimated 1 in 4, or 270,956 children under the age of 18, excluding everyone over age 18, are nonverbal, meaning “they cannot functionally communicate with others using their voice. See Autism Speaks reference. The source data follows:
 - i. Census 73.7 million under age 18;
<http://www.childstats.gov/americaschildren/tables/pop1.asp?popup=true>
SOURCE: U.S. Census Bureau, *Current Population Reports*,
 - ii. CDC 1 in 68 have autism = 1,083,824;
<http://www.cdc.gov/ncbddd/autism/data.html>
 - iii. Autism Speaks Researchers Focus on Non-Verbal Autism at High Risk High Impact Meeting. October 9, 2009. <https://www.autismspeaks.org/science/science-news/researchers-focus-non-verbal-autism-high-risk-high-impact-meeting>
 - c. \$19,300 per student x 270,956 = \$5,229,450,800

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