



*Citation for published version:*

Waldock, K & Forrester-Jones, R 2020, 'An Exploratory Study of Attitudes toward Autism Amongst Church-Going Christians in the South East of England, United Kingdom', *Journal of Disability & Religion*, vol. 24, no. 4, pp. 349-370. <https://doi.org/10.1080/23312521.2020.1776667>

*DOI:*

[10.1080/23312521.2020.1776667](https://doi.org/10.1080/23312521.2020.1776667)

*Publication date:*

2020

*Document Version*

Peer reviewed version

[Link to publication](#)

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## **An exploratory study of attitudes towards autism amongst church-going Christians in the South East of England, United Kingdom**

Access to church communities can be difficult for autistic people. Whilst specific autism guidelines are available for churches to follow, their dissemination among church communities, as well as churchgoers' attitudes towards autism is unknown. Semi-structured interviews were used with twenty-one adult church-goers from four Protestant churches in England, UK. Using a grounded theory approach to analyse the data, three themes were identified: "different understandings of autism", "degrees of ableism" and "idiosyncratic practice". We found positive and pejorative attitudes; this mix of perspectives reflecting the idiosyncratic practice among churches. Recommendations for further research and church practice are provided.

Keywords: autism, inclusion, social inclusion, spirituality

### **Introduction**

Approximately 1% of the UK population is diagnosed as autistic, mirroring global estimates (Baird et al. 2006; Elsabbagh et al., 2012). According to the *Diagnostic and statistical manual of mental disorders, 5th edition (DSM-V)*, autism is diagnosed as difficulties in social communication and interaction along with restricted and repetitive behaviors (American Psychological Association, 2013). Milton (2012) defines the above traits as the key "qualitative impairments" that are used to guide diagnosis of autism. However, many autistic people view autism as an identity (Sinclair, 2013) as it influences all areas of life, including making friends, and finding and maintaining employment. In recent years, understanding of autism, autistic people and their support needs has increased considerably (Silberman, 2015, p299-302; Waltz, 2013, p133-165) as has the growing recognition of the impact different environments have on autistic

people and their support needs (Milton & Bracher, 2013). This paper reports on a study that considers such issues within a Church environment. Church membership in the United Kingdom (UK), as of 2015, is 5,084,498 (Brierley, 2018) with 50,660 churches nationwide (Brierley, 2013). Official statistics show that churchgoers in the United Kingdom (UK) are more likely to be women (Ashworth & Farthing, 2007) and over the age of 55 (Ashworth & Farthing, 2007). We wanted to know how such a culture perceives autistic people.

The aim of our study was to explore current attitudes of UK churchgoers towards autism and autistic people and to discover the process of how such attitudes develop. The objective was to learn more about the interface between spirituality and perceptions of autism, and to see if further work is required. Three broad research questions guided the study: How exactly do congregations perceive autistic people? To what extent are autistic people valued in the church? To what extent does congregations see their church as accessible to an autistic person?

In this paper, we use identity first language (i.e. autistic person) in preference to person first language (i.e. person with autism). Recent research has found that the majority of autistic people prefer identity first language (Kenny et al., 2016) since they consider being autistic as part of their identity (Sinclair, 2013). This also follows and respects an “inside-out” approach to autism (Williams, 1996, p14), whereby autistic voices are key to investigating autistic lived experience. The first author is autistic; therefore, this terminology is reflective of the emancipatory nature of the study. The terms “church”, “congregation”, “faith community” and “faith institution” are all equivocal in meaning and refer to a particular community of Christians meeting together in a chosen location (either a traditional/registered building, or informal setting). A ‘churchgoer’ is one member of

such a community. The size of the congregation is not fixed in Christian faith communities.

Whilst support to disabled people originated from church communities (Miller, 1985, p79), how disability has been defined and viewed by churches has varied over time. Aligned with witchcraft (Kramer & Sprenger, 1928/1971, p45) or the devil (Miles, 2001), or inversely a blessing where the Holy Spirit is working through the individual (for example, the Blessed Fools of Old Russia, described in Frith (2003, p22)), something 'angelic' (Webb-Mitchell, 1996, p48), or 'a gift' (Moltmann, 1998, p120) have all been normalized during one church era or another. The church's historical understanding of autism however is unknown; autism being a relatively recent (Asperger, 1944; Kanner, 1943; Ssucharewa & Wolff, 1996) and heterogeneous phenomenon, arguably gaining prominence within general disability discourse in the last 20 years or so. This is due to an increase in both children and adults gaining a diagnosis (Müller, Schuler, Burton, & Yates, 2003), improved reporting processes from educational psychologists to schools (Hansen, Schendel, & Parner, 2015), more general awareness and recognition of autism aided by social and mainstream media (Hertz-Picciotto & Delwiche 2009) as well as advocacy and self-advocacy groups which have their roots in the civil rights movements of the 1960s and 1970s (Hurst, 1999, p26).

Reflecting improving understandings of autism, UK governments have slowly begun to implement autism specific social policies. The Autism Act (2009) was followed by the first autism strategy for England - *Fulfilling and Rewarding Lives* (Department of Health, 2010). *Think Autism* (2014) built on the 2010 strategy, emphasizing three key areas: building "autism aware" communities; promoting innovation in service provision; and providing integrated care. The Care Act (2014) also specifies that all staff who undertake

autism assessments must have appropriate training, and the Children and Families Act (2014) provides for special education needs and disability support systems, covering education, health and social care for autistic people. A review of the impact of the Autism Act (2009) occurred at the end of 2019, and the need and commitment to improve services for people with autism features in the 2019 NHS Long Term Plan including a new “digital flag” in patient records by 2023/24, to ensure staff know a patient is autistic; the provision of information and training to NHS staff to support autistic people. This will ensure reasonable adjustments are made so that wider NHS services can support autistic people; and the piloting of a specific health check for autistic people – to be rolled out more widely if successful. More awareness training of autism for social care staff also features in the pending Core Capabilities Framework for Autistic People (Skills for Health, 2019).

The rights of disabled people are enshrined in more global policies too. The European Convention on Human Rights Article 9 as ratified through the UK Human Rights Act (1998) requires “freedom of thought, conscience and religion” for “all persons” [our parenthesis] and United Nations Convention for the Rights of Disabled People [UNCRPD] (United Nations General Assembly, 2008), notably in article 5 (equality and non-discrimination) and article 21 (freedom of expression and opinion). These are important, as church members may be influenced by how disability is defined in the secular world (Webb-Mitchell, 1994, p23). Yet despite such changes, relevant guidance for any religious groups is not present in *Think Autism* (2014) suggesting access to religious or humanist groups as a lower priority to other areas of life (e.g. employment).

Religious communities have been found to act as conduits to social inclusion and community participation (Sango & Forrester-Jones, 2017). They also foster a sense of belonging, emotional wellbeing and spiritual nourishment (Baumeister & Leary, 1995),

with spirituality having been shown to play a meaningful part of disabled people's lives, including autistic people (Turner et al., 2004; Liu et al., 2014). Given that autistic people tend to experience smaller social networks (Forrester-Jones & Broadhurst, 2007; Johnson & Hanes, 2018) and limited access to community participation compared to the general population (Gray et al., 2014). Compared to the general population, churches can act as small scale communities may contribute to an autistic person's quality of life.

Yet despite the apparent importance of church life for some autistic people, exploration of attitudes towards autism and autistic people by church congregations is scarce. This is in spite of increasing academic interest in the area in the last decade. A scoping of relevant literature found that whilst studies exist regarding the experiences of autistic people and their families in churches (Howell & Pierson, 2010; Ault, Collins & Carter, 2013) few recorded the attitudes of churchgoers, and none explicitly refer to the UK. The few studies found originate from the United States (US) (e.g. O'Hanlon, 2013) which might not translate easily to UK contexts. Only ten papers found examined churchgoers' attitudes towards autism with six being empirical studies. Some cited rejection and/or misunderstanding (Howell & Pierson, 2010) whilst others reported positive experiences of church life (Liu, et al., 2014).

Patka and McDonald's (2015) study was the only one found to examine the personal perspectives of clergy (n=12 catholic priests) through qualitative interviews, though this specifically concerned intellectual disability (ID) rather than autism specifically. A mixture of attitudes emerged, including the idea that people with ID were "unfortunate innocent children" whilst at the same time being part of "human diversity" (Patka & McDonald, 2015).

## **Materials and methods**

Given the relative freshness of this topic, an exploratory design was chosen using qualitative methods of semi-structured interviews. The interview schedule, informed by previous literature, was piloted on three individuals (one minister and two churchgoers) and amended following feedback. The schedule was also modified throughout the interview process to allow ongoing interaction between data collection and emerging concepts (Charmaz, 2008, p90).

Since the study focussed on the Christian faith, a range of Christian church denominations in the South East of England were invited to participate firstly by emailing information about the study to church leaders followed by a telephone conversation. A purposive and convenient sampling approach was used whereby anyone who attended the churches was invited to participate through an announcement at church services or via word of mouth through the congregation (i.e. snowballing). No personal prior experience of autism in any capacity was required to participate though participants needed to be over 18 years old and have attended a church for at least 1 year. The authors were unknown at the churches to avoid recruitment bias based on prior knowledge of the participants or practices.

A favorable ethical opinion was granted by the University of Kent Ethics Committee (16<sup>th</sup> January 2017). Clear guidance was provided to all potential participants concerning the purpose, nature, risks and benefits, and voluntariness of the research via an information sheet and participants were asked for signed consent (which was kept separately from data collected) once they had indicated willingness to participate. All interviews were carried out in a private location of the participant's choosing (normally in their homes – the

kitchen or lounge, or in a café) and pseudonyms were used from the start of data collection to preserve participant's anonymity. Interviews (lasting between 25 and 55 minutes) were recorded and verbatim transcripts were kept on an encrypted protected folder on an encrypted protected computer where only the researchers had access. The first author also took field notes throughout the interviews of key points to help guide the changing interview schedule.

Originally developed by Glaser and Strauss (1967), grounded theory is a suitable methodology for where the researcher has personal experience of the phenomenon under study (Corbin & Strauss, 1990), and where a social process is being explored. Similar studies have followed the same methodology (i.e. Patka & McDonald, 2015). In keeping with the inductive and cyclical process of grounded theory, the findings emerged from the data with the researcher noting ideas for codes after the first interview. Corbin & Strauss (1990) argue that simultaneous data collection and analysis capture all relevant aspects of the research topic; an element of the highest importance with thick, rich data. The transcripts were repeatedly read by the authors to immerse themselves with the data. Memos, a vital component of grounded theory analysis (Corbin & Strauss 1990), were part of this process through to theory production. Open, axial and selective coding were undertaken as part of the analysis using NVivo to help manage the data set, with constant comparison of concepts, categories and finally themes occurring throughout to assure the themes were 'grounded' in the data (Charmaz, 2008, p100), and generalizability and rigor of the theory produced. The second author independently coded the transcripts and discussion between both authors concerning concepts and categories took place until saturation point was reached whereby no new concepts were arising. Five main themes were originally identified, but comments from the reviewers plus author discussions led us to collapsed these five themes into three.



## **Results**

Twenty-one participants were interviewed from congregations of four denominations of the Protestant Church in the UK including four ministers (one from each denomination) and 17 churchgoers: Anglican ( $n=5$ ); Baptist ( $n=3$ ); Methodist ( $n=5$ ); and Pentecostal ( $n=4$ ) aged between 25-79. The majority of participants ( $n=18$ ) reported knowing an autistic person, either through family or friends ( $n=7$ ), or their employment ( $n=4$ ) or church ( $n=7$ ). The majority of participants were women ( $n=13$ ) and over half ( $n=16$ ) were over 45 years of age, reflecting the national trend (of 55 years old) for UK churchgoers UK (Ashworth & Farthing, 2007). All of the participants identified as being white despite efforts to recruit a diverse sample. Whilst three main themes were derived from the data, we considered the subthemes and interconnection between them to be crucial in terms of how autistic people come to be regarded.

### **Main themes**

#### ***Theme 1: Different understandings of autism***

The study sample's understanding of autism, and therefore how autistic people were perceived by them appeared to be mainly derived by experiential knowledge and/or influenced by theological beliefs of disability (these two subthemes are discussed below). Such beliefs appeared to add a different dimension to the sample's understanding of autism than perhaps is common in the general population – hence the title of the theme.

#### ***Subtheme: Experiential knowledge***

Most of the participants reported that they as individuals as well as a church body knew very little about autism:

I don't know on that. It's as simple as that, I don't know (Leonard, line 143).

The church is very, very set in its ways. And there is so much that the church does not understand about people, and autism being one of the areas (Ben, line 97-98).

Those who claimed to know 'something' about autism reported that their knowledge was based on personal experience of autistic people they had known within various contexts including paid employment, family and friends, and church. Yet such experience was often patchy, exemplified well by Roberta:

I've had a little bit of autism [experience-sic] because I've worked in schools. So, yeah, so - we did have autistic children there (Roberta, line 11).

Roberta's comment - that she had 'a little bit of autism' experience - reflected the study sample's limited knowledge which also tended to be based on observations or "hearsay" and concerned disability in general. For example when asked specifically about autism Ben referred to blind people:

I've always known blind people, right from when I was a tot and we used to have a blind piano tuner, so... you know, I've always had contact with them and I've had friends gone blind so... I try and treat them equally (Ben, line 60-62).

Another participant, Chloe, cited the film *Rainman* as part of her information base, showing the role of the media and the importance of accurate or inaccurate representation:

I mean, we've seen Rainman, that was a film, but it was very educational in itself (Chloe, line 87-88).

Confusion was also reported as to the definition of autism, as described by Jack:

One - one of the problems I have um and you might be able to help me with that is - is in terms of... definition of autism and who's included in being autistic or autistic tendencies. It seems quite a wide parameter um, and I - and I think um that's one of the things I struggle with a little bit. (Jack, line 22-25)

Whilst all of the 21 participants stated that they understood autism to be an invisible disability, and as such, churches are likely to have autistic people among their church body, even if this factor is unknown to the congregation, there were clear misunderstandings around characteristics of autism as recounted by Poppy:

I suppose autism is something that been diagnosed in the not too distant future, isn't it? So, it's quite possible in my life as a nurse that I've come across more people, but... not that you've thought they've got a mental illness... but they are... um... but I suppose because of their lack of communication, you tend to think 'oh they're .... Um... well, I don't want to put... educationally subnormal but having difficulties, you know. My knowledge is not good. Not good at all (Poppy, line 49-54).

We are uncertain as to whether individual's the research study itself highlighted individual's awareness that they lacked knowledge of autism. Nevertheless, many participants reported a wish to know more about it - via training sessions, workshops and educators, as expressed by Zoe:

We, maybe in general... could be helpful for the congregation and maybe particularly the people who are, well... the welcomers and the people who pray - there are sort of set people like prayer people um and the ministry team, maybe to have some form of not training, but awareness raising um... and maybe a bit of training to... to help people to know how to approach those difficulties. Why, yes, there is always room for improvement. Something that would probably be helpful (Zoe, line 137-142).

*Subtheme: Theological understandings of autism*

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Participants' belief structures also appeared to define their understandings of autism and autistic people as well as their views on disability and illness in general. Yet no theological consensus across the group was evident and the extent of experiential knowledge did not appear to impact individual's belief structures. Whilst some participants reported how they took things at 'face value' others had a more nuanced and complex understanding of how Christians ideally *should* understand autism and engage with autistic people. Alternatively, some participants appeared to hold both viewpoints.

The phrase "guidance (from Christ)" was used by many individuals to illustrate how their beliefs guided their lives, including how they should view and interact with disabled

people, including autistic people. This was qualified by Stanley who stated that he was guided by New Testament Biblical teachings:

Obviously Jesus' command to love your neighbors as yourself. (Stanley, line 102)

The testimony of others also appeared to guide and shape some of the participant's views about autism. For example, Isabella explained how her autistic daughter's decision for adult baptism surprised her since she had not imagined that her daughter would publicly give a testimony of her faith:

I mean I never imagined that she would manage - you know, you've got the option in church with baptism whether you get the questions and answers or whether you give a testimony and she didn't even question it - she was going to give her story and it's just like... wow [...] But when she was talking to me about it, she said I can pinpoint um, the first real time we were walking to school and ... she said I was holding the pram and talking and um... you explained what it was because one of us probably asked or something like that and she said that's when I gave my life to Jesus ... and I said oh wow, that's amazing (Isabella, line 209-227).

Thus even with maternal experiential knowledge of autism, this mother - by virtue of her beliefs - had doubted the ability of her autistic daughter engage with a key aspect of traditional Christian practice. Other participants (n=8) demonstrated more

conservative beliefs by talking about disability as undesirable - linking it to historical understandings of the causes and treatment of disability, including demoniacs and 'spiritual healing'. Thus, Stanley stated:

Unless you think of the people possessed by demons. Sort of autism.  
Depends if you believe in the devil or not, which I do. But some people don't. They may think they're autistic or something, but I don't believe that (Stanley, line 106-108).

Here, Stanley clearly evokes a sense of spirit possession as synonymous with autism. In recounting an experience of praying for healing for an autistic individual and the rationale behind this, Josie also demonstrates her belief that autism can be prayed away:

I have friends in this church who have um, a really severely autistic grandson [...] it was heart-breaking but... I mean, and we prayed and prayed for healing, especially for the grandchild um, but to... but you have to trust that God is loving them in that situation (Josie, line 86-90).

Such 'traditional theological' understandings of autism identified from the interview data focused on the difficulties and struggles that autistic people may experience, as well as the challenge these presented to those around them especially in relation to socially appropriate behavior and awkwardness, as described by Jack recounting an autistic church member:

He has a thing, um, hugely able, but he has this thing: he only wants to play three Sundays in a month. Now, if there isn't someone to play on the fourth

Sunday in the month, he still won't play. Because he only plays three Sundays in a month. Um, now me, I think to myself, well if that was me and I've had a week between when I played last and when I'm playing now, I would've thought that that was enough space between the lot, I wouldn't be exhausted (Jack, line 190-195).

In the quote above, Jack highlights the difference between himself and his autistic church colleague. Eddie also expressed how autistic church members may be difficult to relate to:

Oh well, all you can do is offer it. If they can't accept it, it's difficult to get it into their heads. Autistic people are very varying degrees: some of them are more difficult than others. You know, sometimes it's almost impossible to get through to them that you care for them (Eddie, line 180-182).

Reflecting other interviewees, Eddie appears to think that autistic people are unable to understand or accept one of the fundamental underpinnings of the Christian faith - 'love your neighbor as yourself' (Leviticus 19:18 NIV). This view of autism then, is more concerned with the things that autistic people cannot do, and aligns with the medical model of disability; focusing on what is wrong with the individual. Yet, the right to inclusion and the fact that all mankind is equally loved by God featured in 14 of the interviews, as described by Shelby:

It's their church just as much as our church. It's their church, this is their place of worship. They have every right to come into church and worship, and I think we should open the doors to them (Shelby, line 199-201).

Thus, whilst Eddie's quote exemplified how many of the study sample perceived autistic people as having difficulties in understanding the fundamentals of a Christian faith, Shelby demonstrates how 'we' (the church) should still be 'open' to autistic people – almost as though autistic people were 'outsiders' of the congregation rather than inherently part of it.

Others in the sample (n=6 including all of the ministers), reported more nuanced beliefs; understanding autistic people to have individual differences just as humankind is heterogeneous, and that disability may not be necessarily chosen in a deterministic manner, as Jamie expressed:

I don't think that God sits there saying right, you're gonna have this, you're gonna have that (Jamie, line 59-60).

These individuals also reported how the theology behind their faith cannot only be argued one way, but in a multitude of ways, in the same way that the Bible can be interpreted in a number of ways, as described by Leonard:

I think the overriding issue is... um, because you, you can make a claim on scripture for anything you like in some ways, so you can argue it from all sorts of points of view, and some people who might be scripturally based may argue it very strongly (Leonard, line 113-115).

A sensitivity of the heterogeneity of views and how this could impact autistic individuals, their families and the autistic community as a whole was also expressed, as explained below:



I think I'd tread carefully in terms of how I would express that. If it was publicly on a Sunday in terms of calling people, I don't think I'd be saying 'come and be healed of autism', without some thought as to what I was saying. Just because of the effect pastorally on people (Ray, line 250-253).

These more nuanced beliefs linked to more positive theological considerations of autism, Isabella recounting her mother's gift for evangelism, gifted in part by her autistic traits and autism. According to Isabella, God can use disability to reveal God's glory:

My mum is a very good evangelist and she's often said to me "oh if I didn't have Asperger's and this, that and the other" and "oh, I just upset people" and I said "mum, God gave you that and you've always been so good at going, oh yeah". She's just a natural evangelist; she doesn't care what they think in a sense. So, you know, I said to her "it's a gift, it's a gift, it really is" (Isabella, line 187-191).

The interviews therefore revealed a mixture of understandings and perceptions around autism, informed by both experiential knowledge and theological beliefs. However, the extent to which autistic people were 'valued' was more difficult to decipher from people's responses, with only one participant Jack, making reference to it:

He is our main keyboard player. If we didn't have him, we... I don't know what we'd do (Jack, line 188-189).

## *Theme 2: Degrees of ableism*

Perhaps as a result of different understanding and perceptions of autism it was not surprising to find that participants reported a range of behaviors adopted by church members including themselves when faced with an autistic person; three subthemes (avoidance, uncertainty and embrace) were evident here though many participants reporting both types of behavior:

### *Subtheme: Avoidance*

“Avoidance” was reported as a consequence of judging autistic people because they were not “socially appropriate”. Whilst acknowledging that avoiding a fellow churchgoer could be detrimental to that person, there was also a view that such behavior was unavoidable:

I hope when families come in with children of different, you know all sorts of different children that they wouldn't feel sort of judged you know? And I, I know in the past, probably more years ago people going to church and almost being asked not to come back again with children (Amy, line 173-176).

Avoidance also linked to perceived social stigma of being autistic and/or having an autistic family member - Jamie explaining the reaction of some churchgoers when her autistic son sat in the church foyer after becoming “overloaded” (over stimulated by the surrounding environment) one Sunday:

Two ladies came past and they were telling him off while he was sitting there that he shouldn't be there and things and he couldn't get out the words

of: I'm sitting here, my mum's told me to come down um... and as I was coming down the stairs, they were like you're - you're being very rude, you're not even answering us (Jamie, line 239-242).

The example above also demonstrates negative assumptions about the capacity and capabilities of autistic people, which were made by 7 of the participants. This included the use of functioning labels, which do not promote understanding and acceptance of autistic people, but judge based on outward appearances:

There is one little boy [who was autistic] in particular who she used to hold as there was nothing else you could do, really didn't have much... functioning at all (Chloe, line 122- 124).

*Subtheme: Uncertainty*

Perhaps due to limited knowledge about autism, as well as stigma attached to it, many participants reported feeling uncertain as to how to behave towards autistic people, especially those with higher support needs. And perhaps because of this uncertainty, participants held different opinions regarding the extent of their responsibility for meeting an autistic person's needs in a church environment. Ray expressed concern for the parents carrying responsibility for their children, yet also described the church's responsibility of inclusion:

Some of the parents have struggled to bring their children for a season, say on a Sunday, because it's just too much work to manage them (Ray, line 82-83).

It should be um, a responsibility for the whole church to love one another, so if it's in people within the church community, then it's very clear that we should love one another (Ray, line 341-343).

Some participants reported that church members who knew little about autism and who were unsure as to how to react, might experience fear. This was illustrated by Chloe through her own reflection:

What you don't want is in churches is for people to avoid or shun somebody, just because they don't know how to deal with it as it's more to do with their fears than any sort of animosity or ill feeling towards the person who might have an issue or a problem (Chloe, line 220-224).

*Subtheme: Embrace*

This subtheme related to an acceptance of autism, autistic people and their differing needs and also the notion that individuals would want to make people feel welcome in church. Shelby spoke of her optimistic outlook she hoped her church would have when faced with such a responsibility:

I think we could cope. I think we could do it. I don't see why we shouldn't. I'm sure we could do it. We'd have to work at it, and plan it (Shelby, line 224-225).

Acceptance of autism was demonstrated to differing degrees, including accommodating an autistic person's needs and being respectful when talking about autistic people and their

families. Ray described how offence might be taken by some if autism is called abnormal and Rose spoke of the need to accept different people:

There are others who would be reluctant to even talk of it as being ... even being in anyway abnormal or to refer to it as that would be, would be offensive (Ray, line 451-453).

I suppose we sort of had to handle that, um... hmm my goodness, just to make it fair for everybody without favoring one person over another, but also accepting that some people need... treating in one type of way to make them [sic] comfortable (Rose, line 159-162).

These interviews enlighten a variety of behaviours that congregants reported to show in regards to autism; including welcoming (“embrace”) and unfavorable (“avoidance”/“uncertainty”) conduct. No consensus was found across the transcripts.

### ***Theme 3. Idiosyncratic Practice***

This theme refers to how each individual church was set up, how church services and house groups or community groups, were run, and how accessible these aspects of church life were perceived by participants to be to autistic individuals.

#### ***Subtheme: Mixed church activity***

“Mixed church activity” refers to how the church appeared to be organized and painted each church as unique and idiosyncratic, with potentially differing approaches to autism as a phenomenon. Lisa reported that she felt her church was fairly exclusive in this respect:

It was like they lived by the Bible but didn't actually ... live through it. Do you know what I mean? It was like because they've read the Bible, that's it with everything, but they didn't actually ... put, bring it into their lives. And make it a part of them. So they were like, quoting Bible scripture but it wasn't a part of them, do you know what I mean? So they weren't being kind to others, like were [sic] being judgmental and yeah, you know (Lisa, line 160-165).

Whereas Jamie outlined more inclusive practice at her church, through adjustments made for her autistic son:

They've always been very good at wanting to know and then they try and you know, when my son first gets there they'll tell him what the morning, for Sunday school, what's going to happen. Um, so he'll know the order that they'll, you know, if they're going to do games and have drinks and whatever, he'll know a little bit of the order which is going to happen (Jamie, line 264-268).

There was also an awareness of what churches could improve on though for many, the interview appeared to prompt them to think about this for the first time:

I hope that we would welcome all people. Your very asking of that question tells me that there may well be things that we do that do set up barriers (Nigel, line 144-145).

Ray also spoke of the underlying principle of how ‘people do church’, directly linking beliefs to outcome and demonstrating a link to the social model of disability:

I would say love. I would demand that people alter themselves a bit rather than making the person feel like they need to fit in with what the world may see as normal (Ray, line 351-353).

*Subtheme: Limitations and barriers*

In addition to differing practices regarding accessibility and inclusion of autistic people, and disabled people more widely, it was noted by some participants that the lack of guidance, guidelines or knowledge passed available from dioceses, Connexion (a nationwide umbrella organization and community of the Methodist Church of Great Britain) or equivalent organization, with very little church-specific information, was disseminated, potentially leading to a lack of knowledge and understanding. Leonard and Colleen both reported guidelines for physical accessibility and other areas, such as visual impairment, but no guidance for churches regarding autism:

If there’s anything that comes out of this that could actually benefit the church, um, then I’m more than willing to take it to other places as well. So, you know, we get recommendations for the hard of hearing, and the blind, um, and those in wheelchairs and that sort of thing, so um, so it’s good to understand something about that (Leonard, line 143-148).

I’m not sure there’s been input on any - not to my knowledge - of anything, I’m trying to think... you know, about from... apart from the fact that

people have to be aware of disability, um in this day and age and making sure practically that things are in place for disabilities, um... I don't think there's really been much in the way (Colleen, line 210- 213).

There was also a sense that, although each individual wanted to help church become more accessible for autistic people, in particular through being welcoming (n=10), that this might have been difficult to achieve and in some reports, unrealistic. Colleen spoke of the difficulties that her church might face in such a scenario:

I mean obviously we should be welcoming to... to people and I think people at [named church] would like to feel, I'm sure they would like to feel to be able to say that we are welcoming to anybody whatever their problems. But until it actually happens and then it is not as easy or straight-forward as... as people think (Colleen, line 229-232).

*Subtheme: No unified response*

The final subtheme of "no unified response" referred to the notion that church as an institution and the church body not being in a vacuum, rather how some reactions and outcomes may indeed be played out in the wider community. Jamie spoke of this in her consideration of other people judging an autistic person and accompanying family members while having a meltdown in a supermarket and how similar reactions may be gleaned:

I wouldn't say it's necessary down to the Christians who are at church, I think it's just down to - you could have the same thing in a normal cafe or



supermarket, people aren't always aware or you know (Jamie, line 282-284).

There was also the awareness that how churches do things may differ per denomination among other factors and even in the same denomination, as described by Colleen:

Well I should think they vary. They vary really. I don't have a lot of experience of other [denomination of] churches but I think it depends to a large extent on where they are, how big or small they are and what the makeup of the congregation is (Colleen, line 191-194).

The idea here was that any homogenous solutions adopted by churches would be inappropriate.

### ***Theoretical framework***

The themes described above appeared to interact together, creating a theoretical construct on the process of how attitudes towards autistic people may have developed and how this impacts church practice. Figure 1 shows this theoretical process diagrammatically. Theme 1 "different understandings of autism" has two subthemes: "experiential knowledge" and "theoretical understandings of autism". These two subthemes appear not to interact with one another (as previously mentioned) in regards to experience and belief systems impacting each other. These different understandings of autism influence congregants' behavior, encapsulated in "degrees of ableism" (theme 2). "Degrees of ableism" as a theme consists of three subthemes: "avoidance", "uncertainty" and "embrace". The subthemes, "avoidance" and "uncertainty" appeared to interact with each other. That is, difficulty with understanding and accepting autism seemed to

lead to withdrawal and isolation from autistic people. However, the subtheme “embrace” did not appear to interact with subthemes “avoidance” and “uncertainty” because of its opposed nature. Theme 2: “degrees of ableism” seemed to influence and inform idiosyncratic practice (theme 3). This may have been due to the impact of the emotional mindset of the leadership team in each individual church, also illustrated in figure 1. “Limitations and barriers” provided opportunity for “no unified response”, which in turn led to “mixed activity” across the churches. This mixed activity limited accessibility; reinforcing further limitations and barriers.

Commented [KW2]: Update to new themes and how they interact  
Update formulation

## Discussion

Commented [KW3]: Update to the new themes

The findings from this small-scale exploratory study indicate that current attitudes towards autism within a church setting appear to be mixed. Whilst some of the study participants clearly valued autistic members of their congregation, the extent of such acceptance (our first research question) appeared to be limited with other participants displaying pejorative attitudes. This reflects the mixture of experiences and perceptions of autistic people (our second research question) described in previous studies (e.g. Ault, Collins & Carter, 2013; Patka & McDonald 2015). This non-consensus of attitudes also gave way to a variety of attitudes on how accessible to autistic people churchgoers viewed their churches (our third research question). The process emerging from the data demonstrates to some degree, how knowledge and beliefs may influence attitudes and how autistic people may be treated in such contexts.

We found no evidence of knowledge of any guidelines or church-specific information or guidelines regarding autism, notably those written by Memmott (2015) “Welcoming autistic people into our churches and communities. Churchgoers expressed the wish for further training on autism in the subtheme “limitations and barriers”; mirroring participants’ requests in Howell and Pierson’s (2010) research of parental experience

of Sunday Schools. This further reinforces the notion that input to educate and positively change both knowledge and beliefs in churches is required.

The more 'traditional' "theological understandings" expressed by some participants overlap with findings from Patka and McDonald's (2015) study on priests' perspectives towards ID whereby a "deficient" narrative was found which included the concepts of demon possession in relation to disabled people, who needed to be fixed. Stiemke (1994) suggests that such adherence to the medical model acts as a barrier to accessibility for autistic Christians who view being autistic as part of their integral identity (Sinclair, 2013). Any association with "demon possession" understandably deprecates autistic people as humans, further devaluing them as people within the church and wider community. Allport and Ross (1967) found a higher rate of prejudice among churchgoers in the US in comparison to those who did not attend a church, in spite of the teaching and beliefs of inclusivity that have been reported and that are aligned with the Christian faith, for example the "Parable of the Good Samaritan" (Luke 10: 25-37, NIV). This mismatch of views and reactions will inevitably lead to a varied outcome and have a questionable impact on autistic people in terms of accessibility and inherent value. This is also highly contrasted to the neurodiversity movement (Singer, 1999), which is becoming more widely known in the UK, although dissemination is contained to select academic and self-advocate circles. In spite of this limited dissemination, Oliver (1999) amongst others, argues that by providing social spaces that are more inclusive of people with disabilities, the church will also become more open to the general population.

Linked to the accessibility through attitudinal barriers (as described by Carter, 2007)

and perceptions of value is the perceived stigma of being autistic or having an autistic family member. Previous research has shown both autistic people (Johnson & Joshi 2016; Sasson et al., 2017) and family members of autistic people (Broady, Morse & Stoyles, 2017) to experience stigma, echoed in Patka and McDonald's (2015) study regarding stigma by association. In our study, some participants also described autism as 'other' and undesirable, however this sense of stigma was perceived in relation to those autistic people who struggle with their environment, especially with those who could be perceived to have higher support needs.

Our study was small (21 participants), which means that the findings are not easily generalizable to all churches in all countries. However other qualitative studies of the topic area have similarly used small sample sizes (e.g. Patka & McDonald, 2015 (n=12); Broady, Stoyles & Morse, 2017 (n=15)). Small, purposively chosen samples are usually used in explorative, qualitative research, especially regarding specific naturalistic phenomena, to extradite rich and detailed data that would otherwise be missed with large sample sizes (Coolican, 2009, p224). Similarly, whilst the purposeful and convenient sampling approach we used risked gaining a homogenous sample (Emerson, 2015) and the potential for subjective bias in selecting potential participants (Etikan, Musa & Alkassim, 2016), when seeking an information rich sample, such as in this instance, a random sampling approach probably would not have yielded the information we wanted.

Perhaps the main limitation of our study was its restricted focus on religious institutions within the Christian faith, and in particular the Protestant Church (although Catholic churches were invited to participate, but declined the offer). The findings cannot therefore be regarded as representative of all sectors of the Christian church, or other

faith groups. Yet, limiting explorations of particular faiths in order to drill down particular phenomena is not unusual (e.g. Jegatheesan & Witz, 2013 in regards to a study of sibling relationships in Muslim families where there is an autistic child). The sample was also mostly female (8 males as opposed to 13 females) with no representation from black and ethnic minorities and so the sample cannot be said to reflect the whole churchgoing population in the UK; for example, 23% of Pentecostal churches are of ethnic majority (Ashworth & Farthing, 2007). Men and women may have had differing attitudes and experiences of autism, which might not have been observed. However, after much time and effort was spent attempting to recruit a wider sample, we felt fortunate to get our sample; one church who declined our invitation expressing a fear that potential churchgoing participants might “not know enough” or have enough experience of autism. Whilst with any study exploring attitudes, a Hawthorne effect (i.e. that attitudes of participants may have altered simply due to the research being carried out) may impact the findings, we do not necessarily think this occurred here, judging from participant’s quotes.

It is important to note the current climate of COVID-19 and policies of “social distancing” in the UK (Public Health England, 2020) versus the climate under which we collected the data. We understand church services are not occurring in the same format prior to COVID-19 in a physical, in person manner, rather online via conferencing software. We still believe our study to be relevant, as although some physical barriers may be alleviated by attendance via video conferencing, attitudinal barriers will still persist through online engagement with congregants and sermons, and in small group meetings. We also believe post-COVID-19 there is no reason why churches will not recommence physical, in person worship. Therefore, this research remains useful and of interest to church communities.

The first author's personal experience of being autistic and encountering limited understanding of autism and autistic people within faith institutions motivated the topic for this study. Given the first authors' personal experiences, as well as her personal Christian faith, she transcribed all of the interviews herself verbatim and kept a journal of field notes from interviews to avoid inherent bias and meet descriptive and interpretative validity (Maxwell, 1992).

#### ***Further research and recommendations for practice***

Our findings suggest that a church intervention about autism and autistic people would move some way towards enabling autistic people to feel more comfortable in church environments. Recommendations for further practice as a result of this study were created for the participating churches at the request of participants. Moving forward though, an intervention might include a preliminary workshop which would: define and explain autism; describe the lived experience of autistic people; and, provide the theological context of autism, in the knowledge that such an intervention would need to be co-produced by a researcher, church minister/s and autistic people. Since neither the Catholic church of Great Britain, nor independent churches were involved in this small exploratory study, its replication of this population would help generalizability of the findings. Whilst other faith groups were not explored in this study, such groups e.g. mosques, synagogues, temples and non-religious groups' endorsement of improving the knowledge of autism among congregations, led by ministers or leadership teams would be beneficial. This could be operationalized via co-produced basic and flexible guidance to meet the needs of different congregations, perhaps utilizing Memmott's (2015) national guidelines hosted by the Diocese of Oxford as a springboard.

This exploratory study unveils crucial information regarding the perception and value of autistic people in churches, an understudied setting and phenomenon. It illustrates attitudes towards autistic people in a church environment and theological context, as well as a sociological perspective and provides the first step for increasing inclusivity on a practical basis. In the words of John Swinton, as quoted by Father Bill Braviner (2018) at the Church of England Disability Conference at Lambeth Palace: “without the attitude being right, things won’t change. We must start by changing attitudes”.

### Declaration of interest statement

This research was unfunded.

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