

Understanding the Religious Experience of Children with Autism in the Catholic Church:

An Overview of Contextual and Behavioral Factors

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Abstract

In attempting to understand how children with autism fit into the religious context, most previous research has focused on the experience of parents. No previous research attempted to evaluate the multi-faceted experience of people with autism. This study aims to obtain a preliminary understanding of the complex factors associated with the experience of religion in children with autism. A greater understanding of this context may increase meaningful participation of people with autism in religion. The study utilized interviews and surveys of church staff members as well as surveys of parents of typically developing children and children with autism. Inclusion was the most commonly cited concern and obstacle but several other factors were recorded as difficult for people with autism. A preference for routine as well as evidence for the experience of suffering were noted.

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Introduction

The relationship between people with autism and their surrounding world is a topic of increasing consideration as 1 in 59 children are affected by autism (Baio, et al., 2018). The social difficulties, lack of abstract thinking and use of metaphorical language can make negotiating the world especially difficult for someone with autism. Seldom examined, is perhaps the most abstract context of all, the religious and the spiritual. This study seeks to investigate the experience of children with autism raised in Catholic households in the religious context.

Very little is known about the religious experience of children with autism. The majority of study has been on the families of children with autism and the beliefs of the parents. Tarakeshwar and Pargament (2001) found that religion plays an instrumental role in the coping of parents of children on the spectrum. This means that children with autism are commonly raised in households where religion is an important factor, however the experience of the individual with ASD and its potential for coping has yet to be investigated. Furthermore, it has been documented that parents of children with autism and down syndrome undergo significant spiritual changes as they examine their role, their child's role and experience novel sensory difficulties (Segal, 2004; King, et al., 2006). These changes may be a protective factor which increase resilience for families (Greeff & Walt, 2010). Not only do families benefit, but religion has been shown to increase acceptance of diagnosis and increase well-being in other mental health diagnoses (Nosek, 2001; Corrigan, McCorkle, Schell, & Kidder, 2003). Given this information, it is clear that the religious context is an important factor to examine when looking at the roles that people with autism play.

This study examined the psychology of religion as previous researchers have by studying "people in relation to their faith" (Hood, Hill, & Bernard, 2018). This study looks solely on

members of the Catholic Church but it is important to understand the universal components of religion, “Religion may encompass the supernatural... it may also include the practices, beliefs and rituals.” (Hood, Hill, & Bernard, 2018). Because of the hierarchical structure of Catholicism, many of the elements of religion are consistent across churches and geographic areas and so many definitions are standardized across the country which eliminates many variables from this study. Catholic ritual is centered around the Eucharistic celebration (Mass) which involves a community gathering, reading from scripture and consuming consecrated bread (Catholic Church, 1994). Other ritual practices are considered crucial, these are known as “sacraments” which are defined as outward expressions of God’s love which can occur at certain times of life (United States Conference of Catholic Bishops, 2019). Examples include Baptism, Penance and Eucharist. All sacraments involve some sort of sensory experience and prayerful. Catholic belief can be very complex so classes known as “catechesis” are commonly employed to educate young children. Catechesis “is the act of handing on the Word of God intended to inform the faith community and candidates for initiation into the Church about the teachings of Christ, transmitted by the Apostles to the Church.” (United States Conference of Catholic Bishops, 2019).

The most important religious ritual in Catholicism is the Eucharistic celebration, commonly referred to as the Mass (Catholic Church, 1994), this is a communal celebration which may pose a significant problem to people with autism as socialization presents with increased difficulty and may limit religious participation (Dubin & Graetz, 2009). A lack of participation in religious activities by people with autism has, in fact, been documented (Terry, 2015). However participation is not the singular obstacle; a survey of 416 participants indicated that even when children with developmental disabilities are involved in religious activities,

parents are frequently dissatisfied with a lack of support (Ault, Collins, & Carter, 2013).

Religious engagement could provide a solution to the current problem of low social engagement and decreasing community engagement of people with autism as they leave the school system (Orsmond, Shattuck, Cooper, Sterzing, & Anderson, 2013; Tobin, Drager, & Richardson, 2014; Myers, Davis, Stobbe, & Bjornson, 2015).

Preliminary research indicates that people with autism are more likely to come up with their own belief system and less likely to participate in organized religion (Caldwell-Harris, Murphy, Velaquez, & McNamara, 2011). It has also been noted that autobiographical essays written by people with autism frequently contain spiritual experiences (Swinton & Trevitt, 2009). This suggests that people with autism have no less of a desire for the transcendent than the general population (Deeley, 2009). There is no documented evidence that indicates fewer people with autism desire to have or have spiritual lives; however, the significantly decreased religious participation does indicate a qualitative difference in the religious experience.

It is possible that this qualitative difference can be explained in terms of the previously discussed social variable as well as differences in cognition related to language. People with autism have trouble with figurative language and abstract reasoning (Baron-Cohen, 2000; Dennis, Lazenby, & Lockyer, 2001; Landa & Goldberg, 2005) This poses a problem when a significant portion of the Bible is written in metaphoric language and is not to be taken literally. The language difficulties are not only with figurative language. Figurative language is so common in Catholic teaching because there is no language which is considered adequate to describe the abstract concepts which are considered beyond human reasoning, ergo beyond human language. (Catholic Church, 1994). The transmission of abstract concepts into expressions of language is especially difficult given the characteristics of autism and the

tendency for people with autism to “think in pictures” (Grandin, 2008; Kunda & Goel, 2011).

There are significant limitations to expressing religious concepts in language for typical populations. People with autism face even greater difficulty with their limited ability to express concepts in language. Relational language may further complicate this problem as relationships are often used to explain spiritual concepts and relationships are challenging for someone with autism to understand (Swanson, *Autism: Forming Faith through a Community of Inclusion*, 2010). Swanson notes her experiences in a case study where she eliminated the use of language for her student and only used experiential methods of explaining God and had very positive results (Swanson, 2010).

Not only may language and abstractions be at the crux of the autism and religion tension, but language may limit the study of the experience of children with autism on religion (Lewis, 2009). The present study seeks to eliminate this variable by exploring context and observable behavior to establish a clearer foundation to describe the religious experience of children with autism without having people with autism put their experiences into words. The spiritual aspects of religion are sometimes separated from other components for more targeted study; however, this study seeks to provide a comprehensive look at religious experience which includes spiritual experiences and ideas.

A more holistic understanding of the religious experience will aid clinicians, parents and people who work in ministry settings to understand the needs of people with autism. These needs may stretch out among several components of religious experience including participation in community religious practices, understanding and responding to religious content as well as helping people with autism accept their diagnosis and improve their quality of life.

Methods

Participants

Professional Interviews

Five professionals were interviewed, all of whom worked for a Catholic parish in an administrative and direct role in pastoral care for youth, some of whom were on the autism spectrum. All of these participants were women. Their professional titles were either coordinator of faith formation or director of faith formation. All of the women reported that their parishes were in suburban areas though their faith communities were of varying sizes. All of the women had a Bachelor's degree, with two of them having master's in special education. Snowball sampling was the primary means of obtaining all participants. The content of the interviews was used to deepen the understanding of the qualitative results of the staff survey.

Professional Surveys

There were 32 survey respondents in total. Two of the surveys were excluded because they were returned from pastors in other countries; international data is outside the scope of this study. Data was collected from catechetical leaders in 18 different states and 27 different parishes. Seven parishes were described as rural, 17 suburban and 3 urban. Twenty-five respondents identified themselves as directors of religious education and/or youth ministers, 3 reported another ministry position and 2 opted not to identify their position.

Parents Surveys

Two groups of parents were surveyed: parents of typically developing children and parents of children on the autism spectrum. Forty-six parents responded to the survey directed towards parents with children on the autism spectrum. One of the surveys was excluded because the parent reported that his child did not have a diagnosis of autism spectrum disorder. Thirty-four

parents responded to the survey for parents of typically developing children. One survey was excluded due to the fact that the parent reported that his child was not typically developing. Many participants expressed hesitation about filling out the survey because the topic of both their child's potential limitations and spirituality are sensitive topics. Some demographic questions were not asked of parents of atypically developing children due to the personal and sensitive nature of asking questions about the interior life and challenges facing children with autism. Having extremely limited demographic information was to benefit the participants in the study and maximize response rate. Questions about age were asked about the children but not the parents in order to ensure that their anonymity was maintained. The average age of the child with autism whom information was collected about was 10 years old. Twenty-three families reported being from suburban areas, 12 urban, and one other. More demographic questions were asked of the parents of typically developing children as it was assumed that their perception of vulnerability would be less than that of parents of atypically developing children. Thirty-two females and one male responded with a mean age of 38.4 years. The average age of the child they were providing information about was 10 years old.

Materials

Professional Interviews

All interviews were conducted over the phone. Interview questions were those later included on the self-designed survey, discussed in the next section.

Professional Surveys

Snowball sampling was used, with email as the primary dissemination tool. Google forms hosted the survey. The survey was posted by a participant on a Facebook group for people who work for the catholic church who are interested in serving those with special needs. The survey tool was

self-designed and composed of multiple choice, fill in, yes/no and open-ended questions.

Questions were aimed at understanding the demographics of the parish and understanding specific institutional obstacles which impact the religious experience of children with autism in the Catholic Church.

Parent Surveys

Snowball sampling was used, different religious organizations were provided with surveys and encouraged to disseminate them. Surveys for parents of typically developing and atypically developing children were disseminated separately. Surveys were posted by participants to websites and Facebook groups and available at moms' Bible studies. The survey tool was self-designed and composed of multiple choice, fill in, yes/no and open-ended questions. Questions were aimed at understanding the frequency of observed religious behaviors with special attention paid to religious questioning behaviors as it is assumed that questions provide more organic evidence as to the spiritual and religious concerns of children with fewer environmental and community influences.

Design and procedure

Professional Interviews

Interviews were conducted over the phone and ranged in length from 15-40 minutes.

Demographic questions were asked in multiple choice form and all others were posed in an open-ended format. Though all questions posed initially remained constant, follow up questions were posed in order to clarify definitions of gather more specific information on the topic. Notes were taken during the interview by the interviewer and reflections were written following the interview. Content analysis was performed in order to identify major themes.

Professional Surveys

The survey was designed to take 15-20 minutes of the participant's time (varying with the amount of depth provided on the open ended questions). Descriptive statistics were run on demographic information. Content analysis was performed on open ended questions in order to identify major themes. These themes were analyzed in light of the data obtained by the interviews which provided a greater understanding of the contextual factors influencing the experience of religion for families with children on the autism spectrum.

Parents Surveys

The survey was designed to take 15-20 minutes of the participant's time (varying with the amount of depth provided on the open ended questions). Descriptive statistics were run on demographic information as well as on Likert scale measures. Content analysis was performed on open ended questions in order to identify major themes.

Results

Over the course of this study, a substantial amount of data was collected which indicates some difference in the experience of Catholicism between children with autism and those who are typically developing.

Understanding the Context

There is an awareness among catechetical leaders that children have "psychological conditions which change the way that they participate in church activities." Only one person out of 32 surveyed replied that she did not know of anyone in her parish that had one of these conditions. Though almost all professionals surveyed are aware of these functional limitations caused by psychological conditions, that does not indicate necessarily that there would be accommodations in place for children affected by these conditions. Fifty percent of respondents

indicated that there are accommodations at their parish for children with disabilities 47% indicated that there was not and 3% indicated that they were unsure.

Forty-seven percent of the participants who responded to the item on accommodation expounded on this in a qualitative format. Three of these people indicated that they accommodated on an individual level and 11 indicated that they had an established program in place for children with disabilities. One of the trends identified by interview that was not indicated in the general surveys is that frequently one parish in a large geographic area will host a faith formation program for children with disabilities. Other parishes around the area will send families to the designated parish for faith formation. A limitation that the interviewee identified was that the families sometimes feel as though they are not welcomed at other churches or the church they have attended for years. People can feel as though they are excluded only to an alternative program. The presence of an alternative program was corroborated by the parents surveyed. When specifically asked about the population of children on the autism spectrum, all but one respondent indicated knowledge of at least one person on the autism spectrum.

The survey gave the respondents the opportunity to comment on positive experiences and obstacles they had faced in working with children with autism. Figures 1 and 2 show the themes identified on these questions. The most frequently cited obstacle is a lack of staff or volunteers to support accommodations. Multiple respondents discussed that volunteers are in short supply and usually have no training in how to approach a child with a special need. Because of the short supply of volunteers, professionals did not want to burden them with additional training because they were already giving time to help the parish. An unexpected obstacle that religious professionals are facing is that the parents may be limiting their child's participation in religious activities. Staff members expressed that parents were "not confident we can meet the needs of

their children.” An interviewee with a master’s degree in special education detailed an encounter she had with a family when she smiled knowingly at a family whose child was having a meltdown. She said that the family became extremely defensive. She described that sometimes families have a notion that the church is not open to helping their child and so they do not identify the needs of their child to the parish. Also mentioned in both interviews and surveys was that parents are sometimes unaware that parishes are willing to work with their child. Identification of a child’s needs upon enrollment and inconsistent attendance were all challenges identified by staff. Some of the apprehension described by staff in not accommodating children’s needs is because of the challenging characteristics of autism such as sensory needs, perseveration and rigidity as well as the impact these characteristics have on neurotypical children. One respondent stated that some of the neurotypical teenagers felt like they had to “babysit” the children with autism and some of these teens did not come to youth group when they knew children with autism were going because they were uneasy around them and did not know how to interact.

Though some characteristics of autism were cited as too challenging, others were cited as unique contributions and positive additions to the community. The frank and direct nature of children with autism is thought to “bring new insight.” Several stories emerged of children with autism assuming leadership roles in their church with one student “teaching the rest of us church vocabulary ... and sharing excitement for adoration, singing, serving mass, lecturing and praying.” People also reported that overcoming the challenges of autism in collaboration with families leads to relationships with the person with autism as well as allowing the parents to feel as though the church has responded to and cared for them. Inclusion was a frequent theme,

especially in reference to the sacraments. Successful preparation for these spiritual traditions was frequently mentioned as a special moment.

Parent Questionnaires

When parents were questioned about the contextual environment they told a slightly different story than the parish staff. Out of 45 respondents, only 20% reported that there were accommodations present at their parish. Seventy-eight percent of the parents who responded that there were accommodations described their program qualitatively. 57% of these were individual adaptations, 14% said there was an established program and 28% said that they were sent to another parish.

Parents were also asked about the frequency they observe religious behaviors that their children exhibit. Parents of typical and atypically developing children used a Likert scale to rate the frequency of these behaviors 0 (never or almost never) to 4 (very often). The results are shown on Figure 3. Distributions varied between parents of typically and atypically developing children. Typically developing children were more frequently observed exhibiting all religious behaviors.

Open-ended measures also yielded some differences between the two groups. Problems of inclusion were reported the most frequently among parents of children with autism (Figure 4). Parents reported that they felt unwelcome, were criticized and excluded by other parishioners. Parents also reported that Sunday school teachers did not know how to include their child and parish staff frequently did not allow their child to participate. Parents expressed that the issue of inclusion limited their participation in their parish community as a whole, "We no longer attend services," and "Just keeping him physically present is so hard." People also commented that they were asked by older community members not to bring their child to Mass. Parents of children

with autism also reported a greater number of cognitive obstacles in the religious context with their children. Comments such as “We think he just memorizes things” and “She is nonverbal so we are unsure of her understanding,” indicate some of the obstacles parents have in ensuring they are teaching their child their faith tradition. Furthermore, the theme of conveying abstract concepts to children with autism was another frequently reported problem. Parents described that their children being “literal” and “black and white” made it difficult to explain the concepts of God and the Bible. Both groups reported sensory and attention issues; however, they differed in a qualitative way. Parents of typical children reported that their children had trouble sitting still or would act out if they couldn’t see. Parents of children with ASD reported far more dysfunctional behavior getting in the way of their child’s participation in the community such as stimming, having oral sensory problems with the Eucharist, olfactory sensitivity to incense, auditory sensitivity to clapping and music and other sensory behaviors which can impair participation. Interestingly, parents of typical children reported emotional difficulties that were absent in the atypical surveys. Issues of loneliness, controversy, rebellion and embarrassment were present for typical parents but not for parents of children with autism.

Parent’s expressions of positive behaviors were less variable between the typical parents and atypical parents (Figure 5). The most notable difference between the two groups is how frequently parents of children with autism reported that a social event was the most positive aspect event of their religious experience. Most parents who talked about positive social experiences reported feeling welcome and accepted, however; many parents reported a positive experience of inclusion which eventually faded with the age of their child. Two parents reported that they no longer attend their former church because of these challenges and one reported that their positive experience was going to another church which was inclusive. Most other positive

experiences were reported with more frequency by parents of typical children except the categories of repetitive activities and expressing typical behaviors.

Some parents of children with autism reported their child spontaneously exhibiting a typical behavior. One parent responded that her son holds her hand at Mass and at no other time, another that her son does not reject the Eucharist though his diet is extremely limited; most other respondents reported that their child would spontaneously join them in an activity such as the sign of the cross or singing a hymn.

Parents reported the activities they observe their child spontaneously taking part in (Figure 6). Parents of children with autism reported a greater incidence of ritual activities and a lesser preference for spontaneous activities. Parents of children with autism when asked about which religious activities they observed in their children, they sometimes responded with something their child was *not* doing (a negative response). These responses included “he rarely initiates,” “dreads going to Mass,” and “rarely puts himself out into groups.”

There is a difference in the type of questions parents of typically and atypically developing children reported their children asking. Parents of typically developing children reported that their children’s questions were more theological in nature. Children asked about creation and suffering and many other topics, some of them controversial topics frequently in the news (which was absent in the population of children with autism). About 50% of the questions children with autism asked were more personal. Both the frequency and themes of the personal questions asked by children with autism was different than their typical counterparts. Out of the 3 personal questions asked by typically developing children, 2 asked if they were going to heaven or hell and one asked about the validity of his religion. All of the questions asked by children with autism were about their own sufferings (a classmate’s death) or perceived shortcomings in

religion. Two children asked why God did not answer their prayers and one if God would be disappointed if he could not stay at Mass. Many of the questions were related to their diagnosis: “Why did God make things so hard for me? God, please, help me!” and “Why did God make me this way? Why does God let bad things happen?” Were reported questions asked by parents.

Discussion

Conclusions

One of the greatest contextual factors which affects the religious experience of children with autism is the lack of accommodations especially social support. Parents reported that their child did not have accommodations and was not included far more frequently than religious staff and professionals reported. This could be because the convenience sample accounted only for religious professionals who were aware and invested in helping children with special needs. This could also be more evidence of the phenomenon cited by the religious staff; parents are unaware that parishes are willing to work with the special needs of their family. Religious professionals cited primarily a lack of staff coupled with a lack of understanding of how to help people with autism. This deficit was noted by parents but they were more likely to describe their experience as “unwelcoming” than regard it as a logistical challenge. Parents have more of an emotional tone when describing the problems in accommodation than professionals, which is consistent with their respective roles.

The experience of exclusion and inclusion is one of the most visceral experiences for parents. Among parents of autistic children, both the most frequent positive and negative experience had to do with inclusion. This is not the experience reported by parents of typically developing children. The focus on social and community problems and successes sheds light on the experience of parents with children with autism in more than just the religious context.

Parents are clear that they want their child to fit into the world and this is a greater interest over other components of religious experience. Social interaction is directly affected by autism spectrum disorders so this prioritization makes sense. While this does not directly explain what the experience of the child of autism is, it does give information about an important contextual factor. The people around the child with autism (staff and parents) are frequently most concerned with getting them in the door and having them interact with their community members. This is an important component of religiosity but it is not the only component as defined by (Hood, Hill, & Bernard, 2018). The community emphasis on social interaction provides an important contextual factor when evaluating the religious experience of people with autism.

It is also important to note that most of the obstacles cited both by staff and parents are not obstacles intrinsic to autism but to a lack of an infrastructure that can accommodate the needs of a child with autism. It is more common that the obstacles cited were because of communication or staff problems rather than a deficit specific to the diagnosis of autism.

In addition to the themes of inclusion, cognitive factors were noted in many parents' responses conveying abstract concepts to children with autism was notably difficult, these responses make sense given the characteristics of the diagnosis. Understanding the knowledge of the child with autism and what they understand about their faith was also noted in the population of parents with children with autism this aligns with the deficits of language faced by children with autism. Parents of children more frequently expressed difficulty generalizing religious content when compared with the typical population. Generalization is particularly difficult for children with autism in all forms of education so this report makes sense given diagnostic characteristics. Typically developing populations displayed social-emotional difficulty in religion more often than those with autism. This also could be a function of the fact

that people with autism have lower social awareness as well as trouble expressing emotion, therefore even if these difficulties were present their parents may not know because of the lack of emotional expression.

Parents' increased likelihood to report a lack of religious behaviors provides additional insight into the contextual experience; parents can be preoccupied with what their child is *not* doing. No parents of children with autism reported family traditions that involved going outside of the home while some typical families did, this is indicative of differences in family dynamics that has been documented with children with sensory integration deficits.

A lack of playing with religious items or wearing religious items suggests a lack of integration of faith into the everyday life of someone with autism; this could also be explained by developmental delays which affect play and dressing skills to make this kind of integration unlikely.

On all measures of religious behavior, more people with autism were cited as exhibiting religious behavior than not. People with autism are more likely to engage such as prayer when prompted. The results state that children are more likely to prefer routine. The structure of a routine or a prompt provides an opportunity for religious behavior. This structure alleviates the challenges of abstract thinking. Taking abstraction and spontaneous spirituality out of the religious makes religious behaviors more likely to occur. This factor answers a question about how people with autism are engaging but it does not answer any questions about cognitive and emotional engagement. Children with autism are likely to enjoy the routine aspects of the Catholic faith which could occur for a few reasons. Routine can be soothing because it is routine or the routine can be soothing because they are deeply engaging in a practice which has spiritual significance.

The fact that children with autism are engaging at any level in religious and spiritual activity is notable. Frequently echoed is the notion abstract thinking makes religion inappropriate for people with autism. This is clearly not the case given the data.

Questioning behavior is the only behavior which was *not* expressed more frequently than it was expressed. This can be a function of the characteristic of autism which limits verbal activity. People with autism are not likely to express themselves verbally to make the questions into verbal output. The study did not control for people who were nonverbal which may cause the rates of question asking to be lower.

Of the questions that were asked, the quality of questions asked by children with autism was substantially different compared to their typical peers. Children with autism spectrum disorder were four times as likely to ask questions related to their own personal spiritual experience than those who were typically developing. Many of those questions were regarding their own struggle with autism and why God made them the way that they are. Implicit to these questions is a notion of theological belief. The statement, “Why did God give me autism” implies an understanding of the concept of good and the goodness of the supernatural being, God. Furthermore, the question implies an understanding of creation and being a created being. All of this implicit, abstract knowledge contradicts their experience thus the question is asked: “Why did God give me autism.” They are asking the classic philosophical question, how can a good God allow suffering.

The high proportion of spiritual questions about suffering provides insight about the religious experience of people with autism. These questions demonstrate that although children with autism are largely unable to express abstract concepts verbally, they can implicitly understand concepts such as “good” independently of reward system. This also demonstrates that

children with autism indeed suffered similar to spiritual difficulties as the typically developing population, questions such as “Why am I here” and “What is out there” are not solely owned by those who are typically developing. This may indicate a need for clinical practitioners and religious professionals to address these needs.

Limitations

The most obvious limitation in the present study is sampling bias. The participants (both parents and staff) are those who are actively engaged in helping people with autism experience religion. This sample excludes staff members who are unaware of the special needs of people with autism as well as staff members who do not believe it is their duty to help. This sample also limits parents who may cease engaging with religion altogether because of their child’s limitations. The lack of these perspectives biases the sample.

Furthermore, the instrumentation used has never been piloted or tested as there is no standardized tool that fits the needs of the present study.

Implications

The strong results from parents who suggest that their families feel unwelcomed in the Catholic Church given their child’s conditions implies that more intentional efforts should be made to meet the needs of this population.

The results of the questioning studies of children with autism imply a large role of suffering in the spiritual experience of children with autism. This is of note not only to professionals who work in religion but also clinicians. Religious professionals could use this experience of suffering to build a spiritual formation program as suffering is a large part of the typical Catholic spiritual experience. This is also of note to psychological clinicians, social workers and occupational therapists as all of these disciplines work to increase the social

participation of children with autism. Currently, these clinicians make considerations for social difficulties and anxiety but spiritual unrest is not a typical clinical consideration. The results of this study imply that this could be a larger consideration than previously realized.

Suggestions for further research

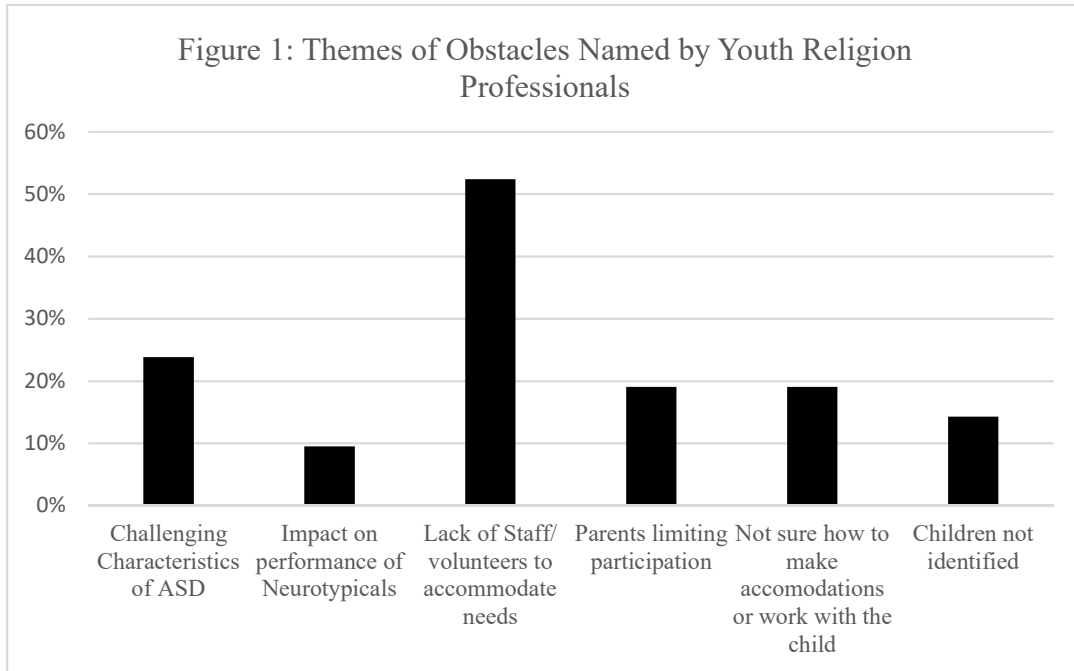
Further research should be done more directly with children with autism in understanding their experience. Getting first person accounts is crucial for this topic to be more well understood. Considerations should be made for the role of language in the spiritual experience. Typical people may adequately translate their experiences into language. This may be more difficult for people with autism so any research done must take into consideration the difficulty of translating abstract concepts into language for someone with autism. The role of language and the use of language to transmit abstract concepts is itself an important area of research for this topic.

More research should be done on how families in the Catholic Church change their religious practice upon a diagnosis of a child with autism. Many people in the study suggested that people may leave their religious tradition all together but understanding the prevalence of this phenomenon or the reasoning is outside the scope of the study.

Conclusion

Understanding the context, behavior and beliefs of children with autism in the religious setting will enable people to meet the complex social, psychological and spiritual needs of people with autism in this setting. Currently, increasing the participation of children with autism is a priority given the high priority put on it by parents as well as the need of people with autism for community engagement. Barriers to engagement include deficits in knowledge on behalf of religious staff as well as lack of communication of staff and parents. Furthermore, it is important

to acknowledge the differences in the way religious behavior is expressed by people with autism, with preference for cueing and routine. One of the most important factors to consider is the personal context of the child with autism who may be experiencing spiritual turmoil and suffering a great deal. Understanding these factors can lead to an increase in the efficacy of professionals working with families and children on the autism spectrum in any context.



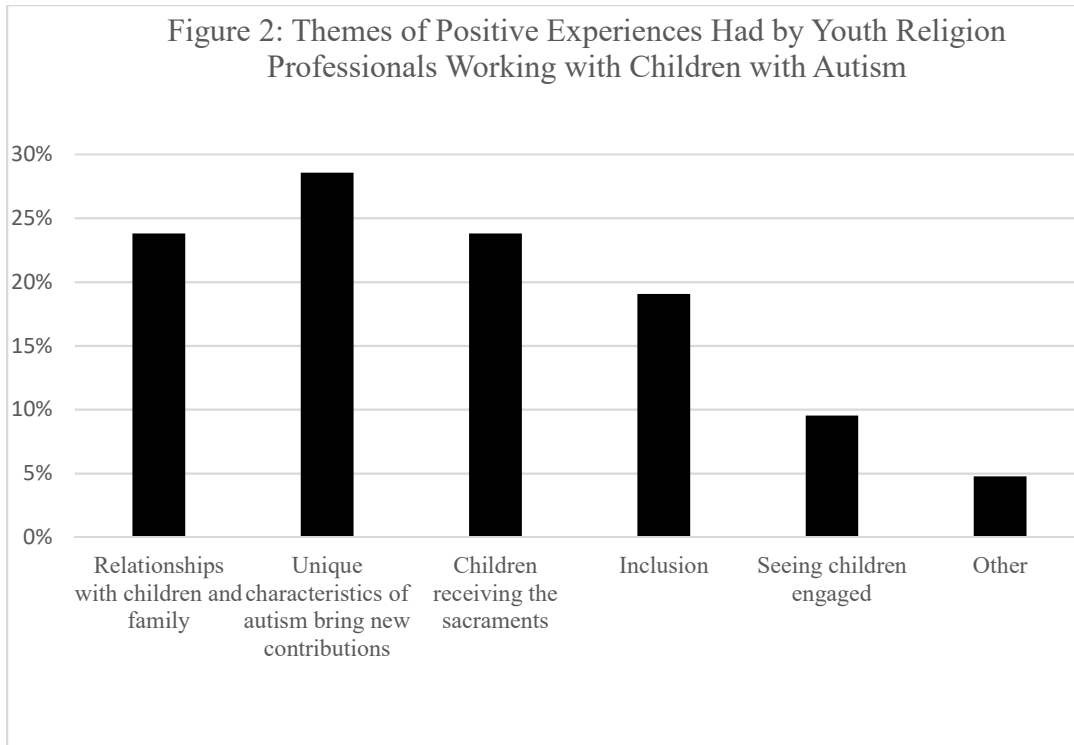
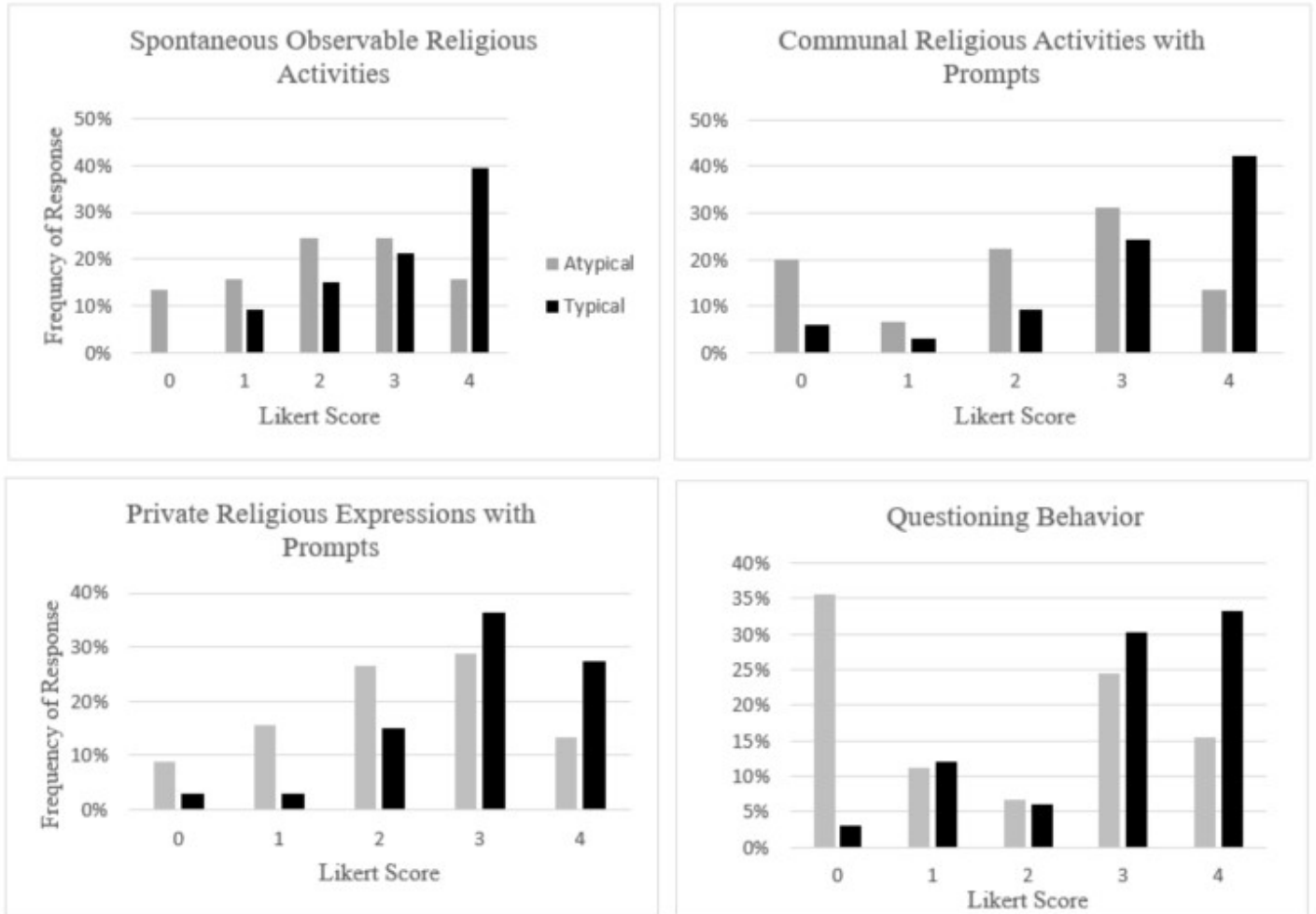
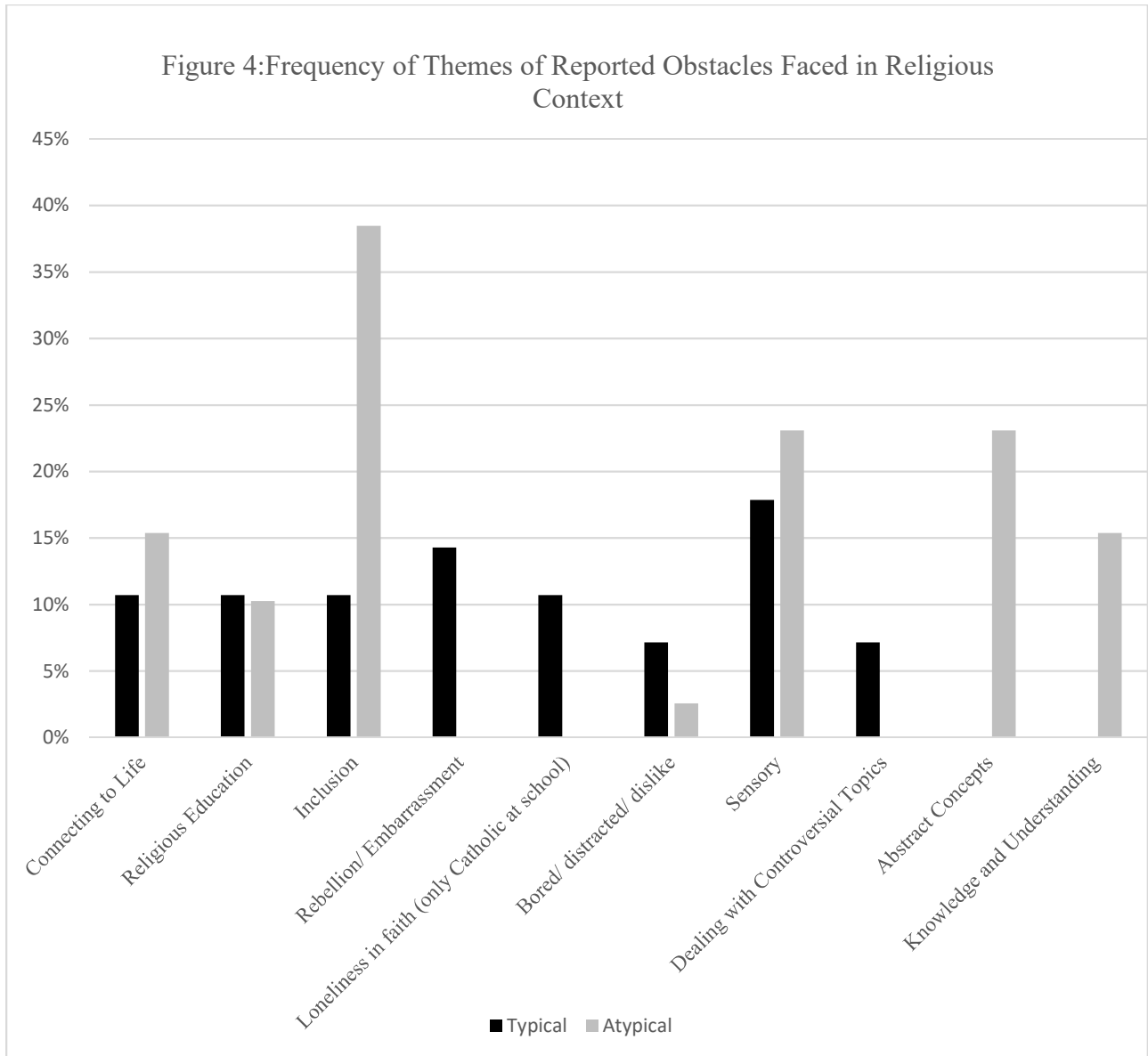
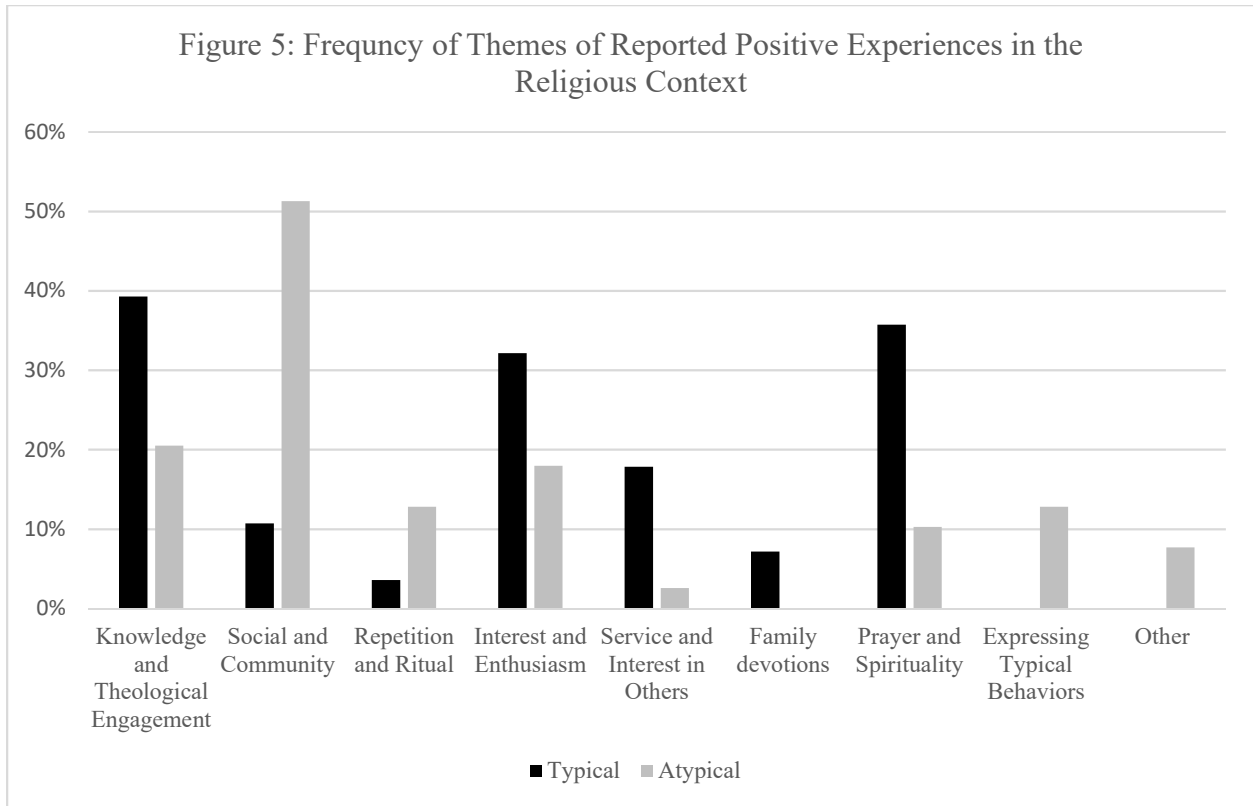
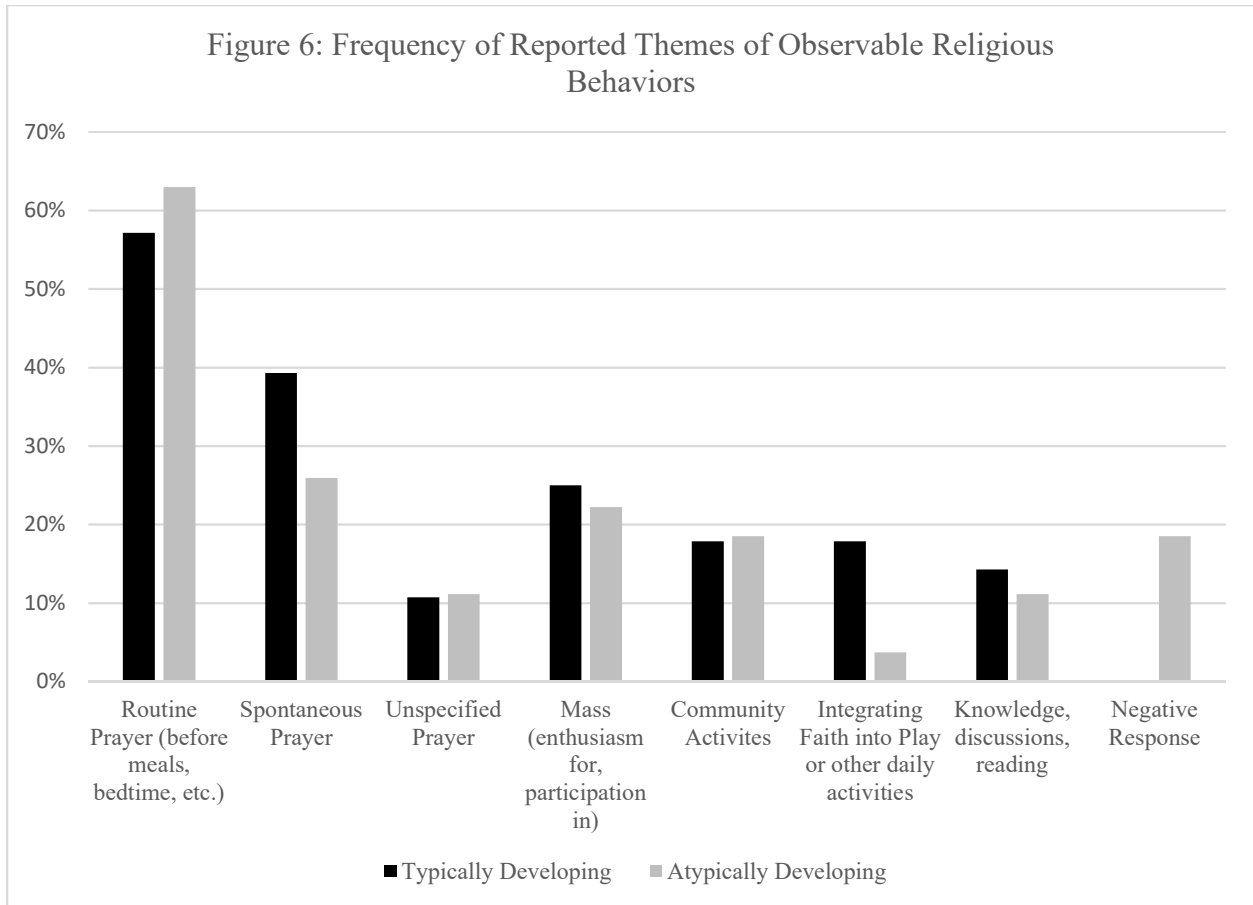


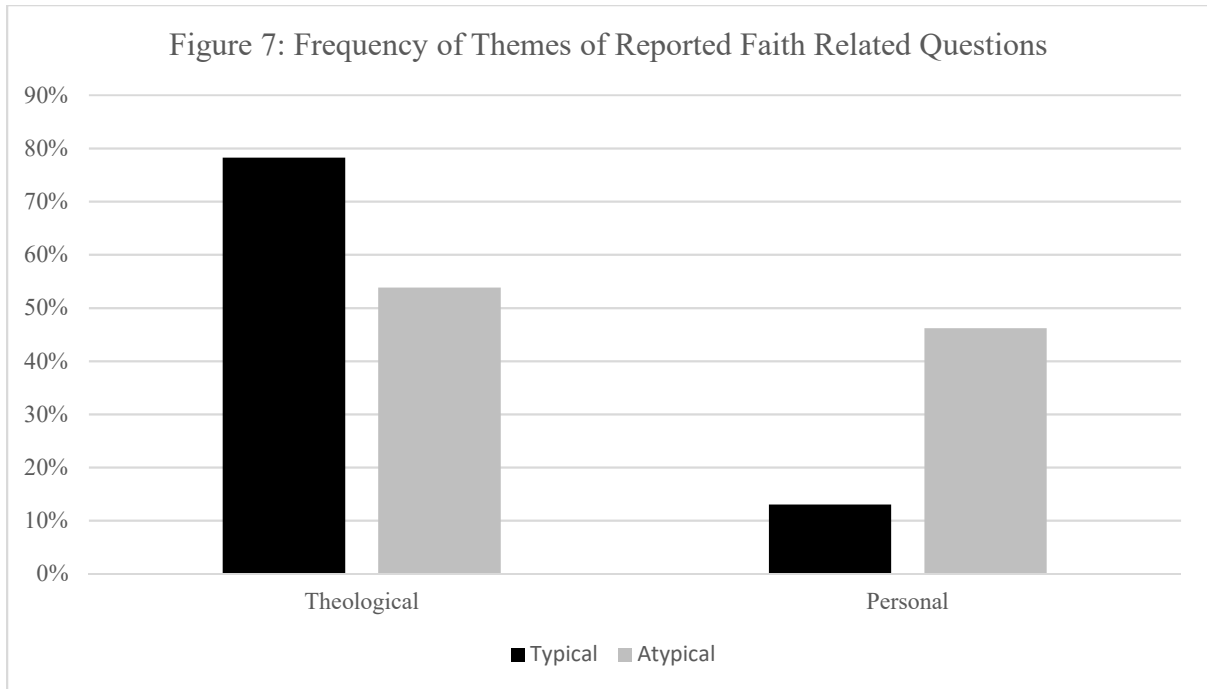
Figure 3: Parent Reports of Frequency that Religious Behavior is Observed in Children











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Appendix A

Autism and Parish Life (Staff Survey)

What position do you hold at your parish

Director of religious education

Youth minister

Pastor/ Associate pastor

Other:

What is the name of your parish?

Where is your parish located (City, State)

How would you describe the area surrounding your parish?

Urban

Rural

Suburban

Other:

Approximately how many families belong to your parish?

How would you describe your parish

Predominantly older adults (65+)

Predominantly families with young children

Predominantly young adults

Other:

How many youth belong to your parish? (K-12)

Are you aware of any children in the parish who have a psychological condition that changes the way that they participate in Church activities (i.e. Mass, CCD, parish picnics, etc.)?

Yes

No

Are you aware of any children with a diagnosis of autism spectrum disorders in your parish (this includes Asperger's syndrome)?

Yes

No

If yes, how many (best estimate)?

Are there any programs or accommodations for children with autism in your parish?

Yes

No

Not sure

If yes, please describe.

What are some positive experiences that you have had with individuals with autism at your parish?

What are some obstacles that you have encountered with having individuals with autism in your parish?

Appendix B

Survey of Parents of Children with Autism

How would you describe the area surrounding your parish?

Urban

Rural

Suburban

Other:

How would you describe your parish

Predominantly older adults (65+)

Predominantly families with young children

Predominantly young adults

Other:

Does your child have a diagnosis of autism (including Asperger's Syndrome and Rhett's)

Yes

No

How old is your child?

Are there any programs or accommodations for your child?

Yes

No

Other:

If yes, please describe.

Does your child engage in any observable religious activities spontaneously (ex: praying, seeking out youth group, saying grace before meals, etc.)

0 (Never)

1

2

3

4 (Often)

If yes, please describe

Does your child generally engage in communal religious activities when prompted (youth group, Mass, etc.)?

0 (No)

1

2

3

4 (With Enthusiasm)

Does your child generally engage in private religious activities when prompted (Saying prayers, spiritual reading, etc.)

0 (No)

1

2

3

4 (With Enthusiasm)

Has your child sought out information about God by asking questions (How does God...? Why did God...?)

0 (Never)

1

2

3

4 (Often)

If yes, please provide examples of questions that your child has asked.

What are some positive experiences that you have had regarding religion with your child?

What are some obstacles that you have encountered regarding religion with your child?

Appendix C

Survey of Parents of Typically Developing Children

How old is your child?

How many children live in your household?

Where in the birth order does your child fall (first born, second born, etc.)

Does your child have any psychological diagnosis (ADHD, autism, seizure disorders etc.)

Yes

No

Does your child engage in any observable religious activities spontaneously (ex: praying, seeking out youth group, saying grace before meals, etc.)

0 (Never)

1

2

3

4 (Often)

If yes, please describe

Does your child generally engage in communal religious activities when prompted (youth group, Mass, etc.)?

0 (No)

1

2

3

4 (With Enthusiasm)

Does your child generally engage in private religious activities when prompted (Saying prayers, spiritual reading, etc.)

0 (No)

1

2

3

4 (With Enthusiasm)

Has your child sought out information about God by asking questions (How does God...? Why did God...?)

0 (Never)

1

2

3

4 (Often)

If yes, please provide examples of questions that your child has asked.

What are some obstacles that you have encountered regarding religion with your child?

What are some positive experiences that you have had regarding religion with your child?