Identity, (Dis)Ability and Belonging: Liturgy and Worship Through the Lens of Autism

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Abstract: Disabled people often feel excluded from church activities. Focusing on autism, this article explores the problematic, relative absence of autistic people in churches. It will be argued that the concept of normalcy lies at the heart of the problem. Normalcy is understood as the set of dynamics that guard the boundaries of communities, in other words, who does and does not belong. These boundaries are part of what Charles Taylor calls the "framework" of the community, which determines what the community values. This article will argue that those with disabilities easily fall outside of the community's boundaries. After discussing the dynamics of normalcy, this article offers a theological critique and a proposal for a framework inspired by the Gospel. This enables a "theology of presence" which envisions members of the community being present to each other in a way that reflects the kenosis of Christ.

Keywords: disability, autism, belonging, normalcy, theology of presence.

Introduction

This article focuses specifically on the experiences of autistic people¹ in the context of church, although the argument is applicable to disabilities more generally.² A persistent theme in stories of disabled people, including those who identify as autistic,

¹ I use identity-first language (i.e., "autistic person") instead of person-first language (i.e., "person with autism"). With this, I follow the current preference of most people in the autistic community in the United Kingdom, the United States, and elsewhere. Person-first language tends to be used more by professionals. Lorcan Kenny et al., "Which Terms Should Be Used to Describe Autism? Perspectives from the UK Autism Community," *Autism* 20, no. 4 (May 2016): 442–62, https://doi.org/10.1177/1362361315588200; Kristen Bottema-Beutel et al., "Avoiding Ableist Language: Suggestions for Autism Researchers," *Autism in Adulthood* 3, no. 1 (1 March 2021): 18–29, https://doi.org/10.1089/aut.2020.0014.

² There is a discussion about whether autism should be seen as a disability. I see the emerging field of Autism Theology as a parallel field to Disability Theology, with significant overlap but also some differences. The differences are due to the fact not all autistic people identify as disabled.

is the exclusion that many have felt in churches. Whilst many, if not all, churches claim that "Everyone is welcome," in reality those with disabilities and their families often find this not to be true. This article addresses the question: what is the reason for this discrepancy? In other words, why do disabled people often feel excluded from faith communities, and how might churches respond? First, I will briefly discuss what autism is. Then, I will present evidence for the fact that autistic people often feel excluded from faith communities, despite their desire to belong and participate. I will then continue by suggesting that the heart of the problem of not-belonging is the concept of normalcy, which determines who is valued and therefore belongs, and who does not. Over and against the exclusion or absence of autistic people from church, I will propose a theology of presence and availability, which is rooted in the Christians' identity in Christ and participation in the Divine.³ Thus, the aim of the article is to explore the reason for the relative absence of autistic children and adults in church services, and suggest a theological response.

A note on context. Most research on autism, including the relation of autism to faith and religion, has been conducted in countries in the so-called "global North." Furthermore, writing as a Western European, currently based in Scotland, I cannot speak into the context of Eastern Europe. However, some issues (such as negative experiences with faith communities or the need to belong) seem to transcend many cultures. The readers of this article, therefore, are invited to interpret the evidence and arguments that I will put forward here within their own context.

Autism Is...

There is instability with regards to the definition and understanding of what autism is. It depends on who is making the statement, and even in the medical profession, in which the diagnosis originated, the definition and diagnostic criteria have changed over time.⁴ That is not to say that autism does not exist as such, it does. However, it is important to be aware of the definition one is working with, how one interprets what it means to be autistic, and that the way one understands autism influences the way one responds to the reality of autism. In this section I give a very brief overview of how autism is defined and responded to from different points of view or discourses: medical, social, neurodiversity. I will also briefly comment on the role of self-advocates.

From a medical point of view, autism is defined by the diagnostic criteria as set out in either the *Diagnostic and Statistical Manual of Mental Disorder*, now in its fifth edition (DSM-5) or the *International Statistical Classification Diseases and Related Health Prob*-

³ The structure of this argument is based on my book *Autism and Worship: A Liturgical Theology* (Waco: Baylor University Press, 2023). Copyright © 2023 by Baylor University Press. Used with permission. All rights reserved. For further details to the discussions in this article I refer the reader to this book.

⁴ John Donvan and Caren Zucker, *In A Different Key: The Story of Autism* (London: Allen Lane, 2016); Steve Silberman, *Neurotribes: The Legacy of Autism and the Future of Neurodiversity*, 2015.

lems, now it its eleventh edition (ICD-11).⁵ The first is issued by the American Psychiatric Association and therefore the default manual for diagnosing autism in the United States; the second is issued by the World Health Organisation, and the default in many other countries. In the latest issue of the ICD, the diagnostic criteria for autism have been aligned with those of DSM-5. In these manuals, the official term for an autism diagnosis is Autism Spectrum Disorder (ASD). The titles of these two "bibles of psychiatry" already put autism in a specific light: it is included as a "mental disorder" (DSM) or a "disease" or "health problem" (ICD). This negative characterisation is also clear from the diagnostic criteria. It is outside the scope of this paper to rehearse the criteria in full here, but the first criterion makes the point: in order to be diagnosed with autism, there must be "Persistent deficits in social communication and social interaction across multiple contexts." Autism is characterised by a "persistent deficit."⁶ The medical (and from that point of view perhaps logical) response to a deficit is to either cure it, or, if that is not possible, to treat it, with the aim of making sure that a person can function "normally."⁷ The medical model has been dominant throughout the history of autism, and still is in many corners of the autism discourse. In many countries, access to support depends on having an official diagnosis, which is made by medical professionals on the basis of DSM-5 or ICD-11.

Over and against the *medical model* of disability and autism, which locates the "problem" of autism in the person themselves, autistic people and others have argued that much, if not all, the challenges and indeed suffering they experience is due to living in a world that is not set up for them. This is called the *social model* of disability.⁸ In this model, it is not the person or their "condition" that is the problem, but the way society puts up barriers for participation, expecting people to work, talk, walk, process – indeed, live – at a certain pace and in a certain way, which in reality only few people can actually live up to. Often simple adjustments to the environment or to expectations can enable a person to participate. The classic example is access to buildings, which is disabling for a wheelchair user if there are stairs, but a ramp enables access. In the case of autism, an example is the bright lights in a room, which for some autistic people are painful – often it might be easy to replace the lights with softer lighting. Thus, in the social model of disability, the "problem" is not necessarily the impairment itself, but the lack of a suitable or accommodated environment.

A more recent model to understand autism is the *neurodiversity model*, which shares much in common with the social model. The term "neurodiversity" is often credited

⁵ American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders: DSM-5*, 5th ed. (Arlington, 2013); World Health Organisation, *International Statistical Classification of Diseases and Related Health Problems*, 11th ed., 2019.

⁶ Autism shares this with how disabilities in general are perceived from a medical model, which some would therefore also call a "deficit model." See for a discussion e.g., Deborah Beth Creamer, *Disability and Christian Theology: Embodied Limits and Constructive Possibilities* (Oxford: Oxford University Press, 2009), 22–25.

⁷ Creamer, 22–25.

⁸ For more on the social model, see e.g., Tom Shakespeare, 'The Social Model of Disability', in *The Disability Studies Reader*, ed. Lennard J. Davis (New York: Routledge, 2013), 214–21.

to Judy Singer (although the term predates her use of it⁹), who in her undergraduate thesis suggested that just like there is biodiversity, so there is a diversity of neuro-logical types, i.e., neurodiversity.¹⁰ This term takes autism (and other neurodivergences, such as ADHD, dyslexia, dyspraxia) out of the negative discourse and deficit model, instead suggesting that neurodivergence is good, just like biodiversity is necessary in the natural world. Nevertheless, those who are neurodivergent live in a neurotypical world, which is why life can be difficult for those who are neurodivergent. With this, one can see that the neurodiversity model is on the one hand biological, but on the other hand social.¹¹

The changes in the discourse is (at least in part) due to the self-advocacy of autistic people. Whilst many autistic people will say that being autistic is disabling, they criticise a purely negative portrayal of autism, including the use of the word "*dis*order." A turning point in this regard was a speech by Jim Sinclair, given at an autism conference for parents in Toronto in 1993, entitled "Don't Mourn for Us."¹² Sinclair was disturbed by the constant message that parents expressed, that having an autistic child was something to be mourned. He argued that autism is not something a person *has*, but something inseparable from the person, part of the person's identity. He accused the parents, therefore, saying that in their mourning they were basically saying that they wished their child had not been born. Instead, Sinclair, argued, mourn for the loss of *your* expectations and dreams for your child, but, "*don't mourn for us.*"

Finally, it is worth noting that autism is seen as a "spectrum" of conditions and expressions of the condition (note that "condition" in itself is a somewhat medical term). Some people may be unable to rely on spoken language (which does not necessarily mean that these people have an intellectual disability as is often thought), some may have high support needs in their daily lives, whilst others may live independently and work in high-profile jobs.¹³ Moreover, the experience of being autistic is not static either. Some would say that autism is a "spiky" condition. This means that a person may excel in one task but may struggle with another, or that whilst they may be able to go to church one Sunday, they might not be able to face the prospect of sensory and social overload the next Sunday.

⁹ Monique Botha et al., 'The Neurodiversity Concept Was Developed Collectively: An Overdue Correction on the Origins of Neurodiversity Theory," *Autism* 28, no. 6 (June 2024): 1591–94, https://doi. org/10.1177/13623613241237871; Vishnu Kk Nair, Warda Farah, and Mildred Boveda, "Is Neurodiversity a Global Northern White Paradigm?," *Autism*, 21 September 2024, 13623613241280835, https://doi. org/10.1177/13623613241280835.

¹⁰ Silberman, Neurotribes, 492.

¹¹ For more on the neurodiversity model, see for example the work of one of the spokespersons, Nick Walker, *Neuroqueer Heresies: Notes on the Neurodiversity Paradigm, Autistic Empowerment, and Postnormal Possibilities* (Fort Worth: Autonomous Press, 2021).

¹² Jim Sinclair, "Don't Mourn For Us," in *Loud Hands: Autistic People, Speaking*, ed. Julia Bascom (Washington: The Autistic Press, 2012), 15–21.

¹³ That is not to say that people with high support needs cannot have high-profile jobs, but in reality they usually don't have those – in fact, unemployment rates for autistic people are extremely high. Marissa L. Diener et al., "Dual Perspectives in Autism Spectrum Disorders and Employment: Toward a Better Fit in the Workplace," *Work* 67, no. 1 (20 October 2020): 223–37, https://doi.org/10.3233/WOR-203268.

This brief overview of different models of autism, as well as the notion of a "spectrum" and a "spiky profile," show that the question "What is autism?" cannot be answered straightforwardly. It is important to keep this in mind for the argument about presence that I will make further down.

Participation of Autistic People in Church

Several studies have shown that autistic people attend church and religious activities less than their non-autistic counterparts. Li-Ching Lee et al. studied the participation of autistic children, compared to those with ADD/ADHD and "typical" children, in religious services, schools and other activities. They found that autistic children were more than 50-70% less likely to attend religious services than others.¹⁴ Andrew Whitehead compared autistic children to those with disabilities and chronic health conditions, based on data from the 2003, 2007 and 2011-2012 National Survey of Children's Health, conducted by the Centres for Disease Control and Prevention in the United States. Like Lee et al., he found that autistic people attended church less than any other group of children.¹⁵ In a study with parents of autistic children and other children with intellectual and developmental disabilities,¹⁶ Melinda Jones Ault et al., found that parents of autistic children felt much less supported by their church than other parents in the study.¹⁷ A study by Naomi Ekas et al. demonstrates that the more support needs the autistic person has, the less their parents feel supported by their faith communities.¹⁸

Whilst these numbers demonstrate that autistic people do attend church, even if less than non-autistic people, when it comes to being active in formal roles, the figures plummet. In a study with over 440 adolescents in Tennessee, Carter and Boehm found that only 13% of those attending church led public prayer and only 11% led Scripture readings in the service.¹⁹ This raises the question whether churches may tolerate

¹⁴ Li-Ching Lee et al., "Children with Autism: Quality of Life and Parental Concerns," *Journal of Autism and Developmental Disorders* 38, no. 6 (July 2008): 1147–60, https://doi.org/10.1007/s10803-007-0491-0.

¹⁵ Andrew L. Whitehead, "Religion and Disability: Variation in Religious Service Attendance Rates for Children with Chronic Health Conditions," *Journal for the Scientific Study of Religion* 57, no. 2 (1 June 2018): 377–95, https://doi.org/10.1111/jssr.12521.

¹⁶ As noted above, equating autism and disability is not straightforward, and one should especially be careful not to equate autism with intellectual disability.

¹⁷ Melinda Jones Ault, Belva C. Collins, and Erik W. Carter, "Congregational Participation and Supports for Children and Adults with Disabilities: Parent Perceptions," *Intellectual and Developmental Disabilities* 51, no. 1 (2013): 48–61.

¹⁸ Naomi V. Ekas, Lauren Tidman, and Lisa Timmons, "Religiosity/Spirituality and Mental Health Outcomes in Mothers of Children with Autism Spectrum Disorder: The Mediating Role of Positive Thinking," *Journal of Autism and Developmental Disorders* 49, no. 11 (November 2019): 4547–58, https://doi.org/10.1007/s10803-019-04165-z.

¹⁹ Erik W. Carter and Thomas L. Boehm, "Religious and Spiritual Expressions of Young People with Intellectual and Developmental Disabilities," *Research and Practice for Persons with Severe Disabilities* 44, no. 1 (March 2019): 42, https://doi.org/10.1177/1540796919828082; see also Erik W. Carter, "Research on Disability and Congregational Inclusion: What We Know and Where We Might Go," *Journal of Disability & Religion*, 8 February 2022, 1–31, https://doi.org/10.1080/23312521.2022.2035297. 42.7% of these adolescents were receiving special education under the category of autism, 37.7% under the category of intellectual disability, and 12.7% under the category of both autism and intellectual disability.

autistic people but not value them as active contributors to the church – as members of the body of Christ each with their own gifts (1 Cor. 12).

In sum, autistic people are less likely to be in church than the general population and even than people with other disabilities, and their parents feel less supported than any other group of parents with disabled children. The above studies all focus on children and adolescents. I am not aware of similar quantitative studies that measure church attendance of autistic adults. However, testimonies by autistic writers show that many autistic adults struggle with attending church services which leads to reduced attendance.²⁰ Even when autistic people participate in church, according to some studies they are less involved in liturgical leadership. To put it sharply, autistic people and their families seem to be less supported – and less welcomed – than anyone else. This seems to be even more the case for autistic people with high support needs.²¹ Why this exclusion of autistic people?

Belonging and normalcy

Rachel, someone I interviewed for my study on autism and worship, said: "Normal people just go to church and don't think any more about it. They just get in their car or walk, they go through the door, they do the service and they go home. And it's never that simple for me."²² Why is it not easy for Rachel? And why do some people belong to the group and are others excluded? I propose that at the heart of the answer to these questions lies the concept of normalcy. Before explaining that concept, however, we need to look more closely at the idea of belonging.

The philosopher Charles Taylor argues that we live in certain frameworks.²³ A framework is a society's constellation of norms and values which govern the ways in which we relate to each other. The framework gives a sense of self, and a sense of what is right and wrong. Frameworks are created by the interaction between people, by what they hold in common and value together. Together, we could say, this makes up what we consider "good." Thomas Reynolds explains this as: "The good is what we find meaningful about life together."²⁴ To belong is one of the things we find "good" as human beings; we desire to relate to one another, to belong to a friendship group, sports club, the fandom of an artist, a nation. In a sense, the desire to belong is not

²⁰ E.g., Monica Spoor, *Spirituality on the Spectrum: Having Autism in the Orthodox Church* (Brave New Books, 2017); Krysia Emily Waldock, "The Impossible Subject: Belonging as a Neurodivergent in Congregations," *Journal of Disability & Religion*, 2023; Claire Williams, *Peculiar Discipleship: An Autistic Liberation Theology* (London: SCM Press, 2023).

²¹ Whilst these studies took place in the United States, in other countries across the world the situation seems to be not much different. This observation is based on conversations I have had with people in different continents, and on research in Singapore. Armand Léon Van Ommen, "Re-Imagining Church through Autism: A Singaporean Case Study," *Practical Theology* 15, no. 6 (2022): 508–19, https://doi.org/10.1080/17560 73X.2022.2080630.

 ²² "Rachel" is a fictitious name. One may question her use of the word "normal" but that is not the point here.
 ²³ Charles Taylor, *Sources of the Self: The Making of the Modern Identity* (Cambridge, Mass.: Harvard University Press, 1989), 14–52.

²⁴ Thomas E. Reynolds, *Vulnerable Communion: A Theology of Disability and Hospitality* (Grand Rapids: Brazos Press, 2008), 53.

only part of what we deem "good" and therefore part of the framework, the framework is also constituted by that very desire to belong. This is because, as stated above, the framework is created by people (over time and usually unwittingly), because together they decide what the norms and values of the group are. Agreement on those norms and values is necessary to create the framework – without that agreement, there would be no framework, and people would be unable to relate to each other, and therefore unable to belong together.

Importantly, the framework is not just a worldview or set of ideas, and it is not made up in the offices of policy makers or academics. On the contrary, frameworks are being played out, and therefore (re)created over time, in the interactions and behaviours of human beings in daily life. Reynolds calls this the "economy of exchange." By this, he means the norms and values and opinions that are constantly shaped by interactions between people. Whilst he does not use the term "economy" in the contemporary understanding of the exchange of money and the consumption and supply of goods, it is useful to think along those lines. The economy of exchange is an exchange in what we value. Crucially, some bodies have more "body capital" to exchange the good they have for the good they want to purchase, including belonging. Such capital is determined by the framework of the (sub)culture or group we find ourselves in. The way we dress, the way we speak, how well we can listen, the jokes we make at the right time, the opinions we express, but also the way we look or how skilled we are in particular areas, all of that buys us body capital. In other words, groups have a particular ideal of what it means to be a human being who can belong to the group. The closer one answers to that ideal, the more body capital one has and so the more valuable one is, hence the more one belongs (and probably gets to places of formal or informal leadership in the group). To put this differently, the more one adheres to the "norm" of the group's ideal, the more one is "in" and "one of *us*." That brings us to the concept of normalcy.

The term "normalcy" has entered the disability discourse through the work of Lennard Davis. In his 1995 book *Enforcing Normalcy*, he states:

To understand the disabled body, one must return to the concept of the norm, the normal body. So much of writing about disability has focused on the disabled person as the object of study, just as the study of race has focused on the person of color. But as with recent scholarship on race, which has turned its attention to whiteness, I would like to focus not so much on the construction of disability as on the construction of normalcy. I do this because the "problem" is not the person with disabilities; the problem is the way that normalcy is constructed to create the "problem" of the disabled person.²⁵

We can replace "the disabled person" by "the autistic person": "... the 'problem' is not the autistic person; the problem is the way that normalcy is constructed to create the 'problem' of the autistic person."

"Normalcy" points to the norms that are dominant in a group or culture. Davis argues that only because certain cultures create a particular norm of what it means to

²⁵ Lennard J. Davis, Enforcing Normalcy: Disability, Deafness and the Body (London: Verso, 1995), 23–24.

be "able," the idea of "disabled" can come into being. That is not to deny the existence of physical or intellectual impairments, but to say that the extent to which these are disabling is largely due to societal structures (the framework). Similarly with autism: autism does exist (bearing in mind the caveats of the discussion in the section "Autism is..." above), but the extent to which that is potentially disabling, or in contrast, seen as a particular gift, is due to the society's understanding of what is "normal."

Again, that understanding is not something cerebral, but in the first place played out in societal structures and daily life. Whilst "normalcy" is a noun, it acts like a verb. Therefore, in my book, *Autism and Worship*, I have defined normalcy as "the set of dynamics by which communities safeguard the boundaries of what and who they deem normal and therefore acceptable. Those who fall within those boundaries can be integrated into or even belong to the community, but those who do not fall within the boundaries either need to change or will be rejected."²⁶ Normalcy is an active concept; it is in fact lived out in the small details of daily life and in every interaction that we have with each other.

If being autistic is characterised by "Persistent [differences] in social communication and social interaction across multiple contexts" (quoting DSM-5 but replacing "deficits" with "differences") as per one of the diagnostic criteria, then it is not difficult to understand why autistic people often feel they don't belong to the group. Note that whether one uses the term "deficit" or "difference," both terms only mean something because of a certain norm from which the autistic person "differs" or (and here it starts to become clear why the "deficit" model is problematic) the norm that the autistic person cannot live up to – hence their "deficit." The societies in which the diagnostic criteria were formulated, that is, the USA and other Western countries, have certain norms for "social communication and social interaction" (in terms of the economy of exchange, norms for what counts as valuable and therefore "body capital") – norms that are now set as a criteria for diagnosing someone as being "deficit" enough in these areas to award them a specific label. The very nature of autism, according to the diagnostic criteria, is that the autistic person cannot live up to the ideal of the majority society.

Churches are part of societies, and therefore influenced by these societies. Faith communities consist of people who live their daily lives in the society that they find themselves in (with the exception of closed religious communities, but even there the influence of society is present). The connection between the dynamics of normalcy in the wider culture and in the church is clear in a story that Claire Williams recounts in her book *Peculiar Discipleship*. Writing as an autistic theologian, she tells of a time she visited an Anglican church, a tradition that is different to her own. Standard practice in an Anglican Eucharistic service is the "sharing of the peace." This is the moment Williams refers to:

I watched as people spun around and shook hands with one another, greeted one another with much enthusiasm and left their seats to find their friends. I didn't have any particular friends. I felt too shy to interrupt these reunions and couldn't quite make out what social dynamics were at play. The spiritual and

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²⁶ Van Ommen, Autism and Worship, 71.

theological import of this praxis was lost on me. The swirling of other people as they confirmed friendships and greeted new people felt like the repeat of every school lunchtime and classroom instruction to 'get into groups of three' – I was left standing on the sidelines.²⁷

Williams found herself in a Christian community, where she joined in with the worship service, but one of the practices was alienating. For many people, being unfamiliar with a certain practice can cause the shyness Williams talks about, but for most autistic people the unknown and therefore loss of control is unsettling and hard to deal with, more so than for most non-autistic people. The point I want to highlight here is that Williams immediately felt the same dynamic of normalcy at play as when she was at school. No doubt the church did not mean to exclude Williams, which underlines the point made above, that normalcy is played out in a million subtle ways, without communities realising it for the most part. This is as true for society in general, as for churches. Williams' example is only one of many more that autistic adults and (parents of) autistic children will be able to tell. Ekas et al. found that more mothers of autistic children with higher support needs ("more severe ASD symptoms" in their words) said that they had negative interactions in their faith communities. The authors suggest that this may be due to a lack of understanding and more criticism of their child's behaviour.²⁸

Now we can understand Rachel better: "Normal people just go to church and don't think any more about it ... And it's never that simple for me." Rachel's use of the word "normal" is understandable and in light of the discussion in this section perhaps exactly the right word. But that is only as long as we have not evaluated the society's framework – what is normal – in light of the gospel. Whilst we can affirm in society that which aligns with the norms and values of the reign of God, faith communities have the obligation to be countercultural where those norms and values do not align.

A Theological Critique of Normalcy

It is hardly possible, if at all, to escape the dynamics of normalcy. Groups need boundaries, otherwise it is unclear what the group is and what it is not. Societies, groups and churches will always operate within a framework they have inherited and continue to recreate. The theological response to normalcy is therefore not to deny normalcy or to try to abandon it somehow, instead the theological response is to critically evaluate the framework (what counts as valuable) and how normalcy guards the boundaries of the community. A theological response can criticise the threshold of belonging

²⁷ Williams, *Peculiar Discipleship*, 179. See for more examples the articles in the Special Issue "Autism and Faith" of *Theology in Scotland*, esp. Emma McDonald, "Autism and Church: A Reflection," *Theology in Scotland* 30, no. 1 (18 May 2023): 5–13, https://doi.org/10.15664/tis.v30i1.2574. The positive examples in Van Ommen, "Re-Imagining Church through Autism" are set against the backdrop of many painful rejections of these same autistic children in other worship contexts. See for more examples of autistic experiences of worship, both positive and negative, Armand Léon Van Ommen and Topher Endress, "Reframing Liturgical Theology through the Lens of Autism: A Qualitative Study of Autistic Experiences of Worship," *Studia Liturgica* 52, no. 2 (2022), https://doi.org/10.1177/00393207221111573.

²⁸ Ekas, Tidman, and Timmons, "Religiosity/Spirituality and Mental Health Outcomes in Mothers of Children with Autism Spectrum Disorder," 4555.

(how much and what kind of "capital" does one need in order to belong) and how that threshold is policed.

As demonstrated above, the group dynamics of many church communities mean that autistic people might feel excluded, despite the message of welcome that these churches no doubt preach.²⁹ There are at least two reasons for this. The first is that the church practices their worship or liturgy in ways that are overwhelming, for example because of a sensory overload, social expectations, or inconsistency between what is preached and how people act. In this case, sometimes accommodations can be made with little effort. For example, the Anglican church that Williams visited, could give clear instructions of who to turn to when sharing the peace. However, whilst there are many stories of churches who have responded well to such requests, unfortunately stories abound of churches who have reinforced their current practice, thereby reinforcing their framework, without questioning the fact that in this situation the threshold for belonging may be too high to pass for the autistic person.

The second reason why the dynamics of normalcy are exclusionary is because normalcy is an avoidance strategy. Reynolds explains that when we are confronted with something we don't know, it upsets our equilibrium. It is worth quoting Reynolds at length as he explains well how this dynamic works and the role of fear and avoidance in it:

It seems only too natural then that we make judgments and behave in ways that protect and preserve the ideals of a community's framework or value horizon. We come to rely upon these ideals for orientation in the world; they grant a sense of place. Negatively, we place under surveillance or exclude those elements and persons perceived as out of place, that do not fit. They cannot be assimilated or integrated and are in effect deemed an impoverishment, perhaps even something dangerous, because they do not present what we consider familiar or acceptable. In fact, we come to fear such elements and people. Their difference puts conventions into question ... Strangeness disrupts the predictable world and so disorients, making us conscious of the extent to which we are vulnerable. Strangeness creates a dissonance that threatens to spoil the fabric of a community's mutually reinforcing sense of the good. The social order is jeopardized. The predictable world is thrown into relief. Because of this, communities develop protective strategies through what I call the "cult of normalcy."³⁰

This quotation shows how the key concepts we have discussed so far are interrelated and how they can result in the fear of the "other." In relation to autism, it is not difficult to imagine (or indeed observe) how people avoid the non-speaking autistic person, because it is difficult to communicate and perhaps we are even a little bit scared. Reynolds points out that that fear is not located in the other person, but the insecurities that it reveals in ourselves. Likewise, autistic people are sometimes perceived as "odd"

²⁹ This is the tension between the espoused (what a church or people say they do) and operant (what they actually do) theologies of churches. Helen Cameron et al., *Talking about God in Practice: Theological Action Research and Practical Theology* (London: SCM Press, 2010), 53–56.

³⁰ Reynolds, Vulnerable Communion, 55.

by non-autistic people, for example because of the way they communicate. Avoiding often seems the easier option than engaging and befriending.

Normalcy, then, works at least in the two ways just described: upholding the church culture and practices despite the request for accommodations, and avoiding because of fear of the "other." Both cases lead to exclusion instead of belonging and valuing the autistic person. Both operations of normalcy are theologically questionable. The apostle Paul writes to the Corinthians: "So from now on we regard no one from a worldly point of view" (2 Cor. 5:16). If church communities are deeply influenced by their surrounding society, as I have argued above, then their members need to do the hard work of theologically evaluating whether they regard one another "from a worldly point of view." This seems to be the case when people get excluded. Moreover, every member of the body of Christ is valuable and has something to contribute. Paul says to the Corinthians, almost mockingly, "The eye cannot say to the hand, 'I don't need you!' And the head cannot say to the feet, 'I don't need you!'" (1 Cor. 12:21, NIV). He continues:

On the contrary, those parts of the body that seem to be weaker are indispensable, and the parts that we think are less honorable we treat with special honor. And the parts that are unpresentable are treated with special modesty, while our presentable parts need no special treatment. But God has put the body together, giving greater honor to the parts that lacked it, so that there should be no division in the body, but that its parts should have equal concern for each other. (vs 22-26)

Theologically, there is no Christian who is not a part of the body of Christ. If the church service (typically on Sundays) is a core practice for the church, then it is hard to see why anyone should be excluded from that. Indeed, whilst autistic people may seem "weaker" in the eyes of society, the church is instructed not to look "from a worldly point of view" but instead treat them "with special honour" because they are "indispensable." (I should add that this logic only applies when working with the categorisation by societies that regard autistic or disabled people as "weaker." Theologically, it cannot be said that these people are "weaker.") If autistic people are an indispensable part of the body of Christ, then the church needs a theology that enables their presence.

A Theology of Presence

I have argued that the absence of autistic people is caused by the dynamics of the framework within which churches live. Those frameworks should be shaped according to the Gospel, but I have suggested that in reality they are as much influenced by their surrounding society. To be clear, there are many good things in societies and most societies uphold good norms and values. Nevertheless, when societal norms and values conflict with those of the reign of God, churches need to be aware of this and shape their cultures and practices according to the latter. For example, things that are valued in Western societies include being able to speak, being socially adept,

independence, speed, making efficient use of time, and many more. Many of these norms conflict with those of the reign of God, but it is easy to see how many autistic people cannot live up to some of these ideals, and therefore do not pass the threshold of belonging.

The identity of Christians is not shaped by physical beauty, speed, economic prosperity, and so on. The identity of Christians is rooted in the identity they have in Christ. The theology of presence that I propose is rooted in that identity, as followers of Christ who was and is present to human beings. Christ became "available" to human beings in the act of the incarnation. I use the word "available" here in the sense of the philosophy of Gabriel Marcel, who argues that being present means being fully available to the other person, being able to sympathise with the other.³¹ Being available means turning outward to the other, giving oneself to the other.³² Theologically, we can explore this further with the concept of kenosis.

The term "kenosis" is mostly associated with the passage in Philippians 2 where it is translated as Christ "emptying himself" or "becoming nothing" (vs 7). Paul writes there:

⁵ In your relationships with one another, have the same mindset as Christ Jesus:

⁶Who, being in very nature God,

did not consider equality with God something to be used to his own advantage;

⁷ rather, he made himself nothing

by taking the very nature of a servant,

being made in human likeness.

⁸ And being found in appearance as a man, he humbled himself by becoming obedient to death even death on a cross!

⁹Therefore God exalted him to the highest place and gave him the name that is above every name,
¹⁰ that at the name of Jesus every knee should bow, in heaven and on earth and under the earth,
¹¹ and every tongue acknowledge that Jesus Christ is Lord,

to the glory of God the Father. (Phil. 2:5-11, NIV)

³¹ Marcel uses the word "*disponibilité*," which is usually translated with "availability." This is a somewhat flat translation, as Marcel himself also has pointed out. *Disponibilité* has to do with having at hand what is required in a given situation. In that sense, "The self-centred person, in this sense, is unhandy; I mean that he remains incapable of responding to calls made upon him by life … He will be incapable of sympathizing with other people, or even of imagining their situation." Gabriel Marcel, *The Mystery of Being: Reflection and Mystery*, trans. G.S. Fraser, vol. 1 (Chicago: Henry Regnery Company, 1950), 163.

³² This should be held in check with self-care and this theory can therefore not be used to require abusive availability from anyone. Furthermore, whilst Marcel talks mainly in situations of one person to another person, radical availability to all members of the congregation is likely only to be sustainable if done by a community.

It is important to note that this passage is not in the first instance an ethical imperative, as it has been often read and preached, but a soteriological narrative.³³ The focus is on what Christ has done (vs 6-8) and God's exaltation of Christ Jesus (vs 8), *so that* everyone should praise Jesus, to the glory of God the Father (vs 10-11). Human action (to praise Jesus and glorify the Father) is a response to what Jesus has done, and what God has done through Jesus. Just as Jesus relates simultaneously to God and humankind by being available – a full giving of himself for the salvation of all of humankind – so the Philippians are to relate to each other ("have the same mindset," which should not be taken in a cerebral sense but encompasses all of one's being, thinking and actions).

For the church this means that being present, being available, to autistic people is not an act of charity, in which "we" (non-autistic people, who have it all together) care for "them" (the poor, helpless autistic people). Instead, it is part of the salvation story that the believers are invited to participate in. Without unity within the church ("every knee should bow" and "every tongue acknowledge that Jesus Christ is the Lord") the story of salvation is incomplete.

Another aspect of relating to each other, and why this is not an act of charity, is because it is rooted not in an ethical command but in the believers' identity in Christ. Throughout the New Testament, the believers are said to be "in Christ." Through baptism, the old self dies with Christ and the new self arises to new life in Christ (Rom. 6). Having that identity, participating in the Divine life through Christ, shapes the "mindset" that Paul exhorts the Philippians to embody. In a way, to embody that mindset is not a request, it is the logical consequence of being "in Christ." This creates a new community, indwelt by the Holy Spirit, in which Christ through the Spirit participates in the community and the community in Christ.

Thus understood, being present and available to one another – the non-autistic person to the autistic person and vice versa – is not an ethical imperative or "just a nice idea" but flows out of the believers' being in Christ. As the Holy Spirit indwells the community, the believers are shaped into a shared new identity. This new identity, and being community in this way, does not allow for avoiding the other. The distinctions of the old frameworks have been redefined. In Susan Eastman's words, referring to Galatians 5:6: "In this new community there is neither circumcision nor uncircumcision, because all old systems of worth are 'recalibrated.'"³⁴ The "criterialism" of the old framework has been replaced by the believers' identity in Christ, the new framework of which is constituted by grace and God's unconditional love.³⁵

³³ John M.G. Barclay, "Kenosis and the Drama of Salvation in Philippians 2," in *Kenosis: The Self-Emptying of Christ in Scripture and Theology*, ed. Paul T. Nimmo and Keith L. Johnson (Grand Rapids: William B. Eerdmans Publishing Company, 2022), 7–23. I base my discussion here primarily on Barclay's chapter.

³⁴ Susan Grove Eastman, *Paul and the Person: Reframing Paul's Anthropology* (Grand Rapids: William B Eerdmans Publishing Company, 2017), 160.

³⁵ The term "criterialism" is used by Eastman, 171.

Conclusion

The purpose of this article was to outline what in my view is the root cause for the absence of autistic people in worship and to provide a theological response. Autistic people are less present in church services compared to the general population. Worryingly, even when autistic people are present, only a small number is involved in liturgical leadership. Even if this only applies to those who have co-occurring learning disabilities, this is still contrary to the apostle Paul's theology that everybody should fully belong and be valued in the body of Christ, and their gifts used to build up the community of believers. When autistic people are excluded from churches, this is most likely because the framework of the wider society has overridden the values of the Gospel. Normalcy is the set of dynamics by which communities safeguard their boundaries, and whilst such dynamics are always at work in a community, they should be critically evaluated in light of the Gospel. Because Christ Jesus participated in humanity, humanity can participate in the Divine life in turn. Such living is not an ethical demand but initiated by the incarnation, by the grace and love of God. Participating in that grace and love changes the way the believers relate to and value one another.

More could be said about how this works out in liturgy and worship for a community that includes autistic and non-autistic people alike, but space does not allow an elaborate discussion.³⁶ However, at the very least we should say that a theology of presence means that believers turn outward toward each other, becoming 'available' to each other, in contrast to avoiding those who are deemed 'other' and allowing them to pass the threshold of belonging. When people are really present to each other, they form relationships and get to know each other. Instead of ticking off a list of 'how-toinclude-autistic-people', by getting to know each other people get to know the gifts and needs of all members, in addition to any accommodations that might need to be made. A community that lives the theology of presence seeks to be blessed by each and every member of the community, whether autistic, disabled, young, old, man, woman, etc. And they will be blessed.

³⁶ One church that is entirely focused on the belonging of autistic people is the Church of Christ Our Hope in Singapore. Elsewhere I have described salient aspects of this church, see Van Ommen, "Re-Imagining Church through Autism"; Van Ommen, *Autism and Worship*, chap. 6.

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Ідентичність, (не)спроможність і належність: літургія та поклоніння крізь призму аутизму

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Анотація: Люди з інвалідністю часто відчувають себе виключеними з церковних заходів. У статті розглядається аутизм зокрема, досліджується проблематична відносна відсутність людей з аутизмом у церквах. Пропонується теза що в основі проблеми лежить поняття нормальності. Нормальність розуміють як сукупність динамік, які охороняють кордони громад, тобто, це про те хто є частиною громади, а кому у ній не місце. Ці кордони частково є тим, що Чарльз Тейлор називає «рамкою» спільноти, яка визначає цінності спільноти. У цій статті стверджується, що люди з інвалідністю легко вибиваються з рамок громади. Після обговорення динаміки нормальності ця стаття пропонує богословську критику та рамку, основу якої взято з Євангелія. Це дозволяє говорити про «теологію присутності», яка передбачає присутність членів спільноти один для одного у такий спосіб, що це відображає кенозис Христа.

Ключові слова: інвалідність, неповносправність, аутизм, приналежність, нормальність, богослов'я присутності.

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