

A SYSTEMATIC REVIEW OF SUPPORTS FOR PARTICIPATION IN FAITH SETTINGS
FOR INDIVIDUALS WITH DISABILITIES

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SUPPORTING PARTICIPATION IN FAITH

Abstract

Individuals with disabilities participate in community settings less than peers. This occurs due to physical and psychosocial barriers. One area of regular community participation is in faith settings, however there is a lack of evidence on how to support inclusion in these settings. This systematic review identifies what supports individuals with disabilities and their caregivers reported that assists with participation in faith settings. A review was conducted and articles were evaluated. The studies were analyzed for specific supports and then compared to determine the frequency at which the supports were mentioned. It was concluded that physical accessibility and a welcoming, supported attitude were top-mentioned supports. Two out of the three top results represent low-to-no cost supports to increase inclusion.

Key Words: Intellectual disability, developmental disabilities, faith inclusion, religion, inclusion

SUPPORTING PARTICIPATION IN FAITH

Introduction

For individuals with disabilities, community participation is considered an important indication of positive health outcomes and overall rehabilitation (Chang, Coster, & Helfrich, 2013). Those with disabilities often experience decreased community participation due to a variety of barriers which can result in decreased quality of life, mental health, overall health, and social outcomes (Amadao, Stancliffe, McCarron, & McCallion, 2013; Chang, et. al., 2013). According to the American Occupational Therapy Association (AOTA), “all people, regardless of abilities, should have access to, choice of, and an opportunity to participate in a full range of community activities” (P. 1, Ideishi, D’amico, & Jerikowic, 2013). According to AOTA’s Occupational Therapy Practice Framework, community participation is defined as “engaging in activities that result in successful interaction at the community level (e.g., neighborhood, organization, workplace, school, religious or spiritual group)” (p. S21, 2014).

Additionally, the World Health Organization’s International Classification of Functioning, Disability, and Health (ICF) lists the importance of considering “community, social, and civic life” when looking at activities and participation of an individual when considering the overall impact of disability (p. 16, 2001). The ICF encourages examination of barriers and facilitators to participation when looking at the environmental impacts on disability (World Health Organization, 2001). In a world where individuals with disabilities are increasingly able to be physically included in different settings, the focus has transitioned to social inclusion as well (Amado et. al., 2013). For individuals with intellectual and developmental disabilities, physical inclusivity is often not the main barrier to participate in community settings (Amado et. al., 2013). The United Nations Convention on the Rights of

SUPPORTING PARTICIPATION IN FAITH

Persons with Disabilities states that social inclusion or participation is a right and an obligation for society (United Nations, 2006).

One area of regular and ongoing community participation for a majority of people in the United States is within faith settings (Kessler Foundation, 2010). According to Boswell, Hamer, Knight, Glacoff and McChesney, participating in faith traditions can provide individuals with disabilities with purpose and meaning, connections with their community, a place to express creativity, and a place to experience acceptance (2007). Minton and Dodder reported that individuals with disabilities express a desire to participate in religious activities (2003). However, it is well documented that people with disabilities and their families participate less in faith-based settings, this is due to a variety of barriers (Kessler Foundation and National Organization on Disability, 2010; Poston and Turnball, 2004). Barriers identified in the literature are physical and psychosocial in nature. Attitudinal barriers, a lack of understanding, acceptance, and support have been noted in various studies (Ault, Collins, & Carter, 2013a; Ault, Collins & Carter, 2013b; Carter, Boehm, Annandale & Taylor, 2016). Many position statements, professional opinion papers, and studies which use religious leaders and congregants as participants call for the need to increase inclusion for those with disabilities in faith settings (Carter, 2016; Collins & Ault, 2010; Collins, Epstein, Reiss, & Lowe, 2001; Goldstein & Ault, 2015; McGee, 2010; Poston & Turnball, 2004; Richie, 2015, Slocum, 2016). However, only recently has research included the perspectives of those with disabilities or family members of people with disabilities in identifying supports for participating in faith settings. There is a mantra from the disability community when discussing disability policy and research that says “nothing about us, without us” that encourages those enacting change to include voices from the disability community (Scotch, 2009). Therefore, the aim of this systematic review is to examine

SUPPORTING PARTICIPATION IN FAITH

supports to participation in faith settings as identified by those with disabilities or their caregivers and families. The question that guided this review is: For people with disabilities or their families, (Population), what supports increased participation (Intervention) in faith-based settings (Context)?

Method

Design

A systematic literature review was conducted as outlined in the following sections. It was conducted by two experienced occupational therapists, one with a PhD and one PhD student. The two researchers conducted the review independently and then compared results until a consensus was reached regarding the inclusion of articles and analysis following the four-step processes of Gough, Oliver, and Thomas (2012). This four-step approach included a systematic search, a screening of the literature, appraisal of literature and data extraction and synthesis.

Systematic search.

The systematic search stage began by accessing the following online journals: The American Journal of Occupational Therapy (all volumes) and the databases EBSCOhost, Cochrane Reviews and PubMed using the specific search engines: Academic Search Complete, CINAHL/CINAHL Full Text, ERIC, Health Source, MEDLINE Psychology and Behavioral Sciences Collection, and Psych Info. This comprehensive search included all of the previously listed databases which have been known to contain information regarding disability research. Searches from the date of inception till present time of all the databases were utilized. The only limits utilized were for articles to be peer-reviewed to ensure rigor, and articles written in the English language. Various interchangeable terms were utilized to identify “inclusion” and “participation” as well as various terms to encapsulate any sort of faith participation. For the

SUPPORTING PARTICIPATION IN FAITH

purposes of this study, research discussing all types and denominations of faith-participation were considered. Boolean phrases and the use of an asterisk with roots of words assisted with expanding the search. The following search terms were utilized:

Disabilit* OR Develop* Disabilit*

AND

Inclus* support* OR inclusi* OR participate* OR integration

AND

Church OR religio* OR faith OR Worship OR congregation

NOT: school, education, employ*

A hand search was also completed with relevant articles to identify any further studies that were not identified through the online searches. The following inclusion and exclusion criteria were applied:

- Inclusion: All types of disability
- Exclusion: Articles that did not specifically include people with disabilities or their caregivers as research participants, community participation outside of church/religious participation, expert opinion, and unpublished dissertations.

Screening of the literature.

After the comprehensive literature search, a screening process was utilized to pare down the relevant information (See Figure 1 for the PRISMA flow diagram). A total of 441 references were identified through EBSCOhost using the various search engines. No additional references were identified through PubMed, Cochrane Reviews, the American Journal of Occupational Therapy, or through hand searches. Of those articles identified, 357 were excluded based on title and/or abstract of the article due to not being relevant to this systematic review. Eighty-four full-

SUPPORTING PARTICIPATION IN FAITH

text articles were then accessed to see if the study met eligibility criteria, of which 79 did not. Of those that did not meet eligibility criteria, 21 were expert opinions, essays or literature reviews, 54 were deemed to be not relevant based on further inspection as they did not relate to the topic of interest, and four were excluded because the subjects did not include those with disabilities or caregivers of individuals with disabilities. A total of five research articles therefore met inclusion criteria and were reviewed, see Table 1.

Appraisal of included studies.

The appraisal for each study included in this review was based on the Mixed Methods Appraisal Tool (MMAT). This tool allows studies that are qualitative, quantitative or mixed-methods in nature to be compared based on methodological quality (Pluye, Robert, Cargo, Bartlett, O’Cathain, Griffiths, Boardman, Gagnon, & Rousseau, 2011). See Appendix A for the application of the MMAT for the studies included in this review. All studies were included regardless of methodological quality for this review. A percentage of MMAT criteria met was utilized to objectively compare study quality across methodological domains.

All of the studies reviewed included clear objectives of the study and utilized data collection that sufficiently answered the research questions. For the qualitative studies included, both studies utilized sources and data analyses that were relevant to address the research questions

The MMAT is comprised of four questions and is meant to be a tool to compare qualitative, quantitative and mixed-methods studies. The questions, while they assist with analyzing the quality of a research study, are limited and not comprehensive for any one type of methodology. The researchers included the analysis table in Appendix A to narratively highlight some of the strengths and weaknesses of each study following the MMAT criteria to provide a

SUPPORTING PARTICIPATION IN FAITH

more comprehensive analysis of the studies. The translational science of increasing inclusion for those with disabilities in faith settings is in its infancy and thus all peer-reviewed literature has been deemed valuable for this systematic review.

Data extraction and synthesis.

Information regarding the study design, population, respondents and a summary of results were extracted by these independent authors from each included article and are detailed in Table 2. The five studies were manually analyzed to determine what supports the respondents listed as being helpful for participation in faith settings for people with disabilities. The results were then compared across studies to identify common supports. The supports were compared between the two researchers until consensus was met to ensure agreement of themes. All supports were then listed in a table and the frequency of a given support were totaled. This information can be found in Figure 2.

Results

Data Description

The total study sample ($n = 1,012$) from all of the articles that were reviewed included 945 respondents that identified as having a disability or being the caregiver of a person with a disability. The Griffin et. al. article (2012) was the only study included that also had respondents that were not individuals or caregivers of an individual with a disability. In this study, the rest of the respondents ($n = 67$, or 47% of study participants) were leaders from various faith communities such as pastors or other lay leaders. All of the studies included respondents that identified from various faith traditions (e.g. Buddhism, Judaism, Mormon, Quaker) but the majority of respondents were from Christian faith backgrounds, including Catholic and Protestant traditions. The participants from all of the included studies were largely individuals or

SUPPORTING PARTICIPATION IN FAITH

families of individuals with an intellectual or developmental disability (n=1,261, 93%). Other identified disabilities included in the articles were: traumatic brain injury (n=20, 1.4%), orthopedic impairment (n= 17, 1.2%), emotional or behavioral conditions (n=42, 3.1%), and significant health impairment (n=16, 1.1%).

Ault, et. al. 2013b used a qualitative, open-ended response survey while the other studies utilized quantitative close-ended surveys (Ault, et. al. 2013a, Carter et. al. 2016, Griffin et. al. 2012). The Hobbs et. al. (2016) article utilized individual interviews for data collection. All of the studies were conducted within the United States and were published between 2012-2016.

For further analysis, the findings were then categorized by the researchers into two groups—physical accommodations and social-emotional accommodations (Table 3). The further classification of the supports can be used for translational change for congregations as practical ways to increase participation for people with disabilities in their congregations. Often, the discussion of inclusion for those with disabilities centers around physical accessibility of the facilities. Faith-based institutions are currently exempt from the Americans with Disabilities Act (1990) which means they are not required to follow physical accessibility guidelines contributing to barriers for individuals with physical disabilities. Additionally, congregations may reside in historic buildings where options for making physical accommodations may not be feasible or may be too costly. This researcher wanted to highlight that improving physical accessibility of a faith-setting is only one of the various supports mentioned in the literature. Likewise, there are many supports that have been mentioned in the literature that include low-to-no cost for people with disabilities. All of the supports to participation mentioned were extracted from the results of the included articles. See Figure 2 below for a chart that displays the frequency of supports mentioned in the literature.

SUPPORTING PARTICIPATION IN FAITH

Discussion

The top three supports mentioned throughout the articles were physical accessibility, welcoming and positive attitudes, and education and training for congregants. These three supports were equally mentioned in four out of the five assessed articles as helpful for increasing participation for individuals with disabilities. While physical accessibility isn't always a problem for individuals with intellectual and developmental disabilities, the top mentioned supports are very applicable in assisting participation for individuals with intellectual and developmental disabilities.

Other supports mentioned in three of the five articles include: parental support during worship services, parental support outside of worship services, spiritual counseling or counseling groups, specialized worship services for individuals with disabilities and accessible materials. All of these aforementioned supports were listed by individuals and families of individuals with intellectual and developmental disabilities as helpful to increase their participation. Supports mentioned in two out of the five included articles included: support groups, the role of a leader or advocate within the congregation to support the person with a disability and providing volunteers, peers or tutors to assist people with disabilities. Other supports mentioned in only one of the reviewed articles include: providing transportation support, providing financial support, offer roles within the congregation that an individual with a disability could fulfill, provide resource centers, have a relationship with a disability community or organization, provide modified services, provide supports for vocational training, encourage parents of individuals with disabilities to take a leadership role to educate the community, and provide adaptive social events or teams.

SUPPORTING PARTICIPATION IN FAITH

The supports mentioned in all of the articles were further broken down into physical and social-emotional supports by the researchers to assist with application. Some supports such as positive and welcoming attitudes and providing specific roles which individuals with disabilities can participate in, are of little-to-no cost to a congregation and could be very practical first steps for a congregation wanting to increase participation for those with intellectual and developmental disabilities. Additionally, one of the supports listed, having an identified leader or advocate within the congregation, could help families and other leaders in the church to bridge the gap of needs that individuals with disabilities and their families may have.

While physical accessibility was a top mentioned support, it was not the only support mentioned in a majority (4/5) of the articles. One of the themes that reoccurred throughout most of the articles was the theme of congregations having positive and welcoming attitudes towards people with disabilities (Ault et. al., 2013a; Ault, et. al., 2013b; Griffin et. al., 2012; Hobbs et al, 2016). This highlights the importance of attitudinal shifts that still need to occur within our society to support participation for people with disabilities. Attitudinal barriers as a limitation to participation in society for those with intellectual and developmental disabilities has been well documented (Anaby, Hand, Bradley, DiRezze, Forhan, DiGiacomo, and Law, 2013; Centers for Disease Control and Prevention, 2017; Law, Petrenchik, King and Hurley, 2007; Rimmer and Rowland, 2008). According to the results of this systematic review, it is understood that these attitudinal barriers that people with disabilities experience in society, also occurs within faith environments. Changing thoughts and attitudes towards people with disabilities often occurs through education and relationship, both of which could be of little-to-no cost to a faith institution as well.

SUPPORTING PARTICIPATION IN FAITH

Three-out-of-five articles included both the need for parental supports during and outside of worship services (Ault et. al., 2013a; Ault, et. al., 2013b; Carter et. al). A majority of parents (55.3%) polled in Ault et. al., reported being expected to stay with their child with an intellectual or developmental disability during worship services instead of allowing the child to attend the children's programming without the parent, thus impeding the parents' own faith participation as well (2013b). Parents and caregivers of children with developmental disabilities are at a higher risk of marital dysfunction, mental illness, and caregiver burnout (McConnell and Savage, 2015; Weiss, 2002). These risks can be exacerbated by isolation due to decreased participation in valued community activities, such as faith settings. Therefore, providing supports like respite or other assistance outside of the weekly worship services may have positive implications for the families and caregivers of individuals with a disability. Other inexpensive actions that can be taken include: spiritual counseling, specialized worship services, accessible materials, providing support groups, having a disability advocate in the community, providing peer tutors, establishing relationships with disability organizations, and providing resources to members.

One surprising finding in the Carter et. al. article was that there was a large discrepancy between the amount of supports rated by parents as being helpful and the amount of supports actually offered at the respondents' respective congregations (2016). This further highlights that individuals with disabilities and their families are not receiving enough support within their faith setting to participate to the extent of which they desire. Ault et. al. reported that almost one third (32.3%) of parents of individuals with disabilities have changed their places of worship due to their child not being supported or welcomed. Almost half (46.6%) of parents surveyed had limited their own participation in a religious activity directly due to their child not being supported (2013a). Additionally, Carter et. al. found a positive link between the amount of

SUPPORTING PARTICIPATION IN FAITH

supports offered within a congregation and the amount and duration of time that a family attends that congregation.

The implications for this systematic review are two-fold. The first implication is to demonstrate that research on community inclusion, and more specifically religious participation, for individuals with disabilities from the perspective of those with disabilities is in its infancy and further studies need to be completed to support this population. Secondly, this study describes important supports that faith congregations can put into place to increase participation for individuals with disabilities and their families.

Often disability inclusion is thought in terms of costly physical accommodations that may not be feasible or affordable for congregations. These researchers wanted to highlight that physical inclusion, which may include costly renovations, is only one support listed in the literature to increase participation for those with disabilities. Furthermore, these researchers found that many supports mentioned by individuals with disabilities and their caregivers or families included low-cost options which congregations could begin adopting more readily than some of the more expensive supports that were mentioned.

The supports were divided between “physical accommodations” and “social emotional accommodations”. The physical accommodations included supports or changes to the physical environment as well as social environment and these supports tended to be costlier. Whereas the social emotional accommodations included low-to-no-cost supports such as congregations having a welcoming/positive attitude towards people with disabilities, having leaders who are knowledgeable about various disabilities and who act as role models to support inclusion, and offering roles within the congregation that those with disabilities could fulfill. These supports to participation could easily be adopted into any congregation or community setting. The list found

SUPPORTING PARTICIPATION IN FAITH

in Table 3 can further provide practical, evidence-based supports for those who want to promote participation for those with disabilities in their congregation.

Limitations:

There are limitations to this study, beginning with the design of the studies chosen which have limited strength of evidence due to their survey design. While the author conducted a comprehensive search of the literature, only five articles were found that addressed this topic explicitly from the perspectives of people with disabilities or their caregivers. Thus, all studies found were included, regardless of level of evidence or quality to begin assisting congregations in ways to be more inclusive. Another limitation of this study is that it is difficult to compare results across studies. The authors tried to facilitate comparison by doing a comprehensive frequency count (Figure 2) of supports that were mentioned throughout all of the articles. Several supports were combined such as respite care which was included under “parental supports outside of worship services.” However, even with the frequency distribution provided, it is difficult to compare results across studies due to the various study designs and how results were reported. For example, even though most parents reported physical accessibility would be a top support for their congregation to have overall, it was listed between “not at all helpful” or only “a little helpful” for their family across studies since the majority of the respondents did not have an orthopedic impairment. Thus, the wide variation of needs for individuals with disabilities necessitates that these are broad suggestions, not specific to any one disability or condition, which may be seen as a limitation to this study.

Another limitation of this study is the concern for validity within studies. Many of the studies utilized instruments that were created by the researchers and not validated in populations prior to their respective studies. Thus, the tools that the authors utilized could have been biased,

SUPPORTING PARTICIPATION IN FAITH

or could have missed valuable information. Additionally, with one of the qualitative studies (Hobbs, Bonham & Fogo), the actual format of the questions were not included, thus there could have been a leading question bias with the interview questions. Additionally, unpublished research articles and dissertations were not included in this systematic review which may have resulted in relevant research findings being omitted. Yet, the authors made every attempt to control for each limitation with their final goal to ultimately increase family participation in faith settings.

Conclusion

This is the first systematic review conducted on identifying specific supports to increase participation for individuals with disabilities in faith communities. The most frequent actions a group can make to increase participation for all members in faith-based settings are:

- Offer welcoming/positive attitudes towards all members
- Make the environment more accessible
- Provide education and training to members
- Offer parental support during worship services
- Equip parents with support outside of worship services
- Provide spiritual counseling
- Host special worship services for people with special needs
- Make available accessible materials
- Provide support groups
- Create the role of an advocate to support individuals with special needs
- Come up with peer tutors, volunteers or hire assistants

SUPPORTING PARTICIPATION IN FAITH

Despite the limitations, this systematic review provides valuable information and insights into specific supports that congregations can provide to increase participation for individuals with disabilities. The World Health Organization's ICF model encourages clinicians to consider barriers and supports to participating in activities such as community life (2001). Until recently, participation in religious settings for individuals with disabilities has not been studied, yet remains an important part of most peoples' lives. Participation in religious communities can have a positive impact on one's physical and mental health (George, Ellison and Larson, 2009). Future research should include more rigorous and generalizable studies so that individuals with intellectual and developmental disabilities can participate to the extent that they desire in congregations. Future studies should focus on evaluating the effectiveness of listed supports on increasing participation for individuals with disabilities in faith settings. Future research could also examine the impact of increasing participation in faith settings on satisfaction and quality of life measures for individuals with disabilities.

SUPPORTING PARTICIPATION IN FAITH

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SUPPORTING PARTICIPATION IN FAITH

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SUPPORTING PARTICIPATION IN FAITH

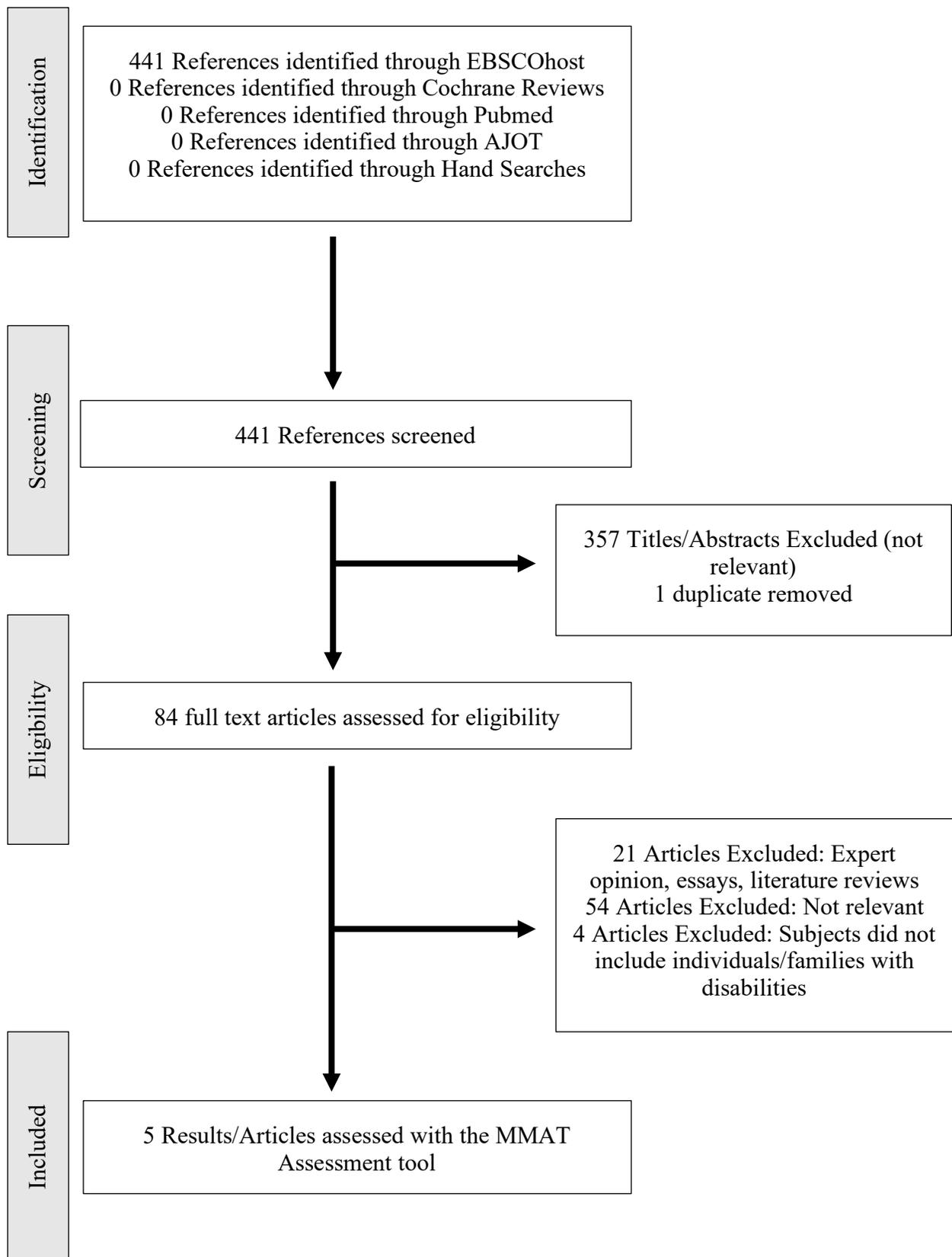
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Figure 1: PRISMA Flowchart of Study Selection



Frequency of Mentioned Supports

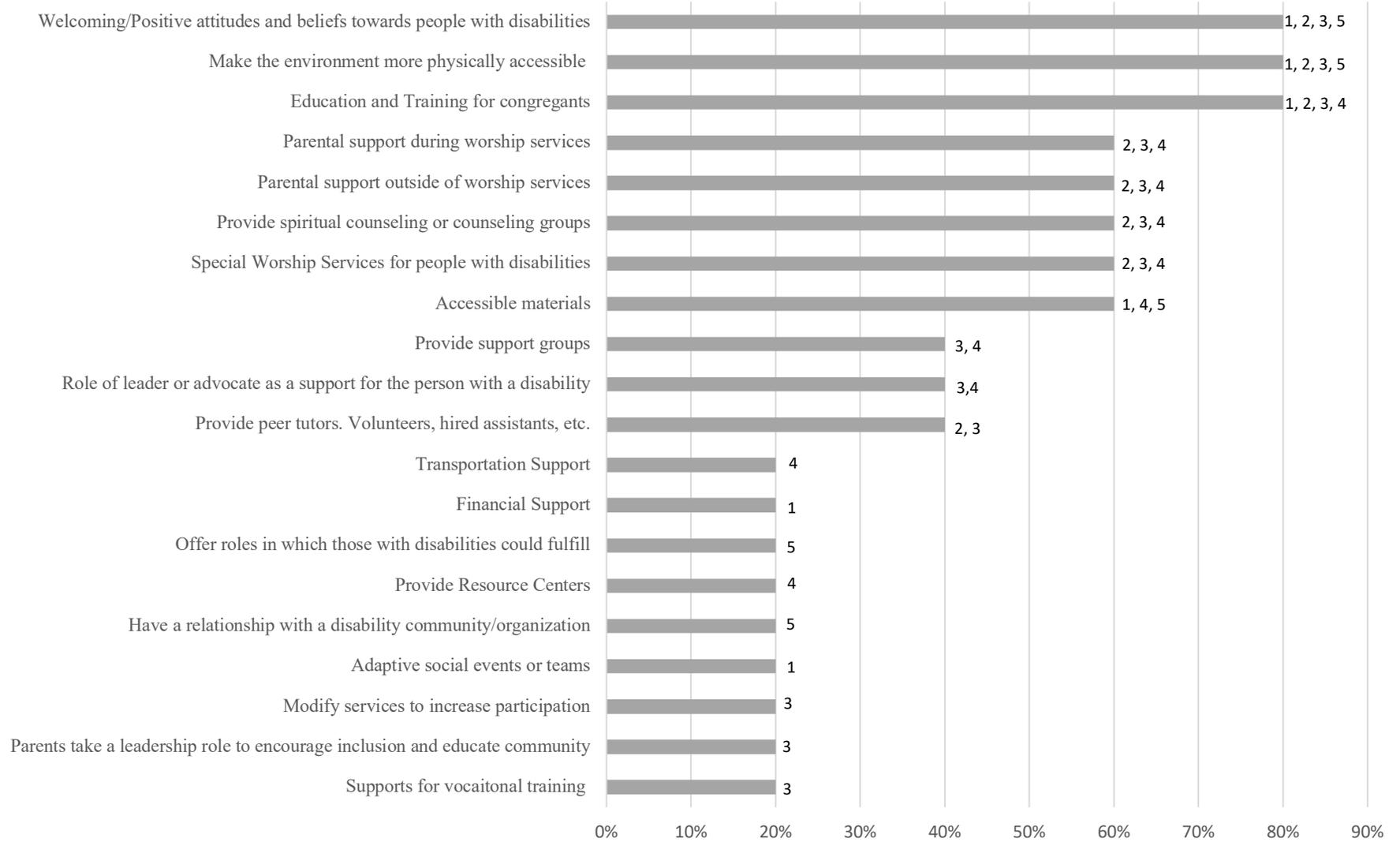


Figure 2: Frequency of Supports Mentioned Key- 1: Hobbs, et. al. (2016), 2: Ault et. al. (2013a), 3: Ault et. al., (2013b), 4: Carter et. al. (2016), 5: Griffin et. al. (2012)

Table 1: Articles Included in this Review

Study Design/ Methodology of Articles Retrieved	Level of Evidence	Number Located	Author (Year)
Qualitative- Semi-structured interviews	5	1	Hobbs, Bonham, & Fogo (2016)
Quantitative- Close-ended survey	5	3	Ault, Collins & Carter (2013a) Griffin, Kane, Taylor, Francis & Hodapp (2012) Carter, Boehm, Annandale & Taylor, (2016)
Qualitative- Open-ended survey	5	1	Ault, Collins & Carter (2013b)

Table 2: Summary of Included Articles

Authors	Title	Journal/ Year	Study Design (n=sample size)	Population	Respondents	Results: Supports That Were Rated as Helpful	MMAT Criteria Met
Ault, Collins, Carter	Congregational participation and supports for children and adults with disabilities: Parent perceptions	<i>Intellectual and Developmental Disabilities</i> 2013a	Quantitative-close-ended survey (N=416)	Families of Children with Developmental Disabilities	Parents and Caregivers of a child with a developmental disability	<p>Top rated helpful supports included:</p> <ul style="list-style-type: none"> -welcoming attitude towards those with disabilities (91.5%) -support to participate in regular activities (67.3%) -supports for inclusion such as specific programs -education for volunteers/staff -accepting/flexible attitudes -respite/child care for children during services -segregated programs -physical accessibility or rooms to take children who may be having a difficult time -parent support groups (48.1%) -accessible facilities (46.3%) 	25%
Ault, Collins, Carter	Factors associated with participation in faith communities for individuals with developmental disabilities and their families	<i>Journal of Religion, Disability and Health</i> 2013b	Qualitative open-ended survey (N=416)	Families of Children with Developmental Disabilities	Parents and Caregivers of a child with a developmental disability	<ul style="list-style-type: none"> -Accommodations and adaptations to increase inclusion based on the individuals needs -Communities that take ownership to include those with disabilities -Strong leaders who advocate for inclusion for individuals with disabilities -Parental support during and outside of worship services <p>Additionally, the authors found that the age of the child and the size of the congregation impacted participation for the family. In general it was</p>	75%

						found that younger children were easier to include compared to older children, and larger congregations tended to have more supports for families compared to smaller congregations.	
Carter, Boehm, Annandale, Taylor	Supporting congregational inclusion for children and youth with disabilities and their families	<i>Exceptional Children</i> 2016	Quantitative close-ended survey (N=433)	Families of children and youth with disabilities	Parents and caregivers of a child, youth, young adult with a disability	<ul style="list-style-type: none"> -Top-rated supports were for the parents instead of directly to/for the child. Top 5 rated supports were: <ul style="list-style-type: none"> -support groups for parents -congregation-wide disability awareness efforts -resource center -advocates to work with families -respite care -Physical accessibility least-helpful rated support -44% of survey respondents indicated that their current congregation offered none of the 14 listed supports. -Larger congregations tended to have more of the supports listed available compared to smaller congregations. -The more supports a congregation offered, the more they were perceived to be committed to the inclusion of people with IDD. 	75%
Griffin, Kane, Taylor, Francis, Hodapp	Characteristics of Inclusive Faith Communities: A preliminary survey of inclusive practices in the united states	<i>Journal of Applied Research in Intellectual Disabilities</i> 2012	Quantitative close-ended survey (N=160)	Individuals with disabilities	Parents/Caregivers with disabilities, individuals with disabilities, leaders in faith communities and participants of faith communities.	<ul style="list-style-type: none"> -leaders committed to inclusion -welcoming to those with disabilities -roles for people with disabilities to fulfill -physical accessibility -use of educational resources to increase inclusion -positive portrayal of people with 	0%

						disabilities -commitment to social justice -positive relationships with community disability organizations	
Hobbs, Bonham, Fogo	Individuals with disabilities: Critical factors that facilitate integration in Christian religious communities	<i>Journal of Rehabilitation</i> 2016	Qualitative semi-structured interviews (N=3)	Adults with various disabilities (blindness, orthopedic impairment, spinal cord injury)	Adults with disabilities directly interviewed	-Physical accommodations -Emotional and social support from the congregation -Acceptance as a contributor to the congregation -Understanding by other congregation members	75%

Table 3: Categorized Supports

Physical Accommodations	Social Emotional Accommodations
<p><i>Physical Environment</i></p> <ul style="list-style-type: none"> - Make environment more accessible - Transportation Support - Supports for vocational training - Accessible materials <p><i>Social Environment</i></p> <ul style="list-style-type: none"> - Parental support during worship services - Parental support outside of worship services - Special worship services for people with disabilities - Parents take leadership role to encourage inclusion and educate community - Modify services to increase participation - Provide peer tutors, volunteers, hired assistants - Adaptive social events or teams 	<ul style="list-style-type: none"> - Education/Training on disability, behavior and inclusion - Spiritual leaders knowledgeable and inclusive that role model to the congregation - Provide support groups - Offer roles for the disabled participants to fulfill - Provide resource centers - Have a relationship with a disability organization - Provide spiritual counseling - Welcoming/positive attitudes and beliefs towards people with disabilities and their families