

Hesed: How Youth Ministry with Teens with Disabilities Helps Restore an Abundant Community

Abstract

The notion of *hesed* grounds this paper, looking at what it means to move from marginalization to inclusion and integration of adolescents with disabilities. This paper draws from evidence in the secular world that supports the benefits of including those with disabilities as well as a theological explanation of the term *hesed*. The combination of these elements creates space for the church to live into four aspects of being church that are only strengthened by the genuine inclusion of those with disabilities.

Key Words: Disability, Adolescent, Hesed, Theology, Church

1. Disability and Inclusion

There's a phrase used in the state of Maine, USA: "You can't get there from here." The idea is that some place might seem tantalizingly close, but a direct route just won't get you there. You have to go the long way around. While churches may long for more inclusiveness, the simple answer is that we can't get there from here, from our traditional theological presuppositions. We have to back up and go the long way around. We have to reconceptualize our understandings and rearticulate our theology starting from the margins.

While the title and frame of this paper focuses on those with disabilities, it is really a paper about ecclesiology and the community. It is a paper about a magnificent notion put forth by God that we too often miss. It is about an invitation to be counterintuitive in the name of restoring an abundant community as God intended. It is about finding our voice so that we may not only say no to stigmas and discrimination against the differently-abled, but also advocate that such discrimination is harmful to us all.

Disability is nothing new and it is not going away. Currently, according to the WHO, approximately 15% of the world's population has a disability.¹ Thus, there are over one billion people with disabilities worldwide.² Regarding youth, estimates suggest there are at least 93 million children and youth with disabilities worldwide, but there is reason to believe the numbers are actually much higher.³ Rates of childhood and adolescent disability have increased,⁴ the reasons for which are widely varied, ranging from ongoing conflict around the world⁵ to the rise in diagnoses of intellectual disabilities such as autism.⁶ Whatever the reason, the number of children, adolescents, and families impacted by disability is on the rise.⁷

1 World Health Organization and the World Bank Group (2011), "Disability – a global picture, in World Report on Disability 2011." p.29.

2 It is important to note that due to major differences in definitions, concepts, standards, and methodology, the actual number of those with disabilities varies a great deal from study to study. Unesco has taken on the task of acquiring more comparable data across the world and is currently in process on the standardization of definitions and methodology in order to conduct such research. Report from United Nations Expert Group Meeting on Disability Data and Statistics, Monitoring and Evaluation: The Way Forward- a Disability Inclusive Agenda Towards 2015 and Beyond Paris, France (8-10 July 2014)

3 <https://www.unicef.org/disabilities/>, accessed 17 November 2016.

4 <https://www.aap.org/en-us/about-the-aap/aap-press-room/pages/Childhood-Disability-Rate-Jumps.aspx>, accessed 17 November 2016.

5 <http://www.un.org/disabilities/convention/facts>, accessed 17 November 2016.

6 <http://www.cdc.gov/ncbddd/autism/data.html>, accessed 17 November 2016.

7 Pediatrics, Sept. 2014, Volume 134/Issue 3. <http://pediatrics.aappublications.org/content/134/3/530>, accessed 8 August 2016.

Disability is used to cover a wide variety of medical, developmental, and cognitive impairments. As such, we cannot always just look at a child or teenager and know whether a disability is present, nor is there one single statistic that gives a total number of adolescents with a disability.⁸ Kidscount.org looked at data analysis from a variety of governmental and national social services agencies and determined that in the U.S. in 2012, there were 11,177,000 children ages 2-17 who had been diagnosed by a doctor as having “autism, developmental delays, depression or anxiety, ADD/ADHD, or behavioral/conduct problems.”⁹ These statistics show there are millions of children and teenagers in our cities with a named, diagnosed disability.

1.1 *Six WHO functional domains*

In 2001, the World Health Organization interviewed 117,192 individuals, in 66 population-based surveys in 57 countries. They identified 400-plus types of disability, which they synthesized into six major categories for describing disability across the world. “These include affect, cognition, mobility, pain, self-care and usual activities.”¹⁰

Here is a brief explanation of each of the six categories:

- **Affect:** Overall in the last 30 days, how much distress, sadness or worry did you experience? (4) time spent feeling happy and cheerful/ sad, empty/depressed/ irritable or in a bad mood/ worried a lot
- **Cognition:** Overall in the last 30 days, how much difficulty did you have with concentrating or remembering things? (4) difficulty in concentrating on doing something for 10 minutes/remembering to do important things/ analyzing and solving problems in day to day life/ learning a new task
- **Mobility:** Overall in the last 30 days, how much difficulty did you have with moving around? (4) difficulty to stand up from sitting down/ moving around inside one's home/ climbing several flights of stairs or walking up a steep hill/ performance of vigorous activities such as running, lifting heavy objects, participating in strenuous sports
- **Pain:** Overall in the last 30 days, how much pain or discomfort did you have? (1) amount of bodily pain or discomfort
- **Self-Care:** Overall in the last 30 days, how much difficulty did you have with self-care, such as washing or dressing yourself? (3) difficulty in washing your whole body/ getting dressed/ staying by yourself for a few days
- **Usual Activities:** Overall in the last 30 days, how much difficulty did you have with work or household activities? (3) difficulty in taking care of household responsibilities/ getting all the housework done that you needed to do/ being limited in the type of household work.¹¹

Not all disabilities are the same. While seemingly obvious, the practical implications are broad. Those with disabilities are people first and, like all individuals, come with their own set of gifts, graces, difficulties and challenges. The condition or different ability is known as the impairment. Each of us has impairment(s) of some sort. For those who fall under the designation of disability, that impairment is large enough to require accommodation or extra attention. Swinton writes, “Disability is not defined by any particular impairment or difference. What forms the core of ‘disability’ is the recognition of a shared experience of oppression,

8 Pediatrics, Sept. 2014, Volume 134/ Issue 3. <http://pediatrics.aappublications.org/content/134/3/530>, accessed 8 August 2016.

9 <http://datacenter.kidscount.org/data/bar/6031-children-who-have-one-or-more-emotional-behavioral-or-developmental-conditions?loc=1&loct=1#1/any/false/1021/any/12694>, accessed 8 August 2016.

10 Ritu Sadana, et al. “Describing population health in six domains: comparable results from 66 household surveys.” Global Programme for Health Policy Discussion Paper No. 43, World Health Organization, March 2002, p. 9.

11 Sadana, “Describing population,” p. 9.

marginalization, and injustice.”¹² Impairment is not the core of disability; the common thread for those with impairment(s) is society’s response of oppression and marginalization.

A few common approaches to disability have been utilized over the past few decades. The first is the medical model. In this model, there is a diagnosable impairment that is approached from the realm of health care, either in a curative or maintenance approach. The disability is seen as something undesirable and all efforts to eradicate that which differs from the norm are desirable. The second model is the social model of disability. In the social model, the focus is on the inadequate manner in which society responds to an impairment and amounts to a form of social discrimination. Finally, the moral model has roots in faith and dominated the conversation for several centuries. This is the model that asks who did wrong? The individual or parents? In some settings, well-meaning Christians have declared the impairment was solely for God’s glory. In our modern world, the church has functioned from a combination of these three offering community, hope, and sadly at times, more discrimination. “What disability amounts to, that is, depends not just on the disabled individual, but on the groups of which that individual is a member.”¹³ The dis-abling portion of an impairment is often the result of a world that is designed for those without impairments and those who primarily function in that space. Every response to disability combines these three models to varying degrees. We turn our attention now to the church’s response that emphasizes the moral model but also includes elements of both the medical and social models.

2. Ministerial perspectives: from the early church to today

The church has an uneasy history when it comes to those with disabilities. Long before there were established Christian doctrines, communities of faith were living out their theology of disability. Throughout scripture we see many examples of those with disabilities including speech issues (Exodus 4:10), a clubfoot (2 Samuel 9), leprosy (Numbers 5:2), blindness (John 9:2-3), and the poor, crippled, blind, and lame (Luke 14:13-23).

Plato, Aristotle, and Soranus each neglected to oppose the common practice of exposure for newborns, in particular those with deformities, due to their inability to contribute significantly to society.¹⁴ The stoics embraced disability in the sense that the soul was far more valued than the body and those with disabilities offered a clear representation of what could be so detestable about the human body.¹⁵

During the period of the early church, many participated in the practice of exposing those with disabilities to the elements, leaving them to die. Those with disabilities were not thought to be contributors to the communal good and, therefore, this action was warranted. The church resisted this approach, seeking a different response by valuing every human life. Augustine and Aquinas were among the early thinkers who struggled to articulate the balance of human value while trying to define what was “normal.” Disability was a lamentable state but an accepted reality. They each held a view that those born from humans bore the image of God and therefore were allowed the grace God offered to all humans.¹⁶ The Cappadocian fathers transition the interaction of the church to those with disabilities into a relationship of philanthropy.¹⁷

12 John Swinton, “Disability, Ableism, and Disablism,” in B. Miller-McLemore (ed.), *The Wiley-Blackwell Companion to Practical Theology* (New York: Oxford University Press, 2011), 445.

13 Alasdair MacIntyre, *Dependent Rational Animals: Why Human Beings Need the Virtues*, (Chicago: Open Court, 1998), 75.

14 *Ibid.*, 26-27.

15 *Ibid.*, 37.

16 Brian Brock and John Swinton, *Disability in the Christian Tradition*, (Grand Rapids: Eerdmans, 2012), p. 14.

17 *Ibid.*, 31-36.

In the 14th century, Julian of Norwich is the first to write extensively on disability. Julian writings relied heavily on her reflections on her own impairment. She viewed disability as a way to find identification with Christ and His suffering on the cross.¹⁸ Two centuries later, Luther infamously suggests the drowning of a boy who is known to only eat and excrete.¹⁹ In all fairness, Luther believed, in concert with his medieval culture, that the boy was not human, but rather a changeling or son of a devil. Our modern category of disability was not a part of Luther's world.²⁰

Fast forward to the twentieth century, we can document a drastic change in perceptions of disability. Bonhoeffer's 1933 visit to Bethel, a village in Germany that existed to care for the fragile and disabled, solidified what he had not yet clearly articulated. Partly as a result of this visit, Bonhoeffer went on to write a great deal toward the inclusion and dignity of those with disabilities. He states, "The exclusion of the weak and insignificant, the seemingly useless people from everyday Christian life in community may actually mean the exclusion of Christ."²¹ In the early 1960's Vanier lived with a couple of men with mental impairments, which fostered conversation regarding the dignity of those with disabilities. Vanier had not intended to found a community, yet this experience led to the establishment of the L'Arche community and introduced to the Christian world the notion of reciprocal relationships with those with disabilities.

In the last forty years or so, ministries with and for those with disabilities have been founded with increasing regularity. In 1979 Joni Eareckson began a ministry for those with disabilities by simply trying to work through questions with her friends after an accident left her as a quadriplegic. In 1980 Nick Palermo stumbled into the idea of inclusion when seeking to build a Young Life Club. In short order, Young Life's Capernaum ministry was founded and began the first wide-scale ministry focused on teenagers with disabilities. In 2002 Key Ministry was founded by Dr. Steve Grcevich offering resources and trainings to churches for the intentional inclusion of children and youth with disabilities (keyministry.org). In 2011 the Collaborative on Faith and Disability began with a conversation of invested partners and has grown into a clearinghouse of information and annual gathering called the Summer Institute on Theology and Disability (faithanddisability.org).

In the last couple of years, several universities and seminaries are beginning the conversations in earnest including California Baptist University, Western Seminary, Dallas Theological Seminary, and Vanderbilt University around ministry and disability. While there are now camps, and countless churches, networks, and conversations taking place, there is no accurate count of those churches and organizations now engaged in ministry with those with disabilities. What is clear is that there is new interest that is spreading. The interest has primarily been for ministry with children and adults; youth ministry has lagged behind in the conversation with a few notable exceptions. Interest is gaining traction and more voices are needed. Resources are few, but they are growing. We have moved a long way from not even considering those with disabilities worth keeping alive, through the era of philanthropy, to the growing conversation of what it means to do life and ministry alongside all people with equally valued contributions to make.

3. Hesed

The shift toward inclusion is in accordance with the biblical principle of hospitality connected with hesed. Inclusion is hospitality as outsiders are invited in. This kind of hospitality is rooted in the concept of hesed believing there is more than enough to go around. Hesed is one of those

18 Julian of Norwich, *Revelations of Divine Love* (Westminster, UK: Penguin, 1999).

19 Martin Luther, *Table Talk* (Geanies House Fearn, UK: Christian Focus Publications, 2003).

20 Brock & Swinton, *Disability*, 187.

21 Ibid., 366.

hard to define words moving from one language to another but it carries with it the sense of abundance that comes only from God. The Bible speaks over and over again of hesed but defies any singular word translation.²² “Hesed includes God’s love and kindness, God’s constancy and devoted attention to the covenant community and the creation...[It] is not only what may be expected, but typically exceeds expectation; it is the overabundance, the extra of God’s grace.”²³ Further, hesed is in line with many Hebrew concepts, connoting activity as well as action. God being rich in devoted love shows God reaching out to others in love, even those deemed by the majority as undesirable. “God does not only reach out to those who expect love and grace from God. God goes overboard and includes” everyone.²⁴ Hesed is a guiding force for attitude and action showing up throughout scripture in interactions with God and as God calls his people to follow in His ways.

Hospitality includes others not as perpetual guests or special exceptions but makes room for them as family who will change the dynamics of a household itself. This is no easy task and requires the presence and guidance of God. Amos Yong elucidates this saying the Holy Spirit is able to make, largely unobtrusively, mutual changes in friendship, so, too, the Holy Spirit is able to make changes through hospitality for all involved.²⁵ When a family has a baby or adopts, adjustments are made to accommodate the new family member, and a new normal is established. Parents find that their capacity to love and to act out their love expands even as their physical space is changed or diminished. When it comes to church, however, we are fantastic at inviting people in without ever making accommodations or getting to know others beyond a greeting as we pass by. We are happy to have those with disabilities as guests and for someone with a special calling to attend to them, but they too often never experience the depth of community established in hesed. This is not only a loss for the person with a disability but for the church as well.

“In a phrase, God blesses through the stranger. How so? In hospitality the center of gravity lies neither in the home nor in the stranger, neither in host nor guest, but in the God of both who is discovered redemptively in the meeting...As boundaries become fluid, the vulnerable stranger, the one who ostensibly has nothing to offer, becomes a source of enrichment to the reconfigured household. This marks the upbuilding and bonding work of the Spirit, through whom the center of the household—animated by God’s economy of grace—is not the inside of a closed circle, protected by fortified walls, but rather on the margins of an open circle. Perhaps, then, in hospitality the Christian community ideally becomes what it is by extending outside of its own identity, by building border crossings that serve as point for reconciliation and partnership instead of separation. This kind of paradox is displayed poignantly in stories of hospitality that depict hosts ‘entertaining angels unawares’.”²⁶

Hospitality establishes both guest and host as equals. Welcoming someone in is simply not enough. Many marginalized people have been invited to the table, only to learn that welcome does not imply inclusion. The host maintains power over the guest. People with disabilities are often welcomed to sit and watch, to be present and silent, to pose for pictures, and to respond with gratitude for whatever is offered to them. This welcome without inclusion keeps those

22 Hesed may be found in a number of passages but a few are as follows: Exodus 34:6-7, Numbers 14:18, Nehemiah 9:31, Psalm 86:15, Psalm 145:8, Jonah 4:2.

23 Lewis Merrick, *And Show Steadfast Love: a theological look at grace, hospitality, disabilities, and the church*, (Louisville, KY: Presbyterian Publishing House, 1993), 11.

24 Merrick, *And Show Steadfast Love*, 11.

25 Amos Yong, *Theology and Down Syndrome* (Waco, TX: Baylor University Press, 2007), 187.

26 Thomas Reynolds, *Vulnerable Communion: A Theology of Disability and Hospitality* (Grand Rapids: Brazos, 2008), 243.

with disabilities in positions of inequality and subordination. Genuine hospitality rearranges the power dynamic, moving host and guest to equal places with God at the center.

To be a host presumes you have something to offer. Giving love, entertaining others is not commanded in order to receive anything in return.²⁷ Hospitality gives out of the overflow of abundance from which we have already received. But from where does this abundance come? Extending hospitality is a declaration of the abundance Christ has bestowed, as seen in 1 John 4:19, “we love because He first loved us.” What we have to offer in hospitality is to be a direct result of the manifestation of God in our own lives including long suffering, abundance, overflow, and plenty. This abundance is part of the very nature of God and shows up in love, kindness, righteousness, constancy, devotion, goodness, and more.²⁸ Hesed proclaims that we have all we need and more to live into the theological concept of hospitality. Hesed rejects the notion that we do not have enough and squelches our fear of scarcity.

However the church has felt about inclusion, too often it has relied upon this “scarcity rationale,” thereby avoiding the inclusion and integration of those with disabilities. Three myths have been used to justify exclusion of those with disabilities. First, there are no people with disabilities in our area. This myth is dispelled by data from the U.S. Census, which shows persons with disability throughout the United States.²⁹ Second, churches say they are afraid they will hurt someone with a disability. This weak justification undercuts itself by our inclusion of infants, toddlers, and the elderly. We ask questions on how to best come alongside these groups, we watch, listen, go to trainings, and are willing to come alongside others who know better. We can do the same with people with disabilities. The third justification speaks most plainly to the fear of scarcity. Churches often claim a lack of resources to minister to those with disabilities whether that is finances, inadequate space, or inadequately trained staff. There is also a concern that if changes are made to accommodate someone with a disability, others may leave. Indeed, some will leave. But others will come. And those who stay are living into the calling of God and the theological principle of hesed. Hospitality is not a zero sum game with only so much hospitality to go around. Exclusion protects what we believe to be ours, inclusion stewards that which belongs to God. Hesed says that there is more than enough to go around and including someone who may need extra time, attention, or money does not mean there will not be enough for others. There is no fear in God’s abundance. God promises (1 Kings 17:12-16) and models (Matthew 14:13-21) generosity as a way of having enough. To be hospitable then, is to follow the way of Jesus.

The converse brings a rather sobering reality. Not to extend hospitality evidences the sin and woundedness in our world. As mentioned above, those with disabilities are not always considered as equals. To not consider someone as an equal creates space to rationalize withholding hospitality. Assuming no harm is done to one worthy of not being harmed. We separate into us and them. Richard Beck describes sin as the force that brings about dehumanization and stratification.³⁰ While our words and even official legislation declare those with disabilities as important, far too many are not experiencing that reality. Dialogue and even legislation have brought the conversation into the public realm. There is an awareness of disability that far exceeds any other time in history. The power of sin prevents this heightened awareness from preventing justifications of exclusion and worse. Without realizing it, we become socialized into patterns of injustice and live contrary to the hesed of God. We live

27 Amy Jacober and Mindi Godfrey, “Hospitality and a God-given identity.” Presented at International Association for the Study of Youth Ministry 6, no. 1 (Fall 2007), 167-181.

28 Johanna W. H. Bos, “The Way of Hesed,” in Lewis Merrick (ed), *And Show Steadfast Love: a theological look at grace, hospitality, disabilities, and the church* (Louisville, KY: Presbyterian Publishing House, 1993), 10-11.

29 www.census.gov/people/disability, accessed August 24, 2016.

30 Richard Beck, *Unclean: Meditations on Purity, Hospitality, and Mortality* (Eugene, OR: Wipf and Stock, 2011), 122.

contrary to hesed when we focus on how something might look if we included those who are flawed forgetting that we are all flawed. We grow accustomed to safety and no longer want to speak out for fear that church leaders, or donors, or parents, or our own family will grow weary of our voice. With each denial of hospitality, the sin of dehumanization is calcified. In God's infinite wisdom, it is profound to note that there is no limit to how much we can deny Christ and God's provision that hesed cannot cover. God, however, has steadfast love and can patiently redeem us from this vicious cycle if we are willing.

4. Inclusion, better for everyone

It is unlikely that the secular world is acting out of an intentionally constructed philosophy of hesed when it comes to those with disabilities. Yet, they have been working towards genuine hospitality in remarkable ways. This manifests itself when accommodations are not seen as a barrier but a reality toward the inclusion of those for whom there is more than enough room. Employment and education are two of the areas where great strides are being made and what once seemed impossible is turning out to be more than possible and actually beneficial for all. There is, of course, still more work to be done, but the barriers are moving.

When it comes to the workforce, it is now well documented that hiring those with disabilities is a low cost, high reward practice. According to the Job Accommodation Network (JAN), a service of the US Department of Labor retention, morale, a decrease in cost for worker's compensation and training, increased productivity, and increased diversity are among the benefits of hiring those with disabilities.³¹ These benefits come with no or low-cost accommodations, typically no more than \$500, with the savings to the employer far out weighing any cost. The US Chamber of Commerce also testifies to the best practice standards of the inclusion of those with disabilities in a variety of industries from insurance, to aerodynamics, to movie theatres, and telecommunications.³² Business may be about the bottom line, but there is also an expressed sense of global responsibility to find accommodations for impairments and to move toward inclusion. In 2007 DePaul University, along with the Illinois Department of Commerce and Economic Opportunity conducted research on employment for those with disabilities. The conclusion landed in favor of the inclusion of those with disabilities, particularly in the areas of retail and hospitality, citing benefits that included greater rates of retention, lower absenteeism, high loyalty, and reliability.³³ In Australia, Deakin University offered a study finding that "workers with disability are no more likely to be injured at work than other employees and there are no differences in performance and productivity. It was also identified that employees with disability actually have fewer scheduled absences than employees without disability as well as increased tenure. On average, employing people with a disability does not cost any more than employing people without disability. Assistance with the cost of making workplace adjustments is available through the Australian Government."³⁴ Across the business world there is awareness of the benefits of inclusion and the realities of accommodations. Biases and struggles still exist but there is a concerted and coordinated effort in multiple countries to raise awareness and opportunity for those with disabilities.

To be fair, while many businesses are making strides, the reality of employment is still bleak for those with disabilities, in particular intellectual disabilities. National employment rates in the US for those with ID remain between 15-20% despite the desire of those with disabilities to

31 Beth Loy, *Workplace Accommodations: Low Cost, High Impact: Annually updated research findings address the costs and benefits of job accommodations*, (US Department of Labor, 2016), 3-5.

32 https://www.uschamber.com/sites/default/files/documents/files/020709_DisabilityInclusion_final.pdf, accessed 28 November 2016.

33 Brigida Hernandez and Katherine McDonald, "Exploring the Bottom Line: A Study of the Costs and benefits of Workers with Disabilities," DePaul University, 2007.

34 <http://www.and.org.au/pages/business-benefits-of-hiring-people-with-a-disability.html>, accessed on 26 November 2016.

work.³⁵ Forty-three percent of those jobs are in segregated settings, settings designed to employ those with disabilities as opposed to work in the general employment sector.³⁶

In 1975 the United States federal government put the Individuals with Disabilities Education Act (IDEA) into law, It ensuring that all children with a disability would receive accommodations that allowing access to free public education tailored to meet their needs in the least restrictive environment. Forty years later, we are still trying to figure out best practices and the long-term impact this inclusion has on the lives of individuals, their families, and our communities at large.

Education, for anyone, is more than mastery of academic subjects. Education includes academia but reaches far beyond with social skills, extracurricular opportunities, and friendship. Inclusion of those with disabilities in public schools has surely been a benefit to those with disabilities. But what of other benefits? Erik Carter, a leading special education professor and advocate has studied this extensively. He writes of integrated typical students that “among the benefits these students report are a deeper appreciation of diversity and individual differences, greater understanding of the value of inclusion, increased knowledge about specific disabilities, improved attitudes toward people with disabilities, acquisition of advocacy and support skills, greater self-confidence, a strengthened commitment to social justice principles, and personal growth.”³⁷ The classroom also was a place for authentic, reciprocal friendships to form. Carter and Brock write of the intentionality of teachers to partner those with disabilities with a buddy or a group of typical students for work. What begins as a status relationship, over time, can transition to reciprocal friendship. In particular this takes places with intentional access to extra-curricular activities, and creating space for social interaction apart from a one on one paraprofessional.³⁸ “Interviews with parents revealed that only 22% of youth with intellectual disability, 14% of youth with multiple disabilities, and 6% of youth with autism were reported to *frequently* see any friends outside of school. Forty-two percent of youth with intellectual disability, 63% of youth with multiple disabilities, and 84% of youth with autism *never or rarely* receive telephone calls from friends. And only 54% of youth with intellectual disability, 38% of youth with multiple disabilities, and 24% of youth with autism get together with friends outside of formal groups at least once each week.”³⁹ It is clear that proximity does not necessarily create relationship. The church has a distinct opportunity not only to advocate for those with disabilities in the greater world but also to be a place providing what secular society may not.

5. What’s at stake? A lesser ecclesiology

Paradoxical relationships have long been a hallmark of the church. Paul describes this in I Corinthians 12:22-23 (NASB). “On the contrary, the members of the body that seem to be weaker are indispensable, and those members that we think less honorable, we clothe with greater honor, and our less respectable members are treated with greater respect.” Jeff McNair agrees and advocates saying that the seemingly weak

“...are powerful in that they are needed by all for something that is critical to the whole body... Thus, in some manner, those thought to be weaker ones have power over those thought to be stronger ones because the seemingly stronger ones cannot do without

35 E. W. Carter, “Ending segregation...in education and beyond.” Invited presentation to the President’s Committee on People with Intellectual Disabilities. Washington, DC. (November 2015).

36 Ibid.

37 E. W. Carter and Brock, M. E., “Promoting social competence and peer relationships.” In F. Brown, J. McDonnell, & M. E. Snell (eds.), *Instruction of students with severe disabilities* (8th ed.; Upper Saddle River, NJ: Merrill, 2016), 374.

38 Ibid., 374-380.

39 Ibid., 380.

them. I may not know why I cannot do without someone, but that does not diminish the truth of the statement and it may be the impetus to cause me to find out."⁴⁰

A common confession in Christianity is that power is perfected in weakness. Including those with disabilities is a clear manifestation of this confession. Teens with disabilities require a different pace and shift the dynamics of any youth group. They cause leaders to intentionally think through lessons, snacks, and activities in ways never before considered. Teens with disabilities also force leaders to be more intentional about what and how ministry takes place. They also allow the typical teens to develop deep friendships, compassion, respect for others, and opportunity to consider the needs of a group above their own. Indeed, many of the very things we desire for teenagers we serve and love are brought to the forefront when we are including those with disabilities.

The church was always God's idea. Jesus uses the word church in two passages, Matthew 16:18 and 18:15-17. What we have come to accept as the concept of church, however, has abundant references and images beyond those associated with Jesus. Most typically we see the church markers being noted from the Nicene Creed: one, holy, catholic, and apostolic. While Ian Markham acknowledges the classic marks, he offers four aspects drawn from modern scholarship that are useful and accessible. They are as follow; Church is the people of God, it is the Body of Christ, it is intended to safeguard tradition, and it exists to create virtue.⁴¹ In these four, those with disabilities are not only included but necessary and valued in order for each to exist in all its fullness.

5.1 *The People of God*

To be the people of God simultaneously seems extraordinary and pedestrian. For many of us in the church, we have heard this since we were small. When we slow down and reflect, we may understand how amazing and humbling it is to have the creator of the universe call us family. Slowing down and reflecting however is not a common act today. For many if not most of us, we take this place in God's family for granted. Unless of course we are one of the many groups being told in subtle and not so subtle ways that we do not belong. Having touched on the history of those with disabilities in the church earlier in this paper, it is clear the church has not always been a welcome place. Even today, with no ill intent, those with disabilities experience a palpable unwelcome from far too many churches and Christian communities.

Whether we as the church have lived into it or not, those with disabilities have always been included by God. Over the centuries, the church's self-understanding of power and strength has been distorted, excluding members who rightfully belong. The church has struggles to live as one who is loved at times choosing instead to focus on the appearance of perfection by excluding the differently abled. As much as this grieves God's heart, God still loves the church and calls her back to her true nature, whom she was created to be: strong, weak, perfect, flawed, and beautiful.

5.2 *The Body of Christ*

First Corinthians 12:18-27 calls the church to her intended existence, wherein each person has a place and a role. No one is more or less important than the other. While we confess this notion, we rarely wrestle deeply with the implications. What it means is that changes would have to occur. Not only changes for now but continued changes as new people with new gifts, graces, and needs enter our communities. For the church to really live as if every single believer was as

40 Jeff McNair, "The Power of Those Who Seem Weaker," *The Journal of the Christian Institute on Disability* Vol. 3, No. 1, Spring/Summer 2014, p. 97.

41 Markham, *Understanding Christian Doctrine*, 159-160.

vital as the next to the health of the church, we would have to change our practice and systems, our norms and patterns. McNair names this clearly.

“People who are ‘typical’ may fear the notion of seeing people who are atypical (due to impairments, social skill deficits, etc.) as their equals because of the demands equality might place on them. If you are not my equal, I may feel I needn’t change. However, if you are my equal, and you experience devaluation from me, that implies that I am very wrong in my interactions with you. Disability ministry, like loving my neighbor, will cost me something.”⁴²

As we begin to value those with disabilities as equals, we move beyond charity and into actual relationship. This challenge forces us to overcome years of separation, isolation, and posturing for our own belonging and legitimacy in the world. This was never necessary. Instead God called us to be his body, his hands and feet, the community of believers gathered to spur one another on to love and good deeds in the world around us. Andrew Zirschky offers insight from the world of teenagers that may be applied to all of humanity, including those with disabilities. “When teenagers who are convinced that their belonging is based upon performance encounter a community of social equality, they often are able to release their anxiety because they experience that their performance isn’t the source of their belonging.”⁴³ We belong because this is God’s design.

Our perspective changes when we see the role of those with disabilities as vital rather than as a burden. For many, an encounter through a family member, age, or accident, causes a perspective change on the topic of disability. All too often a church misses an opportunity when ability changes for one of her members. In most instances, the intent is pure but help wanes over time and the now disabled person and their family fall away from regular contact. The church shows its struggle with disability through its progressive inattentiveness towards its members with disability.⁴⁴ Normalization and blending in become the goal rather than owning the diversity. George White cites Nancy Eiesland, a theologian with a disability herself, writing “Healing has been the churchly parallel to rehabilitative medicine, in which the goal was “normalization of the bodies of people with disabilities.”⁴⁵ Eiesland goes on to say “The church is impoverished without our presence. Our narratives and bodies make clear that ordinary lives incorporate contingency and difficulty. We reveal the physical truth of embodiment as a painstaking process of claiming and inhabiting our actually existing bodies.”⁴⁶ Valuing all people as equals demands that the church contends with the struggles and pains of including those with differing bodies and minds and all the practical implications for life together.

Becoming the body of Christ demands inclusion of everyone as equally valued. We must move beyond welcoming and allowing someone to sit in your space as a permanent visitor never creating space for them to be fully included in ways that are meaningful. For some in our society they experience a cutting off from access to the good things of life many take for granted. These good things include family, friends, a social life, work, good health, belonging, the ability to contribute, and importantly faith formation.⁴⁷ The church, above all places, should

42 McNair, “The Power,” 96.

43 Andrew Zirshcky, *Beyond the Screen: Ministry for the Connected But Alone Generation* (Nashville, TN: Abingdon, 2015), 112.

44 George White writes on a wide variety of ways the church devalues those with disabilities drawing from his own experience as well as the writings of several respected contemporary authors in the field of disability and theology. See George White, “People with Disabilities in Christian Community,” *The Journal of the Christian Institute on Disability* 3, no. 1 (Spring/Summer 2014) 12-35.

45 *Ibid.*, 12.

46 *Ibid.*, 16.

47 Jeff McNair, “What Would Be Better?,” *Journal of Christian Institute on Disability* vol 1, no. 1 (Fall/Winter 2012), 13.

be different as we live out of the understanding of hesed so central to God's character and provision.

5.3 *Safeguarding of Tradition*

Traditions including the beliefs, attitudes, and values of the church are caught the rhythm and rituals of the church. It becomes a part of us even as we choose to practice it. Our very identity as God's people is shaped by the practices we perform like water and its surrounding land. Each has an impact on the other and it is over time that the greatest transformation takes place. Last summer I was a camp chaplain over several weeks. One camper was known by most of the adults serving. She came with her own set of typical teenage struggles overlaid with autism. The week she was with us was just days after she and her entire family had been pulled from a fire that took their entire house and all possessions. For one who needs rhythm and ritual to maintain stability, this was completely disorienting. Camp provided a sort of surrogate as her mother sought to create a plan for moving forward back home. She had many difficult moments but when it came to evening worship, she settled. In fact, in that space it was difficult to tell she had any non-typical behaviors at all. I sat in on a cabin time and asked how she knew what to do so well. She looked at me in utter bewilderment. "I just know it" she said. "I do it because I know it and I know it because I do it." She then went on to explain what each element of service meant, clearly teaching several girls in her cabin. The very rhythms and rituals of faith had not been taught in rote memory or as an intellectual exercise, rather, they were a part of her over years of practice shaping her.

People with disabilities often have a need for routine. Whether we recognize this or not, the routine can prove to be a blessing. In a world with a constant barrage of input, we struggle to escape multitasking and constant change. It is easy to lose focus and get caught up in the details of life, the next meeting, the latest book or blog to read, never ending streams of news and information. People with intellectual disabilities in particular cannot live at this frenetic and fragmented pace. We read and teach that the Sabbath was created for humans but we deny its very existence by never actually sabbathing. Those with disabilities are brilliant at speaking, with words or actions that a frantic pace is not sustainable nor does it draw us any closer to God. They demand that we get honest about the very things we profess to hold so dear. It is with the rhythms and rituals of faith in daily life that those with disabilities are most clearly able to connect with God and God's people. Yet, these very practices, encouraged by those with disabilities, are the very practices they are denied when we do not intentionally include them in church. Assuming safeguarding the beliefs, attitudes, and values of the church to be a key task in passing down tradition, the very presence of those with disabilities is a clear manifestation of the gifts and graces from God to do so.

Paul states in First Corinthians 15:3 that he is passing on to others what was given to him in the teachings and actions of Jesus. Rhythms and rituals shape us as well-worn grooves over time. This passing down of traditions and rituals shapes who we are as a people. The phrase *lex orandi, lex credendi*, (roughly translated as we pray, so we believe) has been significant within the Christian church over the years. It is in the rhythm and rituals of prayer and worship that the paths of faith have created paths for everyday life. We pass on these rhythms and rituals so others too may know the path of faith. Perhaps now more than ever, with the increase in input and pace of life, people with disabilities are vital in our churches. They are vital precisely because they invite us to live what we say we believe in passing down faith from generation to generation not as a class or workshop to be accomplished, but as a community to be lived.

5.4 *A Community that creates virtue*

Our world is fragmented, in disarray and contains only partial understandings of morality. This is the argument of Alasdair MacIntyre in the opening of his well-known work *After Virtue*.⁴⁸ The remainder of the book seeks to understand how this happened and importantly, what it might look like if we lived differently, virtuously. The church is tasked with creating virtue and inviting people into this very different way of living. Virtue may be categorized in two ways; 1) as we serve each other 2) as we serve the greater good. In both we are seeking to live out Micah 6:8, individually and corporately: “And what does the Lord require of you but to love mercy, act justly, and walk humbly with your God.” This is more than a call to lay low or do no harm. It is rather a call to actively serve and do God as if we were serving God in this world.

Acts 2:44-47 tells of those who shared all they had for the greater good. “There are no special qualifications for who gets to give and receive, all are expected to participate in reciprocal relationships. The church should be the premiere place where those with disabilities are free to be themselves and where others are willing to recognize our need for another and make accommodations.”⁴⁹ The overall response of the church after the passing of the American’s with Disabilities Act (ADA) in 1990 often has been a denial of Acts 2. It is true, many churches have found ways to be welcoming and made accommodations. Still, the majority pushed back for a variety of reasons. Even as public spaces were legislating inclusion, churches protested and requested exemptions in the name of budgets, aesthetics, ignorance, and a variety of other struggles. Just now there is a broader, concerted effort to move from welcome to inclusion by the church. There is great opportunity and hope matched only by the great task at hand.

6. A Caveat

While God has and does provide more than abundantly for all we need, there is still effort required on our part. It would be important to note that working with teens with disabilities is no easy task and ought not to be romanticized. Parents and caregivers have often been burned and are overwhelmed by the time their child is an adolescent. They have spent so long advocating for this one child they may lose sight of what is best for a group. Trust needs to be built over time. Patience is key. Understanding that schedules are not often in their control and a missed meeting, or several missed meetings, is not necessarily due to a lack of interest. Emergency room visits, meltdowns, allergic reactions, or a body too tired to continue in a given day may require sporadic attendance. Be relentlessly consistent in your communication, inviting, including, and understanding when life circumstances do not work out. This same relentless consistency is needed when the teenager with a disability is present. He or she may lack social skills, having had few opportunities for relationships not tied to a professional therapist or teacher. Redirect, discipline, and encourage just as you would any other adolescent. We do not offer any favors or dignity when we look the other way regarding bad behavior just because someone has a disability. We move from welcome to inclusion when we respect and value the full humanity of a teen with a disability. We as the church get to extend grace reminding them that they are indispensable.⁵⁰

7. Conclusion

Hesed often shows up in messy circumstances. Jonah cried out in frustration and anger when the Ninevites listened to his words and turned to God. He was angry and blamed God for his abundant kindness and love. The abundance of God is often like this. It is true and covers all needs but it may look far different from the ministries we envisioned. When taken seriously, hesed transforms our ministries to look much more like the unruly and unpredictable abundance of God. Those with disabilities are neither a project nor an object of pity. They are humans to be valued as equal members of our communities. An abundant community is just

48 MacIntyre, *After Virtue*.

49 Amy Jacober, *Redefining Perfect*, (Eugene, OR: Wipf and Stock, forthcoming).

50 Two particularly helpful organizations in thinking through concrete and theoretical issues of inclusion may be found at: <http://www.joniandfriends.org/> and <http://www.keyministry.org/>

waiting to be unveiled. All it takes is a lot of work, a fair amount of faith, and a little, genuine inclusion.

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