The perceptions of persons with disabilities, primary caregivers and church leaders regarding barriers and facilitators to participation in a Methodist congregation

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Abstract

Persistent obstacles prevent persons with disabilities from participation in community life, including church activities. This article presents the findings of a descriptive case study, documenting the perceptions of three distinct participant groups concerning barriers and facilitators to participation in their Christian congregation. From a systems perspective, the findings verified that factors in their congregation's environment hinder, rather than enable, the participation of persons with disabilities. Necessary shifts in the conceptualization of disability that sustain exclusion, and the need to promote belonging and participation in the congregation, were indicated.

Keywords: church; disability; environmental factors; ICF; participation

INTRODUCTION

Although the societal inclusion of persons with disabilities is increasingly recognized and advocated, persistent systemic obstacles prevent their participation in all areas of community life (Breen, 2009; Carroll et al., 2018; Donohue & Bornman, 2014; Philpott & McLaren, 2011). Tacit exclusion is also mirrored in the shortage of literature on disability, particularly on the lived experiences of persons with disabilities within religious environments (Leshota, 2015). While available research confirms that persons with disabilities are familiar with exclusion in their own faith communities (Leshota, 2015; Möller, 2012), limited attention is given to exploring the experiences of caregivers and families with children with disabilities in these settings, and to the probing of contextual factors that may facilitate or hinder their religious participation (Ault, Collins, & Carter, 2013; Fischer, 2018; Simeonsson et al., 2014).

Addressing this shortage, this article presents the findings of a descriptive case study that narrates participant perceptions obtained from three respective focus groups, separately comprising persons with disabilities, caregivers of persons with disabilities, and church leaders from a Methodist denomination. Introducing a novel aspect to the existing literature is the current study's involvement of these three key stakeholder groups from the same congregation. However, since the issues discussed in this article are localized to the specific context of this study, this paper renders neither generalizable findings, nor any universally applicable theological, ecclesiological, or soteriological principles.

Apparent in the link between the way disability is conceived and the way persons with disabilities are treated, ideologies that underpin disability models construct society's perceptions about disability and the persons affected by it (Anderson, 2015; Davis, 2004; Retief & Letšosa, 2018). Despite the paradigm shift from the medical model's view of disability as an inherent defect within the individual to the social model's stance that disability originates within society and not as a result of impairment (Berghs, Atkin, Graham, Hatton, & Thomas, 2016; Simeonsson, 2009), literature still suggests considerable gaps in understanding the construct of disability accurately within unique socio-cultural contexts (McEwan & Butler, 2007). This is particularly relevant in addressing the religious exclusion of persons with disabilities in such settings (Creamer, 2012; Imhoff, 2017; Leshota, 2015). Accentuating the shortcomings of the definitions of disability proposed by the medical and social models of disability, McEwan and Butler (2007) and Raghavendra, Bornman, Granlund and Björck-Åkesson (2007) highlight that neither model can functionally describe disability in its own capacity.

Providing a more comprehensive and alternative definition, the biopsychosocial model – a fusion and further development of the medical and social models of disability – describes disablement as a result of the complex interaction between the individual and their physical and social environments (Berghs et al., 2016). The operative word being *interaction*, the biopsychosocial, or holistic, model of disability focuses on the whole experience of the condition, and thus effectually circumvents causal links between impairment and disability (Kazou, 2017), as the medical model does.

The International Classification of Functioning, Disability and Health

The rising influence of the social model's emphasis on the impact of environmental barriers, as well as increased activism by persons with disabilities themselves, have led to the development of the World Health Organization's International Classification of Functioning, Disability and Health (ICF) (Berghs et al., 2016; WHO, 2001), which is specifically named as such for its focus on health and functioning, instead of on disability only.

Underpinned by the biopsychosocial model of disability, the health and health-related domains contained in the ICF (WHO, 2001) are described on three levels of human functioning, namely body, individual and social levels, as it relates to a person's body functions and structures, and activities and participation. The term *functioning* represents the integrity of an individual's body functions and structures, successful execution of personal activities, and societal participation, while *disability* denotes impairments of the individual's body, limitations experienced in performing daily activities, and restrictions to participation in social life. Also describing the context in which individuals live, the ICF includes a list of *environmental factors* (a component of contextual factors, including features of the physical, social and attitudinal world), that interact with these components of functioning and disability with a facilitating or a hindering impact (Welch Saleeby, 2016b; WHO, 2001).

Considering the biopsychosocial model's integration of biological, psychological and social system elements into a holistic framework, the interactionist nature of the ICF is reflected in general systems theory. Accordingly, these system elements are understood to be interconnected and therefore do not operate independently, since the action of one system element is seen as reliant on the existence and actions of all the other elements, implying that the whole is larger than the sum of its influential parts (McDougall, Wright, & Rosenbaum, 2010; Wachs, 2000). The ICF thus appreciates an individual's functioning, disability and participation to arise from the interaction between their health condition and environmental factors (McDougall et al., 2010; WHO, 2001), and highlights the multidirectional nature of all components of health as interconnected, and influencing each other (Berghs et al., 2016). An individual's functioning is hence associated with factors that enable participation (facilitators), while disability is connected to factors that hinder participation (barriers) (WHO, 2001).

Unlike the limited academic disciplines represented by proponents of either medical or social models of disability, the biopsychosocial foundations of the ICF create a 'universal language' of disability, which transcends beyond disciplinary boundaries (Bornman, 2004; Simeonsson, 2009; WHO, 2002). This renders the ICF a useful tool in making the subject of disability accessible and receptive to influence by scholars from a myriad fields of study, including practical theology, still only nascent in respect to this topic (Leshota, 2015; Lid, 2017; Retief & Letšosa, 2018).

The ICF endorses participation in religious or spiritual activities as an important life area that promotes improved levels of functioning (WHO, 2001). Participation in the ICF is defined as *"involvement in a life situation"*, which incorporates *"taking part, being included or engaged in an area of life, being accepted, or having access to needed resources"* (WHO, 2001, p. 15). Central to this case study's focus on disability inclusion within a specific congregation, is the construct of participation, as outlined by the ICF. The term *participation* thus pertains to the definitive **positive** outcome that is to be achieved from being included in this setting.

The aim of the study was to determine and describe the perceptions of three participant groups (persons with disabilities, caregivers and church leaders) regarding participation barriers and facilitators experienced by persons with disabilities in the ceremonies, activities and events in their congregation. Four sub-aims delineated the study’s main aim, namely i) to explore and describe what the participants regard as ceremonies, activities and events in their congregation; ii) to determine the participants’ perceptions regarding barriers to the participation of persons with disabilities in the identified ceremonies, activities and events; iii) to describe the participants’ perceptions regarding facilitators to participation of this population in the identified ceremonies, activities and events, and iv) to explore whether the participants’ perceptions could be linked to the contextual factors outlined in the ICF.

METHODS

Research design

A qualitative, descriptive case study design using three different focus groups was employed, as focus groups are particularly effective to capture the distinctive features of the participants’ natural context (Qi, 2009), since the interaction between participants encourages them to query and explain, allowing their reasoning to appear (John, Knott, & Harvey, 2018). Furthermore, it produced a detailed account of the previously unexplored experiences and perceptions of disability inclusion and participation within this community of people (Leedy & Ormrod, 2015; Naudé & Bornman, 2018). In coherence with this design, a limited number of participants from a specific geographical area , were included in the study. Instead of focusing on disability inclusion in the Church in general – which is too broad for a case study that does not aim to generalize its findings to the wider population (Leedy & Ormrod, 2015) – the focal point of this study was narrowed down by restricting it to a specific Methodist congregation familiar to the researcher, as a 42-year old, non-disabled female member of the selected congregation.

Context

The selected congregation is situated in an affluent residential suburb in the north of Johannesburg, South Africa, positioned on a built-up campus stretching across three sizable plots of land, including four additional adjacent clergy manses owned by the congregation. The congregation is attended by individuals and families who reside in the area, as well as neighbouring suburbs and townships. At the time of the study, 3800 members were listed on the congregation's data base. In the sanctuary with a seat capacity for 800 people at one time, a total of 950 people attend the congregation on a Sunday, where multiple services are conducted at five different times on the day. Additional programming and ministries occurring during the week is covered in the section presenting emergent themes. In addition to material amenities and facilities, the congregation is serviced by four ordained clergy and four pastors, as well as 38 full-time support staff members, all salaried, and is further resourced by volunteers. Dedicated to its purpose of poverty alleviation and social justice, the congregation prides itself on its language, cultural and race diversity represented in its membership.

Sampling and recruitment

Non-probability, purposive sampling was used to recruit participants for the three distinct participant groups from the same congregation: Group 1 included persons with disabilities, Group 2 primary caregivers of persons with disabilities and Group 3 ordained clergy, pastors, society stewards and other individuals representative of the congregation’s leadership. From this suitably accessible homogeneous context, individuals considered to yield the most information about the topic of disability inclusion and participation were included in the study (Naudé & Bornman, 2018). For participants for Group 1, the study originally proposed to include participants with disabilities from a nearby adult residential care facility, who regularly attend events at the congregation. Permission to recruit participants from the residential care facility was denied. No specific reason was provided. It was then decided to recruit participants for Group 1 in the same way as for Group 2.

For participants for Group 2, additional permission was given by the church leadership to formally invite caregiver participants, as well as participants with disabilities from the congregation. This was arranged by allowing the researcher opportunities to address the congregants in person at the various Sunday services, where written information about the study was also projected electronically. In addition, the researcher handed out information flyers at the doors, as well as displaying these on the notice boards in the church foyer. After an initial poor response of interest, follow-up invitations were printed in the church bulletins for two consecutive Sundays, and included in the congregation’s newsletter, reaching a wider population of potential participants. Some of the caregiver participants and participants with disabilities had not been attending the congregation during the period when participants were solicited, but were notified of the study by means of the church’s communication network or by family members. Some participants were directly approached by the researcher and invited to participate.

Some participants for Group 3 were proposed by the participant clergy member who granted permission for the study. Upon contact with these initial participants, more participants were nominated by them. These, as well as additional participants identified by the researcher, were then approached and invited to participate.

Participants

Participants were considered to best portray the characteristics of the larger population they represent, based on their knowledge and ability to describe disability inclusion and participation with the unique perspectives they brought regarding their own context (Leedy & Ormrod, 2015). Information obtained from three custom-designed biographical questionnaires made it possible to describe the heterogeneous participants comprehensively according to personal characteristics.

Group 1: Participants with disabilities (n=6)

The six participants from the group for persons with disabilities were diverse, with an age range between 30-75 and different education levels. Their diagnoses, duration and severity of their health conditions, as well as the difficulties they experience as a result, also varied somewhat. Two participants had Parkinson’s Disease, whereas the other participants’ disabilities included Cerebral Palsy, Epilepsy, Deafness and Major Depressive Disorder. While two participants were born with their disability, two others’ were acquired during childhood, and two later in adulthood. Two participants described their disabilities as severe, three as moderate and one as mild. Difficulties associated with their disabilities include physical, neurological, sensory, cognitive and psychological challenges, such as difficulties with mobility, tremors, seizures, hearing, impaired concentration and memory, and anxiety. All participants indicated that they must manage their conditions with medication, assistive devices and/or psychological treatment. One participant, who is Deaf, made use of an assistive listening device during the focus group, which allowed sound to be transmitted to his hearing aid through wireless Bluetooth technology. This enabled him to hear and interact with everyone during the discussion.

All participants, apart from one who is isiXhosa-speaking, share English as a home language, and one participant also uses South African Sign Language. The one Black and five White participants in this group – two of whom were male – are all affiliated to the Methodist denomination as full members of the congregation in this study. One participant is relatively new to the congregation, while all the other participants have attended this church for a period between 20-32 years. While five participants can travel to and from church independently, one participant relies on a lift for transport.

Group 2: Caregiver participants (n=3)

The three caregiver participants included one Black and two White, English-speaking females, ranging between 43-76 years of age, with diverse education levels. They are all primary caregivers of a person with a disability, who, themselves and the persons in their care, have former and present connections to the congregation of the study. Varying in the duration of fulfilling their caregiving roles (11-40 years), two participants are each the parent, and one the spouse, of the three represented persons with disabilities. The persons with disabilities in their care are between 11-79 years old, with physical, neurological, congenital and developmental health conditions. Diagnoses include Diabetes, Parkinson's Disease, Autism Spectrum Disorder, Generalized Anxiety Disorder and Down's Syndrome, involving challenges associated with mobility, speech, developmental delays, learning and behavior. While all these disabilities were described as moderate in severity, the level of difficulty experienced by each person in their care, and the extent of caregiving required, differ somewhat. The duration of the caregivers' own association with this congregation, as well as that of the persons with disabilities in their care, range between 8-36 years. Only one represented person with a disability attends additional church-related activities apart from Sunday services, but does so at another congregation.

Group 3: Church leader participants (n=8)

The profile of the eight church leader participant group contrasted in terms of education levels and age, with participants ranging between 30-60 years old. The group consisted of five female and three male, mostly White, English-speaking participants. Two participants have additional home languages of isiXhosa and Afrikaans respectively, while one participant's home language is Setswana. The church leaders' length of service in this congregation (at most 12 years), is relatively brief compared to the duration of membership and attendance of some of the participants in the other two focus groups, making this a comparatively new leadership team. All but one of the church leader participants indicated that they were aware of persons with disabilities in their congregation. Two participants have family members with a disability, while six participants indicated that they have had some experience with persons with disabilities.

Ethics procedures

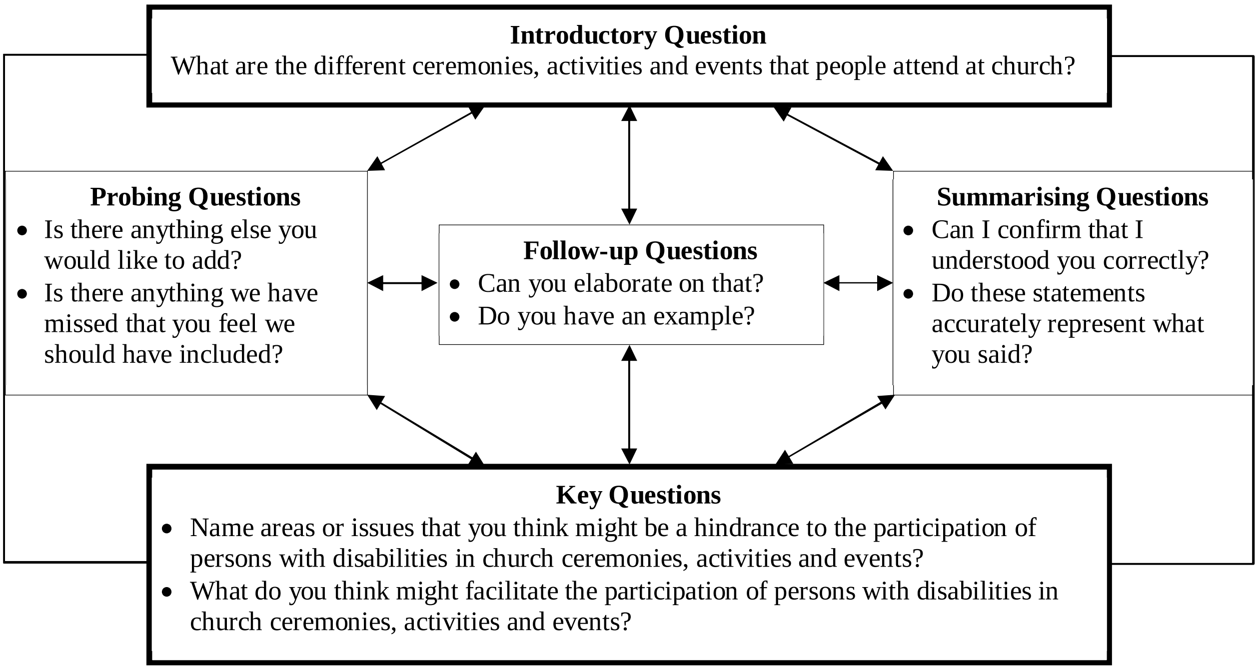
Ethics approval from the relevant university was obtained before participation was solicited. All procedures were in accordance with the ethical principles of the most recent amendment of the Declaration for Helsinki (World Medical Association, 2013). Accordingly, prospective participants received sufficient information in the consent forms concerning the nature, purpose, procedures and duration of the study, as well as specific details about their expected participation and the safekeeping of the data. Thus, participants were able to make informed judgments as to whether or not they wanted to participate. Those who agreed were reminded that their participation is voluntary and that they could withdraw from the study at any point without negative consequences. Informed consent for participation and permission for the audio-recording of their contributions were solicited in writing before data collection, whereupon participants were invited to join in the proceedings. Along with verbal announcements, a written statement concerning confidentiality was included, guaranteeing the elimination of identifying information from the transcripts, dissertation and any potential ensuing presentations. The researcher’s name and contact details were also issued should any questions arise about the study. Permission was granted by the congregation to use private meeting rooms on its premises and subsequently, all the focus groups were held on the church campus.

Data collection

Following the ethics procedures, data collection commenced. Before beginning the main study, the methodology and research instrument was pilot tested to ensure that the study delivered the findings intended by its aims. Two significant changes were indicated, namely the need to clarify the meaning of disability, as used in the focus group script, to promote broad thinking on the topic, and to employ an assistant as a note-taker (McMahon-Panther, 2019; Prior, Waller, & Kroll, 2013).

The focus group for the participants with disabilities (Group 1) was held first and continued for two hours and one minute, while the caregivers' focus group (Group 2) lasted one hour and twenty-five minutes. These two focus groups were conducted in the same venue, on the same day (Saturday), one in the morning and the other early in the afternoon, for a number of logistical reasons, including the availability of the participants, the note-taking assistant, and the designated venue. In addition, this arrangement served as a measure to prevent participants from these two groups conversing and potentially influencing each other, especially since the researcher was expecting relatives and spouses in each unit. Moreover, given the church context, some of the participants in these two groups knew each other, and may otherwise have shared their experiences with one another before the next focus group could be held. Given that the focus group with church leaders (Group 3) was arranged on a week-day evening after work on a day and time most suitable for the participants, the same venue that was used for the first two groups was not available. Despite the different venue used, a similar set-up was achieved. This focus group lasted one hour and forty minutes.

At the start of each focus group, all the participants completed biographical questionnaires. Building rapport from the outset, the researcher, seated among the participants in the role of moderator, facilitated the participants' discussions, while a note-taker captured important discussion points on a flipchart, which stimulated the participants' ideas (Naudé & Bornman, 2018; Prior et al., 2013). A custom-designed, pre-prepared focus group script was used, consisting of semi-structured, open-ended questions. The structure and flow of the verbatim questions is shown in Figure 1.



Introductory Question
What are the different ceremonies, activities and events that people attend at church?

Probing Questions
- Is there anything else you would like to add?
- Is there anything we have missed that you feel we should have included?

Follow-up Questions
- Can you elaborate on that?
- Do you have an example?

Summarising Questions
- Can I confirm that I understood you correctly?
- Do these statements accurately represent what you said?

Key Questions
- Name areas or issues that you think might be a hindrance to the participation of persons with disabilities in church ceremonies, activities and events?
- What do you think might facilitate the participation of persons with disabilities in church ceremonies, activities and events?

Figure 1. Structure and flow of the focus group script questions

Figure 1 shows how this method effectively explored the perceptions of each participant group based on their own interpretations of barriers and facilitators to meaningful participation in the ceremonies, activities and events in their congregation. To prepare and stimulate the participants' thoughts for the main discussion, an introductory question was posed prior to asking two key questions, which were founded upon the research question, respectively concerning barriers and facilitators to the participation of persons with disabilities in church-related activities. Probing and follow-up questions were used throughout to encourage further sharing among the participants and to perpetuate the discussion. The researcher tracked her summarising statements with further questions, which functioned as member checks during, and at the end of the discussions.

The researcher meticulously followed the same script and format for all three participant groups, ensuring that all participants received the same questions to maintain uniformity in the procedure and thus obtain consistency in the findings. Response validation from participants, (i.e. member checks) ensured the accuracy of the information, where the participants had an opportunity to verify whether or not the researcher's impressions match their words and what they intended to communicate (Naudé & Bornman, 2018; Shenton, 2004). The audio-recordings were transcribed verbatim for the purpose of data analysis, after which a summary of the main points was also sent to the participants via email for further member checking.

Trustworthiness

Trustworthiness was secured by considering *credibility* (internal validity), *transferability* (external validity / generalizability), *dependability* (reliability), and *confirmability* (objectivity) (Guba, 1981; Shenton, 2004). Credibility was achieved through obtaining unfiltered participant responses, and using data triangulation, member checking and reflective annotations to demonstrate that the findings of the study are a true picture of the participants' real-life situation. Through rich portrayals of the participants' context and views, as well as detailed descriptions of the data collection and analysis procedures, ample details of the context of the study rendered the findings transferable for other researchers and readers to apply it to their own situations. An extensive description of the research design and procedural implementation ensured dependability, enabling other researchers to repeat the study. By introducing audit trails, the process of data collection and analysis was authenticated, and confirmability established, which validated that the study's findings emerged from the data and not from the researcher's own biases. Accordingly, before the transcripts were analyzed, a process of authentication was initiated by having the audio-recordings and transcriptions checked by an independent proof-reader, who verified the consistency in the focus group procedure for all three groups, as well as the accuracy of the transcriptions. This was done by reviewing 20% of randomly selected verbatim transcriptions of the audio-recordings, with 100% agreement.

Data analysis

The data was first analyzed through open thematic coding applying an inductive approach, to ensure that meaningful patterns in the data were accurately identified, analyzed and conveyed, using Braun and Clarke's (2006) rigorous and well-documented six-phased framework as a step-by-step guide for conducting thematic analysis, so as to arrive at a truthful and persuasive account and interpretation of the information.

Once the inductive thematic analysis process was complete, the deductive phase of coding followed, to describe the data in relation to the theoretical framework of the study, the ICF. To enhance trustworthiness of the linking results, this procedure was executed by employing Cieza, Fayed, Bickenbach, and Prodinger's (2019) most recently revised linking rules as guidelines to direct the process of connecting meaningful concepts in the data to the ICF. Accordingly, all the pertinent ICF environmental categories and codes represented in the participants' perceptions concerning barriers and facilitators to the participation of persons with disabilities within their congregation, were documented. Given the study's aim to identify and describe the presence or absence of barriers and facilitators, and not the degree, no qualifier codes were applied to establish or indicate the extent to which the identified barriers and facilitators in any of the categories were perceived as such. Therefore, by applying an interpretive approach (Cieza et al., 2019), meaningful concepts in the data were frequently linked to more than one ICF code and category to ensure that the full range of connections between the data and the environmental factors was recorded (McMahon-Panther, 2019).

FINDINGS

Before presenting the derived themes, a descriptive backdrop is staged, portraying the observed subconscious affective displays that appeared to underlie the participants' perceptions and determined the emotional climate within each focus group.

Reflective annotations

High in energy and quick in tempo, the focus group for persons with disabilities was characterized by lively conversation. Rising solidarity among the participants seemed to relieve the early apprehension and encouraged the sharing of personal accounts. *"I'm exactly like her. Two peas in a pod"* (P1-6), marked the end of one participant's initial nervousness and reluctance to speak out. An air of annoyance and resentment toward the congregation's leadership filled the somewhat tense atmosphere, where a demoralised 'been there, done that' disposition swayed the group toward cynical expressions, as uttered in this example by one participant, whose recent experience mirrored that of her fellow participants' own thwarted attempts at changing the current system: *"But you see on that perspective, also, if going to someone sometimes doesn't help… I spoke to every minister, I spoke to [Name], I spoke to everybody. Eventually we stopped coming to church"* (P1-4). As the discussion developed, further laments continued. Yet, growing anticipation among the participants seemed to give new impetus to instigate the desired changes in their congregation, and motivated the following statements: *"…I'm glad there's another focus group coming up about the ministers, so everything that they need to talk about, but also what we feel of these things and they don't know"* (P1-2), and, *"…I mean, you're going to collect your data but for us, this has started. When you do your research, hand it in, I'm not that patient to wait for your research to come* *in… So, the fact that you've spoken to us [clicks fingers], I want movement… I want action"* (P1-1).

Although no less engaged in the discussion, the caregiver participants were less animated in offering their contributions. In contrast to the mood in the focus group for persons with disabilities, the caregivers exuded a longsuffering acceptance and tolerance in the tone with which they shared their personal experiences and perceptions, without any sense of agitation or reproof. For instance, one participant's observation, *"…people who don't have those problems don't understand…and they don't tolerate it"* (P2-3), was made not with indignation, but instead with an empathic understanding of people's typical misconceptions of disability. The same spirit was evident in the next two comments, where two participants recalled times when they themselves were once unaware and inexperienced regarding disability: *"…'Cause people are not aware. I wasn't until I got my child. I wasn't, so I'd look at them as naughty children"* (P2-1), and, *"I also taught. I had a child with dyslexia in my class. I had no idea how to handle her; I hadn't been trained… Now, I always go back to my daughter 'cause she's the one I understand."* (P2-2). While the caregivers extended empathy to ill-informed church leaders and congregants, they were still forthright in revealing the ensuing challenges they face in a system seemingly unmindful of disability. Dimmed by the failures of a faith community from whom they presumed support, the caregiver participants did not have the same urgency and expectancy for change as the participants with disabilities.

Well acquainted with one another, as well as with the dynamics of their congregation, the church leader participants were high-spirited and took a light-hearted, yet considered approach to their discussion. Compassion was stirred up and expressed in an *"ag shame"* chorus, followed recurrently after one participant shared his personal encounters with persons with disabilities. As the conversation progressed, reminders of their own good intentions and perceived incapacity to meet all the needs of persons with disabilities in their congregation seemed to prompt feelings of frustration and helplessness in offering them the affordance to access and participation. The impression of self-defence in the notion that their hands are tied, is implied in the following example: *"Um, it would be nice if they came and told me 'cause I might be able to do something about it… there are people sitting in those pews that we don't even know are disabled in some format… but as I've said before, it's not because we don't wanna help… we have tried very hard to fix that"* (P3-1). With most of the church leader participants being relatively new to the congregation – compared to the lifetime most participants from the other two focus groups have been in attendance – the church leader participants appeared to feel burdened by challenges they inherited from the previous leadership, and that with ever-diminishing resources to make the amendments they deem necessary.

The above descriptions bring together different elements from the three diverse participant groups, each playing an equally important part in the overall functioning of their congregation as one faith-based system. Moreover, it informs how the actions of one part of this system is reliant upon and influenced by the actions of all the other components within the system, highlighting that the whole is indeed greater than the sum of its parts.

Thematic structure

The data from the three focus groups was integrated and significantly reduced to capture the essence of the findings, whilst still providing a comprehensive account of the participants' perceptions. The findings are presented according to the four sub-aims of the study.

Ceremonies, activities and events in the congregation

Several areas for participation in what the participants regard as ceremonies, activities and events in their congregation were identified. The participants' responses were coded and grouped into seven categories, and are presented in descending order consistent with the number of comments pertaining to each.

The first category, *spiritual practice and formation*, cover weekly and liturgical services at the congregation, as well as small group activities like Bible studies. In the second category, *church ministries*, community outreach programmes, pastoral care services, and support groups were identified. *Social and recreational activities* as the third category, contains monthly social gatherings, leisure and sport activities, and fund-raising events. The fourth category, *general ceremonies, rites and sacraments*, comprise weddings, funerals, confirmation, Baptism and Communion. *Organizational meetings* represented a fifth category, including annual general meetings, and gatherings for women's and men's Methodist groups. The sixth category, *education and training*, involve workshops, courses, seminars and conferences. Finally, *public and workplace activities* incorporate the use of the church amenities for public hire, workplace activities in the offices, and the pre-school on the church premises.

Emergent themes

Sub-aim 2 (focussed on barriers) and 3 (focussed on facilitators) are addressed jointly. The participants from each focus group identified many participation restrictions to the identified ceremonies, activities and events. Unanimously, all the participants from all three focus groups concluded that their congregation is generally not disability-friendly and acknowledged the need to reform the status quo. In response to the question regarding facilitating factors, the participants in all three focus groups appeared to struggle to veer their thoughts away from the many barriers they identified. Their views about aspects that they initially considered as existing facilitators, soon changed as they recognized that the said enablers were in fact insufficient in meeting the needs of persons with disabilities. They subsequently stipulated many conditions for inclusion and meaningful participation and offered suggestions for improvement.

Pervasive throughout the data corpus, four predominant themes, with a total of nine sub-themes, were identified during the thematic analysis. While the themes are interrelated and entwined, the first and overarching theme, from which all the others seemed to develop, is that of *Social Status*. The second theme is *Addressing Needs*, followed by *Awareness and Understanding*, and *Access* as third and fourth themes respectively. These main themes, each delineated in relation to the specific context of this study, are outlined in Table 1, including their respective codes and sub-themes (indicated in italics), and concise data samples relevant to each.

Table 1 portrays the progression of the data reduction process and the refinement of the inductive thematic analysis, showing extracts from the data, as well as the codes and sub-themes from which each of the four main themes were derived and defined. Together, these themes encapsulate the participants' perceptions in response to the study's research question. The themes included perceptions concerning the social standing of persons with disabilities, aspects related to addressing their needs, disability awareness and understanding, as well as access to physical spaces and resources within their congregation – all considered to have a significant effect on the involvement and participation of persons with disabilities. From here onwards, each theme is presented individually, including more detailed verbatim data excerpts that illustrate the pertinence of each theme.

Theme 1: Social Status – Frequently referring to their awareness of being different, and that persons with disabilities do not conform to the so-called norm, the participants in the groups for persons with disabilities and caregivers presented themselves as the underrated minority and reported feeling outweighed by a substantial majority in respect of the numbers, value

Table 1. Theme Development and Descriptions

Themes and sub-themes	**Codes**	**Data extracts from the three participant groups** (P1 = Persons with Disabilities; P2 = Caregivers; P3 = Church Leaders)	**Theme description**
Social Status *Conformity* *Belonging* *Reciprocity* (73 Comments)	Majority rule	*"We're a minority"*; *"…'cause you're different"* (P1-1)	Guided by underlying conceptual models of thought, social status refers to the sense of worth and agency bestowed upon an individual based on their level of conformity to the set norms and identity of the congregation, their perceived membership, as well as their perceived benefit to the congregation (Brock, 2011; Cabrera et al., 2015; Meininger, 2008; White, 2014).
	Mainstream criteria for inclusion	*"…they never thought about what I need, or you need…"* (P1-2) *"…they had a child who was autistic and could…not sit still… So, we then made a plan for them to go to a different venue…"* (P3-3)	
	Fitting in	*"… where do we fit in?"* (P1-2)	
	Dependent minority	*"...come to us if you have needs that we can meet for you"* (P3-4)	
	Mutual benefit	*"Those with disabilities teach those with abilities. Each benefits"* (P2-2)	
Addressing Needs *Communication of needs* *Accommodation of needs* (121 Comments)	Ownership to reveal needs	*"But anyone with a need…you identify yourself…if you don't, there's nothing that can be done for you"* (P1-1)	Aspects of ownership regarding the communication and resulting accommodation of personal needs (Bell & Clegg, 2012; White, 2014).
	Asking for help is futile	*"I spoke to everybody…"; "…eventually, you'll keep quiet"* (P1-4)	
	Uncovering and meeting needs	*"…we don't always know…what their needs are"* (P3-4)	
Awareness & Understanding *Social constructions of disability* *Education* (150 comments)	Stigmas related to disability	*"…the congregational reaction to the person…can be a deterrent to whether they want to come back again"* (P3-4)	The level of awareness and understanding of disability as a result of oblivion, socialization and stereotypes, the impact it has on interpersonal relationships, and ways to increase awareness to promote accurate understandings of disability (White, 2014; Yong, 2009).
	Raising awareness through education	*"…the way to deal with the ignorance is to educate"* (P1-2)	
	Personal transformation	*"… there's education and awareness, and then there's actual experience…and our own personal work"* (P3-7)	
Access *Accessibility of the physical environment* *Access to necessary resources* (152 Comments)	Restricted access on church property	*"I don't think the church is geared for wheelchairs"; "They've got odd ramps here and there, but…not all over"* (P2-3)	Includes the accessibility of the physical environment of the church premises within which ceremonies, activities and events occur, as well as the affordance of access to the necessary means to enable involvement and participation, including technological, financial human and transportation resources (Bell & Clegg, 2012; White, 2014).
	Technological resources	*"…control the technology and make sure it works"* (P1-2)	
	Financial resources	*"…we didn't have the bucks to spend…on a proper loop system"* (P3-1)	
	Human resources	*"…it's very difficult to get volunteers"* (P2-3)	
	Transport resources	*"I can't drive"* (P1-4)	

and power they occupy within their congregation. For example, a participant with a disability remarked, *"I think the problem is more of…'there is one or two people with the problem. We've got 300 in the service, so when it affects 50 or a 100, we'll look into it'…"* (P1-4). A comment from a caregiver participant echoed in accord: *"I mean, are you going to get a person to come and sign the services for five people? Or 10 people? …Are you going to do a whole…new electronic system to facilitate…five people?* (P2-3).

Concerning the accommodation of their differences and needs, further expressions among the participants with disabilities and caregivers revealed a general sense of being disregarded, as a participant from the group for persons with disabilities frankly captured her own and her fellow participants' perspectives: *"It's a 'majority rules and minority'; it's not a 'stuff you', but it basically boils down to that… 'you're in the minority, so…we'll kind of ignore it and hope the problem goes away, or you sort it out yourself'…"* (P1-4). A caregiver participant confirmed this stance from her own viewpoint as she shared how her son's needs are overlooked, which led to his reluctance to attend children's church because he is unable to join in with the usual activities: *"…in terms of just the concentration, …you have to do certain things over a prolonged period, yet his concentration…span is quite short… After 15 minutes, it's just too long, then he needs to do something else. So obviously that's structured in a way for people without any disability… the problem is that it caters for only mainstream"* (P2-1).

Concerning sentiments of participation being contingent on imposed conformity, all three participant groups also discussed social norms and attitudes operative in their congregation that tend to highlight the misfit between conduct considered socially appropriate and behaviors exhibited by persons with disabilities, that do not conform to those standards. A statement from a participant in the group for persons with disabilities epitomizes this perception: *"They've got a lot of church decorum…'Cause they've got a lot of expected* *behavior of the person in the church"* (P1-1). This comment was preceded by another participant in the same group, who described the disapproving glares she receives from congregants' in reaction to her attempts to prevent the impending onset of a light-induced epileptic seizure owing to camera flashes during some services: *"It's like when I put my sunglasses on in church sometimes during the Baptisms…and people look at you as if to say 'what are you doing?'…but people don't understand that there might be a legitimate reason… and what happens is…I'll go out…"* (P1-4). A caregiver participant represented her groups' view by saying, *"…if there's an autistic child that has an episode in the middle of Sunday school, the other parents would have quite a lot to say about it, I'm sure"* (P2-3). Referring to her son's widely misunderstood behaviors, another caregiver participant explained that he *"…acts in a way that he'll have everyone going, 'what's happening'?"* (P2-1). A church leader participant denoted her group's stance as follows: *"Our programmes… necessarily have moments of silence, which can be problematic for people who are unable to keep quiet. Um, it draws attention to yourself if you are unable, either physically or psychologically, to keep quiet in moments of silence. People notice that. Um, which can be a deterrent 'cause it can make you feel like you're disturbing people… It's behaviour that doesn't always meet the requirement of that particular moment"* (P3-4). Referring to the involvement of children with special needs in the congregation's current setup for children's church, a caregiver participant candidly noted, *"They can't really be integrated with the other children"* (P2-3). An example of this situation was illustrated by another caregiver, who explained her child's situation as follows: *"For some of the services, I have to take him with me because he'll be complaining that 'there's too much noise, they're making too much noise'… he was saying he doesn't want to come to church"* (P2-1). A related comment by a church leader participant corroborated this scenario, when she explained how a child in her care on Sunday mornings is excluded from the group because the *"…worship songs…are* *loud and they're active and it makes him feel very uncomfortable… he has to go and sit where it's quiet"* (P3-4).

Participants from the group for persons with disabilities also questioned their worth after enduring incidents of scorn: *"I even got joked at"* (P1-4), as well as their sense of belonging, on account of their basic needs not catered in their congregation: *"…my question is, why am I here?"* (P1-2). Sharing experiences of rejection, others' lack of understanding and acceptance, as well as their fears of judgement toward their own differences, and that of the persons in their care, participants from the focus groups for persons with disabilities and caregivers have respectively alluded to their desire for increased involvement in their congregation's activities and a deeper sense of belonging, as encapsulated by these statements: *"I'm very ambitious about going up the ranks of church leadership and I sometimes worry that my disability will get in my way"* (P1-1), and, *"…we end up not attending a whole lot of things. You see in church we only come for Sunday, because I'm thinking, 'God, if I come for this, then, what do I do to my child?' Can't even attend the sports because he'll be running around… I mean, we've had nasty experiences, so we prefer to be home"* (P2-1).

Theme 2: Addressing Needs – One of the main reasons offered by the church leader participants as to why basic needs remained unmet, is that persons with disabilities and caregivers *"don't always…take active responsibility for their needs and say, 'I have these problems, and these are the things I need'…"* (P3-4). The same participant later added, *"…some of the problem is…we don't always know who's sitting in church and what their needs are… I mean, I don't know because nobody ever says anything"* (P3-4). The participants with disabilities broached this subject from an entirely different angle. Although they acknowledged the importance of conveying their own needs, they expressed that sharing their requests with the church's leadership was futile, with the consequence, *"…eventually,* *you'll keep quiet"* (P1-4). They added that they did not trust that their requests verbalised to the leadership were honored, and equally so, the ones they submit in writing. On the same topic, another participant sarcastically retorted, *"Sometimes the ministers are deaf, there, I've said it"* (P1-2), and yet another, *"It's a lack of the powers [that] be, that they're not listening"* (P1-6). In contrast to the church leaders' perceptions that the onus of communication is on the person with the need, or on their caregivers, the participants with disabilities asserted that this responsibility is not theirs alone: *"…sometimes, don't wait for us to say, offer… That's the problem, it's so hard to speak up"* (P1-1). The caregiver participants expressed similar views to the persons with disabilities but concurred with the church leaders' in that it is useful when parents or caregivers contribute to informing the church leaders of the support needs of the individuals in their care. However, with an outlook that nowadays *"…every second child is Special Ed…"* (P2-3), they pointed out that the church leaders, especially those involved with the children's ministry, ought to be abreast with this reality and that, by this time, they needed to be prepared to cater to the needs of children with special needs. One participant expressed her disappointment at the idea that the leadership is not proactive in making allowances for disability, and that the church environment and activities are not set up from the outset in such a way that barriers are removed, and everybody's needs considered. She explained: *"You think of a church, you think of that place that will open up its gates for everyone, so…for a person to miss these in churches, then, I mean…it's the first place you run to, so when you only go there, then to find that you're not catered for, it's just, it's disheartening"* (P2-1).

The obvious lack of disability accommodation within their congregation was targeted and explored by all three focus groups while reporting many relevant instances. With concurrence of opinion among the participants of the group for persons with disabilities, one participant contended: *"But why is it if you ask…the church to assist you…they don't sort it* *out with immediate effect? 'Cause if you don't sort it out with immediate effect…this is the reason why they are losing members, because people are getting fed-up"* (P1-6). The church leader participants also acknowledged the congregation's shortcomings in disability accommodation. The outcome of this limitation is seen in the following example: *"…we had a couple with a son, he was about 12…when they stopped coming… we didn't…really have people trained among the Sunday school workers that could properly look after him… So, that was a point which would have been good if we…had someone trained, or knowledgeable to be able to, to just focus on that, because they needed one person just for him, and understand him"* (P3-3).

Theme 3: Awareness and Understanding – The church leader participants openly admitted their own lack of awareness and experience with disability and mentioned that they do not necessarily possess the practical know-how to treat persons with disabilities with dignity, and in a manner that does not demean them. One participant said: *"… you don't know if you're doing the right thing, or then you overcompensate, and then it borders around you patronizing them and then they can see that and then, you know, there's a friction there already…"* (P3-2). For the church leaders, it was also the *"…lack of knowledge about how to be inclusive…of people with disability*" (P3-7), and more specifically, the reactions of uninformed people, that were perceived to make persons with disabilities feel unwelcome and unlikely to return to their congregation. An example of this view was given by a church leader participant who witnessed the discomfort in the reactions of a group of adolescents, when a girl with albinism joined their youth group: *"…I mean, she could tell…because she walked in and everyone stared… at times, people don't know how to act, or behave"* (P3-8).

Referring to the conspicuous differences persons with disabilities sometimes display in their appearance or behavior, the subsequent question contemplated among the church leader participants was: *"Do you ignore it, or don't you ignore it?"* (P3-4). The church leaders' view that people typically feel particularly awkward about engaging with people with specific types of disability, was captured by the statement: *"…I think…it's easy to…accept, or interact with someone that's got…sight loss, than someone with a disability when you struggle to hear what they say. And you're not able to communicate with them, so you rather avoid them"* (P3-3). A participant from the group for persons with disabilities, who is Deaf, shared his actual experience of such avoidance, when a congregant, who initially approached him, turned silent and walked away from him upon noticing his hearing aids. In a wry comeback after recounting his encounter, he uttered: *"That doesn't help… You know, I'm not going to make you sick. Yes, you can touch me. It's ignorance!"* (P1-2).

Theme 4: Access – In an all-embracing statement concerning the poor accessibility of the physical spaces on their congregation's property, a comment by a caregiver participant consolidated all three participant groups' perceptions in this regard: *"So, it's the whole infrastructure…which needs to be more accessible…the toilets, the ramps… parking"* (P2-1). The participants from the focus groups for persons with disabilities and church leaders made specific mention of the number of stairs on the church property that impede the physical access of persons with disabilities. For instance, a participant from the disability group explained, *"…I have…Cerebral Palsy, so I find it difficult to climb up and down the stairs and so, if there's any activities that we have to climb up stairs, or hold two things at the same time, I find that awkward"* (P1-6). On the same topic, a church leader participant addressed one of the other participants in her focus group about the unsuitable nature of the venue designated for the congregation's youth gatherings, saying, *"If you have physically disabled youth, they cannot come to you"* (P3-1). After contemplating this observation, the addressee concurred, *"I think it's seven stairs down, plus another seven, so it's 14, just to get to the room"* (P3-8). With reference to the availability of ramps to ease the access of wheelchair users or others who cannot use stairs, the church leader participants remarked that the quality of the existing ramps on the church property is very poor, with uneven surfaces and unexpected drops, especially the one leading into the sanctuary: *"But even the ramp going down, as you get to the bottom, it suddenly slope[s], and you almost go into the garden… we'll have to even it out because, even if you walk down there, the elderly, I have to always caution them to stay on the other side"* (P3-3). A participant from the group for persons with disabilities described her own experience as follows: *"…it looks nice when you come in that there's a wheelchair ramp…but having brought someone…in a wheelchair… let me tell you… coming down that ramp in the church…is a nightmare… Trust me, it, it looks lovely, that it's wheelchair-friendly; this church is not very wheelchair friendly"* (P1-4). Expressing similar perceptions, the caregiver participants also pointed out that the ratio of ramps to building entrances were insufficient for providing wheelchair users access to most of the venues on the church property, for example: *"…there's the one going into the main church…but to get to…the meeting rooms, down stairs and whatever, they couldn't, and up to the offices…they can't do that"* (P2-3).

The participants from all three focus groups pointed out the necessity of specific resources without which the participation of persons with disabilities in their congregation are obstructed. These include technological, financial, human and transportation supports. Aspects pertaining to acoustic, or sound quality in the sanctuary received much attention among the participants in all three focus groups, as a Deaf participant in the group for persons with disabilities described, *"…sound…for me is fundamental. That's my primary one"*, and added the importance of *"…having someone to control the technology and make sure it works"* (P1-2). In addition, the participants in the groups for persons with disabilities and church leaders raised concerns about persistent audio-visual delays, as both groups perceived this as having a substantial impact on people who are Deaf or hard of hearing, who cannot follow the message that is preached, or the songs that are sung when there is insufficient visual input on the projection screen. The church leader participants shared their own frustrations and challenges with audio-visual lags, for instance, *“I am not disabled in any of those forms and I cannot look at the screen when there’s no synchronization”* (P3-1). In addition, a church leader participant living with hearing impairment himself explained: *“…I learnt to read lips to compensate… the difficulty is, if I look at the projection, there’s a delay, so the lips and the sound [don’t] correspond as well”* (P3-3). The Deaf participant from the group for persons with disabilities made a parallel comment saying, *“…when you’re talking, I need to be able to see you. If I…can’t see your lips, I’m gonna battle”* (P1-2).

During all three focus groups, availability of finances was mentioned as a barrier, the presence of which was said to make for an excellent facilitator to address many of the barriers they have identified. For instance, realizing that they had not identified access to finances as a hindrance to participation earlier, all the caregivers agreed when one participant added, *“Finance absolutely…should be at the top… Huge barrier”* (P2-3). The church leader participants also made recurring references to a shortage of funds, as one of them explained why they were unable to update their electronic systems, and were still experiencing issues with acoustics in the sanctuary: *“…short of spending many thousands of Rands to re-thingy…the venue, we would have to put…sound and all sorts of very expensive stuff in it… that’s why we haven’t done it because it’s a money issue”* (P3-1).

The need to marshal volunteers to provide transport services was raised by the church leader participants, who expressed their awareness of the difficulties faced by many persons with disabilities known to them in the surrounding community, who do not have any means to get to the congregation by themselves. Building onto one another’s ideas, suggestions were made to appeal to congregants who discerned a calling for disability ministry with the purpose of lifting persons with disabilities to and from church, as echoed by one of a few examples:

"Yes, then we could also somehow try and solve the transport issue… pick them up and…bring them to church" (P3-2).

The subsequent section presents the abovementioned findings in relation to the deductive coding process that was followed as a final step in the data analysis. Conceptualizing functioning and disability in line with the biopsychosocial model of the ICF (WHO, 2001), the following segment of the findings connects the participants' perceptions to the interaction between the health conditions of persons with disabilities, and the external influences on their functioning (or disability) within the unique context of their congregation.

ICF Environmental Factors represented in the emergent themes

Fulfilling the study's fourth and final sub-aim in exploring if the participants' perceptions can be linked to the ICF as a theoretical framework, the deductive coding process emphatically connected the participants' themed responses with the ICF Environmental Factors, where the interaction between the health conditions of persons with disabilities, and the external influences on their functioning (or disability) within their congregation, were demonstrated. The ICF environmental codes represented in the participants' perceptions are documented in Table 2. Limiting the code listings to the context of the *Religion and spirituality* code (d930) of the ICF's Activities and Participation component, the details of the coded categories in Table 2 are abbreviated and modified to fit the church-specific context of the study, and do not include the full code descriptions related to other broader environments included in the ICF.

Table 2 reveals that all five chapters of the ICF Environmental Factors were represented in the participants' perceptions concerning barriers and facilitators to the participation of persons with disabilities within their congregation. A total of 27 environmental codes were linked to the data, 16 of which are documented at the second-level (indicated in italics), and 11 at the third-level of classification. Table 2 also draws attention to

Table 2. ICF Environmental Factors Represented in Participants' Perceptions

ICF Code	ICF Category description	(No. of data links per category)	No. of ICF codes per category
Chapter 1:	**Products and technology**	**(146)**	*three e1 second-level codes**; five e1 third-level codes
e145	*Products and technology for the practice of religion and spirituality*		
e1451	Assistive products and technology for the practice of religion or spirituality		
e150	*Design, construction and building products and technology of buildings for public use*		
e1500	Design, construction and building products and technology for entering and exiting buildings for public use		
e1501	Design, construction and building products and technology for gaining access to facilities inside buildings for public use		
e1502	Design, construction and building products and technology for way finding, path routing and designation of locations in buildings for public use		
e165	*Assets: Products or objects of economic exchange, e.g. money, goods, property and other valuables that an individual has rights of use*		
e1650	Financial assets		
Chapter 2:	**Natural environment and human-made changes to environment**	**(27)**	*two e2 second-level codes**; three e2 third-level codes
e240	*Light: Electromagnetic radiation by which things are made visible by artificial lighting*		
e2400	Light intensity: Level or amount of energy being emitted by either a natural, or an artificial source of light		
e250	*Sound: A phenomenon that is or may be heard, such as banging, ringing, thumping, singing, whistling, yelling or buzzing, in any volume, timbre or tone*		
e2500	Sound intensity: Level or volume of sound determined by the amount of energy being generated		
e2501	Sound quality: Nature of sound as determined by the wavelength and wave pattern of the sound		
Chapter 3:	**Support and relationships**	**(147)**	*four e3 second-level codes**; zero e3 third-level codes
e325	*Acquaintances, peers, and community members who are familiar to each other and share religious creed*		
e330	*People in positions of authority with decision-making responsibilities for others and who have influence or power based on their religious roles*		
e335	*People in subordinate positions whose day-to-day life is influenced by people in positions of authority, such as members of a religious group*		
e340	*Personal care providers and personal assistants: Individuals who provide support services to individuals on a remunerated or voluntary basis*		
Chapter 4:	**Attitudes**	**(170)**	*four e4 second-level codes**; zero e4 third-level codes
e425	*Individual attitudes of acquaintances, peers, colleagues, neighbors and community members*		
e430	*Individual attitudes of people in positions of authority*		
e460	*Societal attitudes: General or specific opinions and beliefs held by people of a social group about individuals that influence behavior and actions*		
e465	*Social norms, practices and ideologies: Abstract systems of values and normative beliefs that affect or create social norms of moral and religious behavior*		
Chapter 5:	**Services, systems and policies**	**(60)**	*three e5 second-level codes**; three e5 third-level codes
e515	*Architecture and construction services, systems and policies for the design and construction of public buildings*		
e5150	Architecture and construction services: Services and programmes for design, construction and maintenance of public buildings (e.g. building regulations)		
e540	*Transportation services, systems and policies for enabling people to move or be moved from one location to another*		
e5400	Transportation services aimed at moving persons by public or private transport, including those who provide these services		
e555	*Associations and organizational services, systems and policies relating to groups of people who have joined together with an associated membership structure*		
e5550	Associations and organizational services and programmes provided, such as religious services		

* Second-level codes are italicized

Chapter 4 of the Environmental Factors of the ICF, *Attitudes*, as the category holding the highest number of data links between the participants' responses and the ICF environmental codes, followed by *Support and relationships*.

Identified barriers to participation

Given that no statistical analysis was carried out, the frequencies at which the environmental codes occurred as barriers or facilitators were not measured. However, the nature of the environmental factors, that is, whether they were viewed as barriers or facilitators, was inferred by the qualitative input from the participants' responses. Links between the ICF environmental codes (e-codes) and the emergent themes from the participants' perceptions are presented in Table 3.

Table 3. ICF Environmental Codes Linked to Emergent Themes

e-Codes	Nature of e-code	Theme / Sub-theme	No. of times stated	Theme #
e1451	Facilitators absent	Access to necessary resources	19	4
e1500	Facilitators inadequate	Accessibility of the physical environment	35	4
e1501	Facilitators absent	Accessibility of the physical environment	46	4
e1502	Facilitators inadequate	Accessibility of the physical environment	25	4
e1650	Facilitators inadequate	Access to necessary resources	21	4
e2400	Barriers imposed	Conformity	3	1
e2500	Barriers imposed	Belonging	8	1
e2501	Facilitators inadequate	Access to necessary resources	16	4
e325	Barriers imposed	Belonging	23	1
e330	Barriers imposed / No facilitators	Addressing Needs / Access	93	2/4
e335	Barriers imposed	Conformity / Belonging / Reciprocity	14	1
e340	Facilitators absent	Access to necessary resources	17	4
e425	Barriers imposed	Conformity / Social constructions of disability	32	1/3
e430	Barriers imposed	Conformity / Social constructions of disability	31	1/3
e460	Barriers imposed	Conformity / Social constructions of disability	48	1/3
e465	Barriers imposed	Conformity / Social constructions of disability	59	1/3
e5150	Barriers imposed	Accessibility of the physical environment	15	4
e5400	Facilitators absent	Access to necessary resources	10	4
e5550	Barriers imposed	Conformity / Accommodation of needs	35	1/2

Table 3 shows the participants' themed responses in relation to the ICF and includes the participants' perceived nature of the pertinent environmental factors. Notwithstanding the presence of environmental factors that may facilitate the functioning of persons with disabilities in the congregation of the study, the ICF constitutes a facilitator that is absent or insufficient (despite its existence) a barrier (WHO, 2001). Considering this, the participants' perceptions were fraught with barriers associated with the codes presented in each category. From Table 3, it is thus evident that the participants generally perceived the environmental factors at work in their congregation to hinder, rather than enable, the functioning and participation of persons with disabilities. Apart from all five environmental chapters being demonstrated in the data, Table 3 also shows how the documented environmental codes were evident in each of the four derived themes as well, suggesting a noteworthy resemblance between the participants' perceptions of the wide-ranging external factors that influence the participation of persons with disabilities in the unique setting of their congregation, and that encompassed by the ICF.

In the documented codes from the first chapter in the Environmental Factors component of the ICF, *Products and technology*, barriers to participation were denoted by all three participant groups in ample illustrations of the absence and inadequacy of assistive products and technology, such as Braille (e1451), parking spaces, ramps (e1500), toilets, audio loop systems, accessible seating (e1501), signage (e1502) and finances (e1650). These limitations obstruct persons with disabilities' physical access, as well as their access to resources essential for their participation.

Included in the second chapter, *Natural environment and human-made changes to environment*, the participants with disabilities presented the light intensity (e2400) discharged by photographic flashes in the sanctuary during Baptism services as a case in point concerning participation restrictions imposed upon individuals with photo-sensitive epilepsy. Unlike those who fit in with the norm and remain unconcerned of any adverse effects resulting from such sensory stimulation, affected persons must remove themselves from the environment to avert an imminent epileptic seizure, and thus cannot partake in these services. Barriers in this regard were considered to result from the perceived inconsiderate customs maintained within the congregation. Additionally, sound intensity (e2500), specifically the sound volume in the noise levels during activities at children's church, were acknowledged as a barrier by all three participant groups. They described how children with autism spectrum disorder are frequently removed from the setting, and therefore excluded from participation, when they become perturbed. The sound quality (e2501) and the hampering effects of dull sound areas and reverberation in the sanctuary owing to inadequate sound equipment, also featured among all the participants as a lack of necessary resources.

The third chapter, *Support and relationships,* which concerns the general physical and emotional support afforded to persons with disabilities, is relevant with reference to the purported barriers inflicted on persons with disabilities through the deficiency in care and assistance offered to them by others who share the same religious interests (e325), and their subsequent exclusion from the congregation of which they are a part. The perception of the church leaders' apparent incapacity to assert their influence and effect the necessary changes to support persons of disabilities (e330) were considered hindrances by all the participants, but for different reasons. While the church leaders attributed their limitations to a lack of resources, the persons with disabilities and caregivers regarded the church leaders' non-intervention as neglect and indifference to engage with the needs of persons with disabilities. Out of all the linked environmental codes, e330 obtained the highest representation in the participants' comments, the majority of which came from the focus group for persons with disabilities. In addition, the presumed subordinate social ranking of persons with disabilities (e335) is evident in all three sub-themes of the first theme, Social Status, which was perceived to determine the level of support provided to persons with disabilities and the types of relationships cultivated with them. Moreover, the provision of personal care to persons with disabilities by staff and volunteers in the congregation (e340) was represented, where supports such as assistance for wheelchair users and volunteers in the children's ministry were highlighted as lacking.

Environmental codes related to *Attitudes* covered in the fourth chapter, were perceived as the main barriers to participation, where congregants' stereotypical views of disability (e425), and the misconceptions of certain disabilities among church leaders (e430) were attributed to a lack of disability awareness and erroneous understandings, including misconstrued theological beliefs about disability. The reported negative societal attitudes (e460) exhibited by congregants, and most prominently, the social pressures exerted to fit in with norms considered acceptable in their congregation (e465), were perceived to adversely influence the attendance and participation of persons with disabilities.

In the fifth and final chapter, *Services, systems and policies*, the environmental code covering aspects related to architecture and construction services and programmes for the design, construction and maintenance of public buildings (e5150), was also associated with participation restrictions. All the participants described how the related services provided by their congregation, imposed barriers to persons with disabilities, despite previous attempts at affording facilitators. In addition, the lack of transportation services to lift persons with disabilities (including the elderly) to and from church (e5400), was attributed to the lack of volunteers to fulfil such roles. Finally, the reported unsuitable services and programmes provided in children's church and Bible studies (e5550) were addressed as barriers to the participation of persons with disabilities.

DISCUSSION

This study contributes to the growing body of evidence confirming the immense impact of systemic factors on persons with disabilities' own functioning, societal participation and quality of life, as well as that of their primary caregivers and families, be it in relation to the disability-related supports received, or the lack thereof (Ault et al., 2013; Breen, 2009; Carter, Bumble, Griffin, & Curcio, 2017; Erasmus, Bornman, & Dada, 2016; Fischer, 2018; Kazou, 2017; Light & McNaughton, 2015; McDaniel & Pisani, 2012; McDougall et al., 2010; Murray, 2007; Prendeville & Kinsella, 2019; Schlebusch, Dada, & Samuels, 2017; Vernhet et al., 2019; Walsh, 2012). The findings of the current study corroborate the latter outcome, where the perceptions of all the participants culminated in the collective observation that their own congregation does not yet reflect disability inclusivity that would enable participation and make persons with disabilities and their families feel welcome and accepted. In addition, this study also supports the notion of disability as a social construct, localizing the problem of disability *outside* persons with disabilities in this faith community but *in* the environment of their congregation (Lawson & Priestly, 2017), which, through failures to create ability among those who do not fit the physical, mental and social profile of their typical non-disabled congregants, have excluded persons with disabilities from participating in this crucial area of life (Koenig, 2012). From this vantage point, the findings instead recognize and highlight the significant interplay of the various systems processes, and present the experience of disability among those who live with impairments as an occurrence produced by environmental hindrances and not by their impairments.

The ICF framework of functioning and disability

Although the extent to which the ICF environmental codes were perceived as barriers or facilitators was not determined, the significance of the findings is in the outcome that *no* facilitators (as defined by the ICF) were identified in the participants’ responses, either owing to the absence, or inadequacy of enabling features in the congregation’s environment. Despite reporting a number of facilitators in their congregation, the participants highlighted their shortcomings, rendering any such potential facilitator, a barrier to participation (WHO, 2001).

Using the ICF as a framework for describing the process of functioning and disability within this faith-based system, the findings provided sufficient evidence to suggest that the physical, social and attitudinal environment of the congregation have a prevailing hindering impact on the participation and functioning of persons with disabilities, their caregivers and families – to the degree of imposing disability on them. The findings also reiterate the results of other research motioning the need for an increased shift in conceptualizing disability and functioning holistically, that is, as a dynamic interaction between the health conditions of persons with disabilities and their unique contexts, so that the disabling factors in their environment can be addressed and their participation ameliorated (Leshota, 2015; Möller, 2012; Welch Saleeby, 2016b; WHO, 2001).

Interlacing key aspects from the medical and social models of disability, this section applies the theoretical principles of a systems approach to the current study, where persons with disabilities, their caregivers and families, and their congregation can all be viewed as individual systems, each with their unique characteristics. However, the aforementioned systems are not regarded as systems based solely on the individual characteristics they each possess (Wachs, 2000). Contrary to the unilateral viewpoint of the medical model that defines and labels a person by a single feature of their disability without considering the interplay of their wider systems (Berghs et al., 2016), the general systems approach as applied in the ICF prevents viewing the person with a disability as an isolated unit. Equally, without reducing the whole, compound concept of disability to only one of its component aspects, this framework also balances the social model's shortcomings in discounting bodily impairment and attributing disability entirely to social injustice (WHO, 2002). Instead of focusing on individual or isolated features, the key factor within this systems framework that delineates the person, the family, and the congregation – each as a complete system, yet interrelated – is the nature and degree of the *linkages* that exist between the elements *within* each system, as well the relationships *between* these systems. Consequently, the complex phenomenon of disability is a challenge at the level of both the individual person's body and at the social level. It is only in employing the biopsychosocial model's interactionist perspective, that disability can be understood as a social process and thus the result of the interaction between individual features within the person with a disability, and features of their larger context (e.g. their family, their congregation, and society at large) (Bartlett et al., 2006; McDougall et al., 2010; WHO, 2002). This multidimensional, interactive framework of general systems theory is vividly reflected in the ICF, where the components that represent an individual's functioning at the body, individual activities, and participation levels are all potentially interlinked, implying that change in one subsystem can cause change in all the other systems and vice versa (McDougall et al., 2010).

Positioning this multi-perspective framework within the context of the current study, the *functioning* of persons with disabilities in their congregation would have been achieved if there was a positive outcome arising from the interaction among their body functions and structures (physiological and psychological functions, and anatomical integrity), activities (execution of tasks or actions), and participation (involvement in their congregation). Ultimately, the environment of this congregation has produced the opposite effect for persons with disabilities, where *disability*, the negative outcome flowing from the interaction among their impairments (problems with body functions and structures related to health conditions), activity limitations (difficulties executing activities), and participation restrictions (problems related to involvement in their congregation), has become the end product. Since this framework recognises that the occurrence of disability often starts with a health condition leading to impairments, which are perpetually influenced by contextual factors that subsequently contribute to activity limitations and participation restrictions, the occurrence of disability in persons with disabilities in the context of this congregation is thus understood to have resulted from the dynamic interplay between their health conditions and hindering environmental factors (Welch Saleeby, 2016b; WHO, 2001).

Among the participants’ responses, examples of a wide range of impairment of body functions and structures that interact with all the abovementioned components included depression, anxiety, hearing impairment, deafness, visual impairment, blindness, dyslexia, speech impairment, epilepsy, Parkinson’s disease, Down’s syndrome, autism spectrum disorder, cerebral palsy, albinism and physical deformities as a result of burns or polio. Additionally, several references were made to mobility difficulties and moderate to severe physical and intellectual disability. Views held in the ICF emphasize that it is not the said health conditions of individuals that cause disability and participation restrictions, since these impairments may not at all produce disability in a different environment (WHO, 2001). From a systems theory perspective, all these components (or system elements) are interrelated; however, their connection is thought to be non-linear rather than sequential, meaning that the relationship between the system elements and their impact do not necessarily have a specific causal link between them (Wachs, 2000). An application of this principle is demonstrated in the ICF, where the functional components can be equally influenced by physical and psychosocial systems, with no presumed aetiological association between the presence of impairment and disability (Kazou, 2017; McDougall et al., 2010).

Correspondingly, the findings of this study highlight that constraints on the participation of persons with disabilities in this congregation do not directly relate to their impairments per se. Moreover, although still applicable to the current study, it is not primarily the observable built environment or absence of assistive devices that were perceived to hinder the participation of persons with disabilities. Rather, the most prominent barriers are situated in the invisible social spheres of this congregation, as evidenced in the noteworthy connections between the ICF environmental factors and the participants’ responses relating to the categories, *Support and relationships* (Chapter 3), and *Attitudes* (Chapter 4). These strong connections accentuate that it is predominantly perceptions of the church leadership's alleged lack of support (e330), the congregation's apparent preconceptions and negative reactions to their impairments (e460), and the seeming uncompromizing normative structures sensed within their congregation (e465), that cause the affected individuals to become disabled, and ultimately excluded from participation.

While the findings of this case study cannot be generalized, the numerous compelling connections between the participants' responses and the ICF's environmental codes, validate the comprehensiveness and universality of the ICF, and its suitability as a theoretical framework for understanding the causes and consequences of disability on the functioning of persons with disabilities, not only in the faith-based setting of the current study, but also across any given context and discipline (Welch Saleeby, 2016a). The focus on the nature of the environmental factors in this study can help to initiate the development of interventions to create facilitators, alleviate or eradicate barriers to functioning and participation, and ultimately produce social change. It is this extensive applicatory potential of the ICF that has earned its endorsement by the World Health Organization and the World Bank in the World Report on Disability (Welch Saleeby, 2016b; WHO & World Bank, 2011), making it a reliable tool for understanding the outcome of functioning and disability on the health of persons with disabilities in the congregation of this study (McDougall et al., 2010).

Social deconstruction of disability

The subsequent segment of the discussion focuses more generally on the emergent themes in comparison to the relevant literature from a broader systems perspective. Seeing that the congregation of the study is enmeshed in many systems, it needs to be understood according to its interrelated system processes (Gregory, 2012). Informed by the theoretical underpinnings of systems theory, disability in this context is deconstructed by subjecting the themes to the principles of *systems thinking* to provide a practical means for analyzing, understanding, and ultimately, changing this complex system (Cabrera, Colosi, & Lobdell, 2008).

In review of the emergent themes, a thematic map is presented in Figure 2, which shows the relationship among the themes and indicate how certain abstract conceptual models of thought have found concretization in the congregation.

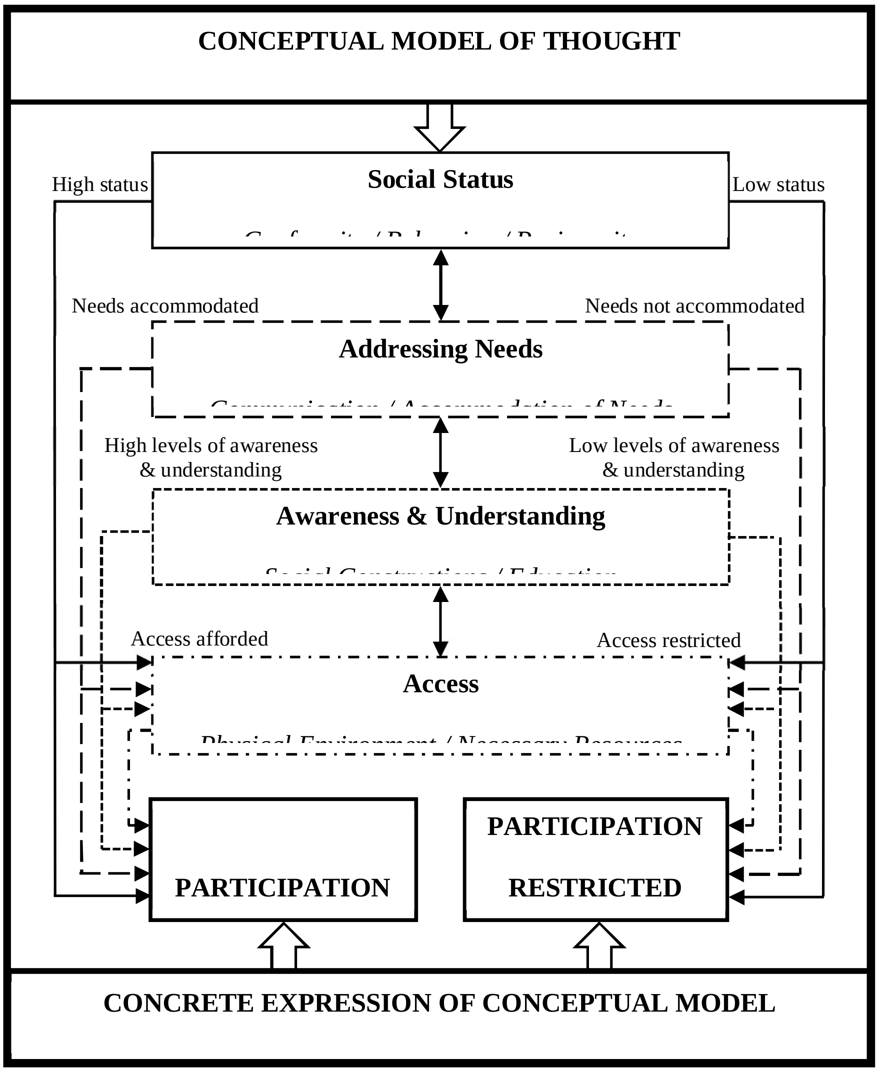


Figure 2. Thematic map of emergent themes

Figure 2 shows how the extent to which needs are perceived and addressed, and accessibility and participation enabled, are tangible expressions of the conceptual thought models espoused within this faith-based system, where, in essence, distorted worldviews have led to the exclusion of persons with disabilities. The findings further revealed that persons with disabilities have basic needs that must be met before their participation in their congregation's various activities can occur. To achieve this, increased awareness and accurate understanding of disability is required so as to fully appreciate and fulfil these needs, some of which involve practical, observable affordances, such as creating access to the physical environment and necessary resources, while, on a more complex and covert level, exists the most pressing need for a sense of belonging to a faith community, where persons with disabilities are recognized as equal to non-disabled members in respect of their value and the contributions they have to share.

However, unless some drastic change in awareness occurs at a heart and mind level, it appears that the manner in which these needs will continue to be addressed, relates to the status bestowed upon persons with disabilities, which is influenced by negative attitudes and ideologies concerning social norms for appearance and behaviors upheld by the congregation. There is thus a distinct association between the affective and the social transformation that needs to occur within this congregation. While it is important to remember that ideas (thoughts and concepts) constantly develop in cognitive systems like the human mind, concurrently changing in response to other concepts by linking, conflicting, or coexisting with them, human minds are not only responsible for cognitions (Cabrera, Cabrera, & Powers, 2015). They also process feelings, and motives along with thoughts, with a definitive link between affect, cognition and motivations for behaviours (Decety & Yoder, 2016), each of these systematically influencing and reinforcing the other.

Disability: A systems thinking perspective

It is thus preeminently the unwavering flawed conceptual models, consisting of parallel thoughts and feelings regarding disability in this congregation, that need to change before persons with disabilities' needs are addressed and their participation enabled. If the changes the participants deem necessary are to occur within their congregation, there is a need to change the way they think. While changing the way everyone involved thinks will not spontaneously resolve the issues they face, changed thoughts will nevertheless reframe how they think about the identified barriers and what the best solutions may be (Cabrera et al., 2008).

Beneath the concept of systems thinking lie four rules or principles universal to human thought, representing four cognitive functions as a problem-solving algorithm to form renewed understandings. These principles, which go by the initialism, DSRP, involve distinctions, systems, relationships, and perspectives, where *distinctions* can be made between and among people and concepts, people and concepts can be organised into *systems* (where both parts and wholes can be distinguished), *relationships* are formed between people and concepts, and people and concepts can be viewed from the *perspectives* of other people and concepts (Cabrera et al., 2015). Making distinctions involves boundaries that differentiate between who is *in* and who is *outside* the set boundary, and given the distinction between the two parties, there must be some relationship between them, even if it is only the relation of being distinct from one another. Any group of interrelated people or concepts are naturally viewed as a system, since a system is defined as a whole made up of two or more related parts. In addition, people and concepts carry with them a perspective, or frame of reference, which distinguishes between the point from which something is viewed and that which is viewed (Cabrera et al., 2008).

Since making distinctions and gaining awareness of systems, relationships and perspectives are interconnected and co-occur simultaneously, these principles are not reviewed individually or consecutively in separate sections in this paper, but instead interwoven with the rest of this discussion to demonstrate its application.

In the literature, it is understood that awareness of one's own thinking, or metacognition, including one's own feelings, encourages the balance between the needs of the self and the other, and increases empathy and understanding, as well as interpersonal awareness, which promotes introspection and prosocial behaviours (Bogdan, 2017; Cabrera et al., 2015). The findings suggest that such levels of awareness have not occurred for all the participants of this study. While introspection toward a prosocial approach was to some extent noted in the perceptions of the caregiver participant group, this was not the case for the groups for persons with disabilities and church leaders, who each seemed to view the reasons for unmet needs solely in respect of their own frames of reference. One-sided perspectives like these blind side people and are not helpful, as it only observes the situation at hand from a single vantage point (Bogdan, 2017). A systems perspective, however, allows for all other viewpoints to be considered and greater levels of understanding to be achieved (Cabrera et al., 2015), but this can happen only *"when first you see the world through the eyes of another"* (Churchman, 1968, p. 231). Accordingly, granted an awareness of the interrelating factors (relationships) that created the existing barriers in this congregation, any potential blaming of each other is soon replaced with understanding of why or how each stakeholder has interacted as part of their wider systems, giving meaning to reasons they acted (or not) in the way they did (Cabrera et al., 2015).

Having a bird's eye view of the situation (perspectives), it is clear to see the church leader participants' lack of knowledge about the needs of persons with disabilities and their caregivers in the congregation, and likewise, the participants with disabilities' and caregivers' lack of awareness of the church leaders' predicament. A reason as to why neither persons with disabilities nor their caregivers voluntarily communicate their needs, is that they may engage in avoidance behaviors (Krypotos, Effting, Kindt, & Beckers, 2015) as a coping strategy. This is as a result of past experiences of strained relationships with family and friends after the announcement of the disability, and they may therefore find it difficult to reach out for support to people even further removed (Vernhet et al., 2019), such as the church leadership and other congregants. While it is important for persons with disabilities and caregivers to develop agency and speak out about their needs, desires and preferences (Gurbai, 2014), it is also important that the church leaders are aware of possible avoidant behaviors to enable them to reach out to persons with disabilities and caregivers, instead of waiting on them to come forward by themselves. In order for this awareness to occur, it will be necessary for the persons with disabilities, caregivers, and church leaders to develop trusting face-to-face relationships where fruitful dialogues can be had to jointly identify the areas where action is needed most (Carter et al., 2017).

The two most important areas calling for change in this congregation are indicated in the need to shift the conceptualization of persons with disabilities and their families as 'apart from', to 'a part of' the body of Christ, and to move from the mere inclusion of persons with disabilities and their families, to their belonging and participation.

'Apart from', to 'a part of' the body of Christ

Apparent subconscious polarized thought processes exist in the perceptions of the participants with disabilities and church leaders, which suggests the presence of division, in that these two groups seem to lack a sense of solidarity between them. Accordingly, both the participants with disabilities and the church leader participants appear to have divided themselves into *us-them* identities (White, 2014), with persons with disabilities in one camp, and the church leaders in the other, juxtaposing *them*, who are different, against *us*, who are not different

(Meininger, 2008), and vice versa, where persons with disabilities seemed to view the congregation's leadership as the opposing 'other' (Cabrera et al., 2015).

Echoed in the findings of the current study, Gaventa (2012) points out a tendency in some Christian congregations for persons with disabilities to become the 'other' through discriminating acts against them and their families. However, concerning persons with disabilities and their caregivers within the current study, Scripture compellingly validates their true status in their belonging to their congregation as part of the body of Christ. For example, *"The body is a unit, though it is made up of many parts; and though all its parts are many, they form one body"* (1 Corinthians 12:12, New International Version).

There is a striking similarity between the metaphor used to describe the church – *The body of Christ* – and the modern-day definition of a system. Seminal author, Boulding (1956) images general systems theory as a living, unified body of knowledge held together by a core, or skeletal structure. This definition is somewhat reminiscent of the Biblical understanding of the interconnectedness among various members as individual systems within this congregation. Confirming the role of each body part, the body analogy is continued in verses 24 through 27.

> *But God has combined the members of the body…so that there should be no division in the body, but that all its parts should have equal concern for each other. If one part suffers, every part suffers with it; if one part is honored, every part rejoices with it. Now you are the body of Christ, and each one of you is part of it.*

These verses implicate that union among the members of this congregation require joint efforts by everyone involved, where the obligation for ensuring unity rests on all its members (George, 2011), including persons with disabilities as a part thereof, whether or not they view themselves as such. This also applies to the caregiver participants, who need to learn welladjusted ways to face uncomfortable encounters, instead of developing a tendency to avoid challenges (Vernhet et al., 2019). While the terms *inclusion* and *participation* are not originally Biblical, this account presents a Biblical basis for viewing every member of the study's congregation as an active participant, and for receiving the gifts of all members, regardless of their differences. Furthermore, within this framework, every person is seen as an equal member who offers diverse but indispensable contributions to the whole, where the individual believer is not merely a body part, but a *functioning* member of the body, with a unique purpose (Brock, 2011).

The importance of understanding disability from a systemic perspective is reiterated by studies such as those reported by LoBianco and Sheppard-Jones (2007), where the perceptions of others toward persons with disabilities have been investigated. Findings of that particular study highlighted that, once integrated into social settings, persons with disabilities felt less perceived as having a disability, and generally, people's perceptions of disability changed with increased contact with persons with disabilities. It can thus be inferred that the intentional inclusion of persons with disabilities in the current study's congregation will yield a reciprocal recompense for all involved, helping all the members of the congregation to discover their likeness, interdependence and need for each other (Gurbai, 2014; Leshota, 2015). From a systems perspective, grasping that the whole surpasses its interrelated parts, this realization is essential, not only in the interest of persons with disabilities, but also – and perhaps more importantly – for the sake of this congregation's overall health and welfare (George, 2011). As it is at present, however, without the inclusion and full participation of persons with disabilities, this congregation can be conceived as missing a few vital body parts where it has inflicted both impairment and disability upon itself in its neglect of proper self-care (Haythorn, 2003).

The findings also suggest that the participants in the groups for persons with disabilities and caregivers may at times consider themselves helpless, and as a result become passive in the face of their challenges, turning into *"victims of their impairment"* (Retief & Letšosa, 2018, p. 6) as it were. However, unless they become aware of this mindset, they may be complicit in perpetuating the conceptualizations of the medical model of disability, conceiving disability as victimhood (Creamer, 2012; Retief & Letšosa, 2018). For true inclusion, belonging and participation to occur, it is crucial that this us-them mentality changes, where everyone, including persons with disabilities, primary caregivers and church leaders, shift their perspectives from viewing persons with disabilities as 'apart from', to 'a part of' their faith community (Gaventa, 2012), in which they recognize one another as equal members of their part-whole faith system, the body of Christ (Brock, 2011). This congregation can thus only become a supportive and transformative agent (Pillay, 2017) in the lives of persons with disabilities and their family systems if they consider *all* people, including persons with disabilities, as part of their interconnected and interdependent Body (systems/relationships).

From inclusion, to belonging and participation

Another critical area for change pertains to the church leaders' understanding regarding the meaning of participation. Participants from this group expressed their awareness of many persons with disabilities in the surrounding community, who do not have any means to get to their church. The church leaders subsequently planned solutions to the transportation difficulties faced by individuals with disabilities. In these instances, the focus was solely on lifting persons with disabilities to and from church. During their discussion, the church leader participants' dialog seemed to be predominated by ideas of disability and inclusion in terms of severe physical and intellectual impairment, evidenced by the numerous references made to the residents of a nearby disability care centre, none of whom participated in the study.

Except for two participants in the group for persons with disabilities, the church leaders did not indicate any awareness of the other persons with disabilities who participated in the study, nor of any other members of the congregation. This might explain why the participants with disabilities expressed that their needs are overlooked in this congregation. Going unnoticed seems to relate to visible versus invisible disabilities, where the severity of disabilities that remain unseen, appear to be underplayed and ultimately neglected (Baraza, 2017). It appears to be this invisibility that led to the perceptions of exclusion of persons with disabilities in this congregation.

There seems to be the presumption (perspectives) by the church leader participants, that, if individuals can *attend* church services – as is the case for all the study's participants with disabilities – their participation is not restricted after all. However, the participants with disabilities and caregivers all shared many ways in which their participation is indeed hindered. There appeared to be an assumption among the church leader participants that inclusion, belonging and participation are synonymous, and that participation is single-handedly achieved through church attendance. Echoing Swinton's (2012) supplication that *"inclusion is not enough"* (p. 182), there is a need for this congregation's leaderships' thinking to move *"away from the idea of inclusion and towards the experience of belonging"* (Swinton, 2012, p. 182), where true belonging means (among other things) that persons with disabilities are known and missed when they are not at church. If persons with disabilities are seen as the 'other' or placed in the 'out-group' (distinctions), the church leaders will not recognize their need for belonging as they experience it, nor will they understand what true participation means as the ICF defines it. If participation is envisioned purely from an inclusion angle (perspectives), it can be expected that the church leaders may fail to consider the indispensable deeper relational aspects of cultivating authentic friendships (relationships) through acceptance, mutual social exchanges and interdependence, which constitutes participation through fellowship at the heart of belonging (Leshota, 2015).

The participants with disabilities, as well as the caregivers appeared to wrestle with their apparent attributed value as signified by their forgotten status. They expressed that, if they were indeed deemed part of this Body (systems), they would not have to campaign for their needs all the time, as they would be regarded as important and accordingly accommodated in the first place. Considering the length of time most of these caregivers and participants with disabilities have been attending this congregation, as well as their reported efforts to communicate their needs, it is no surprise that they would expect certain basic support structures to be in place by now.

This study confirms that the deepest suffering that persons with disabilities and their families in this congregation endure is caused by feelings of being excluded, leaving them questioning their worth and whether their presence and contributions are indeed needed and welcomed by the rest of their congregation (Hauerwas, 2000). Anderson (2015), however, reiterates that the value of persons with disabilities is inherently bestowed upon them by the One whose image they bear and is thus not contingent on the contributions they make. Therefore, their worth is unalterable, even if they cannot, or choose not to, contribute something to the benefit of others (Anderson, 2015).

Without any mention of adults with disability, both the caregiver and church leader participants included their opinions on the necessity of accommodating children with disabilities through the provision of a specialised assistant, skilled in the recognition and service of special needs. Previous attempts at disability accommodation in this congregation barred inclusion and participation during family services, since persons with disabilities and their caregivers were removed from the rest of the congregation. The presumption of discomfort and personal choice for isolation on the part of the caregiver or the person with a disability frequently resurfaced during the church leaders' discussion and may in fact be projections of their and the congregants' own true feelings about the presence and behaviours of persons with disabilities in their midst. However, in their respective further discussions on this topic, the perceived impact that this type of situation may have on the parents, both during children's and family services, were viewed very differently. Where the caregiver participants perceived parents and caregivers in these circumstances to feel misunderstood, judged and unsupported, the church leader participants perceived the likely feeling to be one of being a nuisance to the congregation. Contrastingly, informed by their own experiences as parents or caregivers, the caregiver participants did not perceive themselves or the persons in their care as a burden *to* the congregation, but rather burdened *by* the congregation, who appears to lack awareness and understanding of their situations and their need for consideration and unconditional acceptance.

This study highlights how thought processes, based in misconstrued assumptions (perspectives) and stereotypes about persons with disabilities, their caregivers and families, have regrettably led to the non-participation, exclusion and disablement of not only the person with an impairment but also their entire family unit, where the families of individuals with disabilities in this congregation experience inequality and discrimination – or so-called *"disablement by proxy"* (Murray, 2007, p. 216). This is sad, since research underscores the positive care structures that religious supports can and should be the lives of families with children with disabilities (Prendeville & Kinsella, 2019). Given research evidence provided earlier that caregivers and parents of children with disabilities typically do not receive adequate social support, it is imperative for their congregation to intervene (White, 2014). As important as this is, such intervention should not be limited to children and their families only. Consistent with the caregiver and church leaders participants' focus on supporting children, recent research on the participation of persons with disabilities in their faith communities shows that congregations generally give more attention to younger children, than to adolescents and adults concerning their accommodation and inclusion (Carter et al., 2017). In order to honour their equal right to inclusion and participation in this congregation, it is important that the same level of support is extended to *all* persons with disabilities, children, youth and adults alike.

Evaluation of the study

This section critically considers both the strengths and limitations of the study, where several limitations indicate possibilities for future research.

The intersection of religion and disability has received limited attention in the literature (Carter et al., 2017), to which this study positively contributes. This research also included among the participants' perceptions the "oft-missing voice" (Leshota, 2015, p. 2) of persons with disabilities regarding aspects perceived to affect religious participation in their own faith community.

Considering the extensive literature available on the application of the ICF related to Body Functions, there is a paucity in the body of research around Religion and spirituality (d 930) in Chapter 9 (Community, social and civic life), as part of the Activities and Participation component. This study has added to the comparatively small number of studies addressing the component Environmental Factors and its interplay on the health and functioning of persons with disabilities within this domain (Simeonsson et al., 2014).

The case study design provided an intensive analysis and description of a single social system, providing both emic (from within the case) and holistic (the whole system's context) perspectives (Qi, 2009) concerning the Methodist congregation of the study. In this system, the persons within it could be simultaneously viewed as a part and a whole, as they function both as individual members of their congregation but also as a united entity as one faith-based system. While this case study does not claim to represent the interrelational dynamics and outcomes among persons with disabilities, caregivers and church leaders in other Christian congregations, it is nonetheless important to consider this congregation as a microcosm of its wider system – that is, the Church in its broadest sense – the body of Christ. Although the findings from this case study may not be generalizable to wider populations, it can, however, be transferable to other settings (Anderson, 2010), where other researchers and readers with similar experiences may potentially see their application (Qi, 2009).

Despite its advantages, the case study method of the current research holds little basis for scientific generalization, given its single case in-depth exploration and the small number of participants involved, especially pertaining to the focus group for primary caregivers. However, as this study was a first attempt at understanding and describing the participants' perceptions, this method was appropriate.

The research question directed the use of a qualitative method to gather, analyse and interpret the data in an elaborate, meaningful manner, which would not have been achieved through pure quantitative measures that reduced the data to statistics (Anderson, 2010). Although focus groups are conventionally only used qualitatively, quantitative data through feedback forms, handouts, or electronic surveys completed by the participants before or after the focus groups may have been useful to improve the trustworthiness of the study's single-method instrument of focus groups (Naudé & Bornman, 2018).

In addition, no statistical analysis was carried out on the data links between the participants' responses and the ICF environmental codes. As a result, the frequencies at which these codes occurred as barriers or facilitators were not measured. Moreover, since no qualifier codes were applied to the pertinent environmental factors, the degree to which the codes were considered as barriers or facilitators was not established. However, the aim of the study was to identify the participants' perceptions on the presence of barriers and facilitators to participation, and not the extent to which they were perceived as such.

The study’s focus was limited to the perceptions of three main participant groups, that is, persons with disabilities, primary caregivers, and church leaders within their congregation. In their respective discussions, these three participant groups made ample references to the congregants of their Methodist community, who accordingly, featured significantly in the findings and discussion of this research. However, no representation from this prominent group was included in the study’s sample to corroborate the participants’ inferred perceptions of them. While the study was concerned only with exploring the participants’ lived experiences, and not with authenticating the actuality of their perceptions, it is important to be cognizant that there are other viewpoints from this important part of the congregation that are amiss, and that they may have added a different perspective to the current view the study provides. Whether or not it would have altered the findings by including a sample of the congregants is immaterial at the present time. What is important though, is the recognition that the current study does not present the full picture. To quote Margaret Wheatley (2002): *“Everyone in a complex system has a slightly different interpretation. The more interpretations we gather, the easier it becomes to gain a sense of the whole”.*

Future research

Given the Methodist context of this study, no Christian theologies, apart from Wesleyan doctrines were explored. It is known that the diverse theologies on disability and healing in different church denominations directly impact the treatment of persons with disabilities, and that a congregation’s adopted theological approach and attitude toward disability will accordingly shape the experiences of persons with disabilities within their faith community (Swinton, 2011). This was also found in the current study; however, no direct inquiry regarding theology of disability and healing was made, and therefore, no links could be made between the participants’ experiences and any specific theological aspects concerning disability and health. Since it is church leaders’ responsibility to provide their congregations with accurate theology on disability and to take the necessary stance against negative attitudes and practices (White, 2014), it will be necessary to understand what their disability theology is at present. Building extensively on the current study whilst still maintaining the interests of its present stakeholders, future research can be conducted on a comparison between the experiences of participants from a variety of Christian denominations, with a particular focus on investigating contextual factors such as preachers' espoused theologies on disability, health and healing, and how this impacts their attendance, sense of belonging and participation in their congregations. Such a study should substantially further develop the research design and sampling of the current research, ensuring that persons with disabilities, primary caregivers of persons with disabilities, church leaders and congregants from each denomination are suitably represented in a sample large enough to additionally perform statistical analyses of the data obtained from a mixed-method approach, where multiple instruments are employed through both qualitative and quantitative measures. In this way, the findings may be generalized beyond the study's parameters and make considerable contributions to the existing literature.

CONCLUSION

Numerous connections were made between the participants' themed responses and the ICF, with 27 links between the data and the corresponding ICF Environmental Factors component, representing environmental codes from all five chapters. Most data links were within the category, *Attitudes* (Chapter 4). Since a facilitator that is absent or insufficient (despite its existence) comprises a barrier (WHO, 2001), the participants identified no enabling factors in their congregation. Participant responses linked with Chapter 1 related to the absence, or inadequacy of facilitators, while data links with Chapters 2-5 were associated with imposed barriers. Participants thus considered the environmental factors at work in their congregation to hinder, rather than enable, the functioning and participation of persons with disabilities.

These compelling links between the health conditions of persons with disabilities and the external influences on their functioning, confirm the occurrence of disability as a social construct, implying that disability is not caused by bodily impairments but instead by debilitating features within the physical, social and attitudinal environment of their congregation. Necessary shifts in the conceptualization of disability that sustain exclusion, and the need to promote belonging and participation in the congregation, were indicated.

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The authors declare no conflicts of interest concerning the research, authorship, and/or the publication of this article.

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APPENDICES

Tables 1-3. with table captions on individual pages (p. 60-62)

Figure 1. Structure and flow of the focus group script questions (Attached separately)

Figure 2. Thematic map of emergent themes (Attached separately)