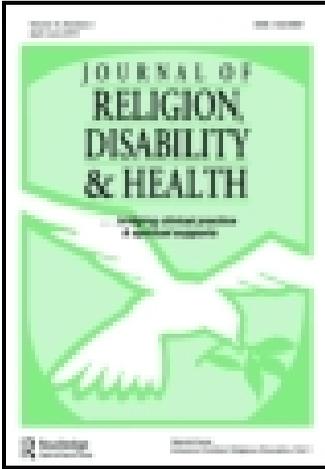


This article was downloaded by: [Biola Library]

On: 02 October 2014, At: 11:41

Publisher: Routledge

Informa Ltd Registered in England and Wales Registered Number: 1072954 Registered office: Mortimer House, 37-41 Mortimer Street, London W1T 3JH, UK



Journal of Religion, Disability & Health

Publication details, including instructions for authors and subscription information:

<http://www.tandfonline.com/loi/wrdh20>

Youth Ministry, Religious Education, and Adolescents with Disabilities: Insights from Parents and Guardians

Amy Elizabeth Jacober ^a

^a George W. Truett Theological Seminary-Baylor University, Waco, Texas, USA

Published online: 23 Apr 2010.

To cite this article: Amy Elizabeth Jacober (2010) Youth Ministry, Religious Education, and Adolescents with Disabilities: Insights from Parents and Guardians, *Journal of Religion, Disability & Health*, 14:2, 167-181, DOI: [10.1080/15228961003622310](https://doi.org/10.1080/15228961003622310)

To link to this article: <http://dx.doi.org/10.1080/15228961003622310>

PLEASE SCROLL DOWN FOR ARTICLE

Taylor & Francis makes every effort to ensure the accuracy of all the information (the "Content") contained in the publications on our platform. However, Taylor & Francis, our agents, and our licensors make no representations or warranties whatsoever as to the accuracy, completeness, or suitability for any purpose of the Content. Any opinions and views expressed in this publication are the opinions and views of the authors, and are not the views of or endorsed by Taylor & Francis. The accuracy of the Content should not be relied upon and should be independently verified with primary sources of information. Taylor and Francis shall not be liable for any losses, actions, claims, proceedings, demands, costs, expenses, damages, and other liabilities whatsoever or howsoever caused arising directly or indirectly in connection with, in relation to or arising out of the use of the Content.

This article may be used for research, teaching, and private study purposes. Any substantial or systematic reproduction, redistribution, reselling, loan, sub-licensing, systematic supply, or distribution in any form to anyone is expressly forbidden. Terms & Conditions of access and use can be found at <http://www.tandfonline.com/page/terms-and-conditions>

Youth Ministry, Religious Education, and Adolescents with Disabilities: Insights from Parents and Guardians

AMY ELIZABETH JACOBER

George W. Truett Theological Seminary-Baylor University, Waco, Texas, USA

Youth ministry may not openly oppose the inclusion of teenagers with disabilities, but the actions—or lack of action—of many programs communicates a low commitment to this goal. As an initial step toward understanding and improving the experiences of youth with disabilities in the church, 17 parents and guardians of youth with disabilities were interviewed. These individuals expressed a desire for their children to be included within youth ministry programs and shared what their child might bring to a youth group.

KEYWORDS *adolescents, disability, youth ministry, education, parent*

Youth ministry has made great strides toward holistic teaching. Even the literature and textbooks in this field discuss the concepts of teaching in the physical, mental, emotional, social, and spiritual realms (Arzola, 2008). There is encouragement, at least within colleges and seminaries, to address religious education as far more than simply memorizing scripture or being able to recount a story accurately with proper theological interpretation. As with any shift, there is a lag between what occurs in training and its manifestation within the local church. Even with these strides, there is great room for improvement. As emphasized by Lambert (2004):

Thanks to Alayna Goins for going above and beyond the call of duty in transcribing. Thanks to Dr. McKinney for her consultation on the interview questions. Thanks to the Association of Youth Ministry Educators (AYME) for grant support for this research. Other work arising from this data includes “Ostensibly Welcome: Exploratory research on the youth ministry experience with families with teens with disabilities” in the *Journal of Youth Ministry* (2007).

Address correspondence to Amy Elizabeth Jacober, Associate Professor of Practical Theology & Youth Ministry, George W. Truett Theological Seminary-Baylor University, One Bear Place #97126 Waco, TX 76798-7126, USA. E-mail: amy_jacob@baylor.edu

The future of the church is in trouble, and those of us who teach youth need to step up and take our share of the blame. God has entrusted us with a high and holy calling, but we've treated it like it's just another chore in life. We rarely take the time to do it well, and often would prefer not to do it at all. We wait until the last minute to get ready (if we take the time at all), and only put in effort to do it right when we know something special is happening, like visitors or evaluation (p. 9).

These are harsh words for the beginning of an article. Interestingly, these words were not written with teenagers with disabilities in mind, but rather to youth workers in general. While it may be that youth workers are "missing the boat" with substantial numbers of teenagers, it does not change the reality that so many youth with disabilities have been all but ignored in the pedagogical process within religious life.

There is little research stating exactly how many teenagers with disabilities are present in youth ministries, but there is a growing discussion about the absence of these teenagers from many youth ministries. In a report to Young Life's Capernaum—a ministry to teenagers with disabilities—Sisneros (2006) noted,

There are more than 54 million Americans with disabilities and 26 million of those have a severe disability. Of this number, more than 8 million are under the age of 18. The population of disabled young people has steadily increased and is projected to rise dramatically over the next 10 years due to teen pregnancy, drug and alcohol abuse, environmental factors and advances in medical technology which has increased the rate of survivors after an accident.

Sisneros' report was based on a 2004 study by the National Organization on Disability (Washington, DC) and the Harris Survey, which documented trends within the disability community in the United States. Moreover, the 2000 United States Census revealed that "one of every twelve children and teenagers—5.2 million—has a physical or mental disability" (Cohn, 2002, p. B01). The differences between these two figures may be explained by the methodology used in each study and the age range each focused on (Stern, 2003). Nevertheless, it is clear that there are millions of children and adolescents with disabilities in this country and the number is on the rise.

Youth ministry has long been discussed and modeled around the incarnation. Just as Jesus stepped out of heaven into this world, so too are youth workers called to step into the worlds of teenagers. The difficulty is that many youth workers go where it is familiar and comfortable, leaving behind entire segments of the youth population. This is not what Jesus modeled. He was at His most recognizable and identifiable embracing human frailty and vulnerability, emptying Himself out for our sake. The number of youth

with disabilities and their families missing from Christian communities begs the question of why this issue has not and is not being addressed in a more concerted manner.

Additionally, theology should help to have a significant impact on youth ministry and the importance of reaching all teenagers. Scripture states, “all have been created in the image of God, male and female He created them” (Gen 1:27). As living, breathing persons, we have been gifted with the capacity to reflect the personhood of God. This is not to be taken lightly and demands that all humans, regardless of gender, ethnicity, and ability, be recognized with dignity and respected as those who embody the *Imago Dei*, even as it is expressed in a variety of ways. God’s power is perfected in weakness and His presence most easily recognized as a person decreases and God increases. God works best in those who empty of themselves. The image of God is not diminished in any way as it co-exists with disability. To state so denies the doctrine of the *Imago Dei*. For youth ministry to exclude teenagers with disabilities communicates a functional denial of the incarnation and *Imago Dei*.

Incarnational youth ministry involves introducing others to the person of Jesus *and* journeying with them to grow in Christ. This journey of becoming and continuing to be a follower of Jesus comes through discipleship. Discipleship allows each person to discover not only the unique gifts they bring to the kingdom, but also the little ways each day in which they may honor God and others. It affirms that youth with disabilities have something valuable to offer. We, in the body of Christ, need them as much as they need us. This is no trivial platitude. If we are to truly catch a glimpse of who God is, to the best of our ability in this finite world, we must celebrate and include everyone. To do anything less is to irresponsibly consider the revelation of God.

PURPOSE

The purpose of this exploratory study was to discover the experiences—in their own words—of families with adolescents with disabilities and their interactions with a variety of churches, church programs, or youth ministries. As the study unfolded, it provided a glimpse into the worlds of adolescents and their families in a variety of areas (not all of which are addressed in this paper). Parents of children with disabilities spoke about their desire to be seen and heard, faith issues, friendship, dreams for their children, struggles, isolation, and the impact of disability on their marriage and family (Jacobson, 2007). A prominent theme was their clear concern for teaching their children about God, Jesus, faith, and the church. Parents and guardians spoke distinctly about the religious education process that did—and too often did not—take place with or for their children with disabilities. Such findings are in keeping with the secular trends noted by Osgood and colleagues (2005):

There is growing awareness that despite a generation of legislation aimed at creating equal opportunities for people with disabilities—in education, health services and the workplace—the reality does not fully match the promise. A 1998 Harris Poll reported several functional indicators of adult life that show major discrepancies in what those with disabilities have been able to achieve in education/school, employment income earned, and social relationships. In addition, discrepancies have been seen in emotional well-being (p. 328).

This article focuses on the experience of religious education, both implicit and explicit, for adolescents with disabilities and its impact on families.

Unfortunately, limited research is available regarding youth ministry and teenagers with disabilities. The literature on ministry to individuals with disabilities tends to focus on ministry with younger children or adults (Keefer, 2004; Pierson, 2002). This exploratory research allowed the voices of those impacted by disability to be heard and to identify issues most salient to these individuals, rather than having researchers approach the topic with initial hypotheses in hand. This study was designed to provide insight into the types of issues that should be pursued further related to youth with disabilities and their relationship with the church. Given the large number of youth with disabilities, the number of families connected to these teenagers, and the diminished active involvement of both in local Christian ministries, the field faces an important opportunity to reach a generally neglected community.

Recognition of someone or something greater than oneself is a universal experience. This is no less the case for people with disabilities. John Swinton and colleagues (Swinton & Mowat, 2006; Swinton & Brock, 2007) conducted an extensive research project on spirituality and people with intellectual disabilities. Findings from a literature review and numerous interviews with people with intellectual disabilities, their families, caregivers, and support workers, led them to the following conclusions:

- Spirituality is a common human phenomenon that includes but is not defined by religion.
- There is evidence to suggest that spirituality plays a significant role in the lives of many people with [intellectual] disabilities.
- Carers and support workers are often unaware of the significance of this dimension and consequently fail to address it.
- Training is required to enable those supporting people with [intellectual] disabilities to recognize and deal effectively with this aspect of their experiences.
- People with [intellectual] disabilities need to be given accessible information and opportunities in order that they can make informed spiritual choices.

- Faith communities have the potential to offer support and friendship, but they need to be aware that certain exclusive forms of practice (Swinton & Mowat, p. 230).

It is not a question of “if” religious education should exist in the life of an individual with a disability. Assuming youth workers are called to serve *all* youth, the question becomes “how” do youth workers holistically to teach all teenagers.

METHOD

Participants

Parents or guardians from 17 families including an adolescent with a disability participated in this qualitative study. Interviews were conducted with the parent(s) or guardian(s) of households professing Christianity, including mothers, fathers, grandmothers, and female guardians. For the purpose of this study, the focus was on the experiences of families with adolescents (i.e., grades 7–12). When asked to share the nature of their child’s disability, participants reported a range of developmental disabilities, including Down syndrome, cerebral palsy, muscular dystrophy, fibrodysplasia ossificans progressiva, autism, adolescent arthritis, and a broad range of intellectual disabilities.

Snowball sampling was used as the primary approach for identifying interview participants (Vogt, 1999). This sampling approach involved identifying one or more parents from a family to be interviewed, who were then asked if they knew of anyone else who fit the study criteria. These families were then invited to participate and, if interviewed, asked the same question regarding referral. Participating parents and guardians lived in Seattle, Washington, San Jose, California, Phoenix, Arizona, Denver, Colorado, and Buena Park, Colorado. Several dozen additional families and teenagers were interviewed informally to gather additional insight and suggestions.

Although many people could have been contacted and interviewed, the study was limited to immediate caregivers, parents, and guardians. Previous informal discussions with numerous youth workers, church leaders, and youth ministry professors led to this decision. Before the study began, more than two dozen youth workers and youth ministry professors were asked if they had any students in their youth group or knew of any teenagers with disabilities in their churches. The answer consistently was no. At best, they would know of a youth, but add that the family had decided the youth group was not a good fit. Or they indicated they had no idea how to include a youth with a disability and did not want to hurt or offend anyone by making a mistake. This, coupled with the lack of research and resources focused on the perspectives of parents, led to the decision to first interview immediate family members.

Interview Procedures

This study was intentionally and explicitly emergent. No specific hypothesis was directly tested. A literature review was conducted early in the study to inform the author about the topic. The specific interview questions were developed in cooperation with Dr. Jennifer McKinney of the sociology department at Seattle Pacific University and designed not to be leading. The interviews began in 2004 and were completed in 2006. Sample interview questions are included in the Appendix. In accordance with institutional review board guidelines for human research, each participant received a full explanation of the research, was given the opportunity to decline participation, and received a copy of the agreement they and the interviewer signed offering further explanation and future contact information. Interviews were conducted at the home or other location requested by the interviewee. Due to the nature of the interviews, it was determined that participants should determine the most comfortable and convenient location. Each participant agreed to the interview and for the interview to be recorded, understanding that in the final presentation, actual names would not be used. Each participant was also given the opportunity to determine when the interview would begin and end, as well as decide whether to postpone or terminate the interview once it had begun. Each interview was recorded and professionally transcribed. Although each interview was comprised of the same questions, the interview length varied from 25 minutes to nearly 2 hours. Interview length was determined solely by the brevity or verbosity of the interviewee. These interviews generated 280 single-spaced pages of transcription.

Data Analysis

Grounded theory was used in this study (Glaser, 1994; Mark, 1996). Data collection, note taking, coding, writing memos, and re-coding all took place concurrently. As the transcripts were reviewed, core codes and sub-categories emerged. Those categories emerging repeatedly over the 2-year interview window comprised the major issues addressed in this paper. These themes and categories were then considered with attention to where they may have appeared previously in the literature. For example, Hoeksema (1995) summarizes some of this research:

In recent years more is being learned about the religious dimensions of life for individuals with developmental disabilities. . . For example, those with mild mental retardation will learn more faith concepts and be more interested in why people act like they do than those with moderate mental retardation.

However, very little research has specifically focused on adolescents with disabilities within a youth ministry context.

RESULTS

Perspectives on religious education were offered abundantly throughout the interviews. Each of the following sections begins with several direct quotes excerpted from the larger interviews. The goal is not to reframe what parents and guardians said, but rather to offer a voice to perspectives that too often are absent within the literature. As these are direct quotes offered in response to interview questions, they include fragments and, at times, partial thoughts and sentences. This was done to preserve the integrity of the voices in their own right, rather than changing or “correcting” them. There were many times when one question was asked and the person being interviewed spoke uninterrupted for 20 minutes or more, no longer explicitly responding to the question initially asked. The following themes are discussed because the author perceived them to be most helpful to current and future youth ministers: 1) teaching adolescents about Christ; 2) community and connection; 3) positive encounters with ministry; 4) negative encounters with ministry; 5) what teenagers offer to a community; and 6) words of wisdom from families.

Teaching Adolescents About Christ

- “I think the evangelical church is almost spiritually starved to be sensitive to what we are talking about.”
- “So it is hard, I guess just inclusion as much as possible, in a small church it would probably be very, very tricky, but in a larger church where there may be a small population, maybe offer a special needs classroom. There is such a range of abilities, that would be hard too, it almost has to be one-on-one or two-on-two and I guess like in the school setting to just include them in the social part of it.”

One of the struggles in youth ministry has been how passing on faith has occurred in the past and how this is defined today. Religious education should be more than a cognitive exercise or intellectual gymnastics. As noted by Lambert (2004), this has been a growing concern within the field of youth ministry:

Somehow, over the past several decades, teaching in the church has become dominated by several troubling tendencies. In some congregations, teaching is focused entirely on memorizing portions of Scripture. In others, ill-educated lay people facilitate discussions for groups of other lay people—which too often amounts to the blind leading the blind. Other churches feature teachers who talk for the entire time (p. 15).

Richard Osmer (2005) devotes a great deal of time looking into the teaching ministry of congregations. Even with his emphasis on teaching as exemplified

by Paul, he recognizes two main areas within three tasks of the teaching ministry. The two main areas are formation and education, which go hand-in-hand. According to Osmer, “Formation has to do with the relationships, practices, narratives, and norms of a community’s shared life . . . education has to do with those practices that focus directly on teaching and learning” (p. 27). The three core tasks are: 1) catechesis (i.e., handing on of scripture and Christian tradition); 2) exhortation (i.e., moral formation and education); and 3) discernment (i.e., understanding God in their daily lives). The concern for more holistic and developmentally appropriate religious education is already present within youth ministry education. What still is largely missing, however, is consideration of the developmental needs of teenagers who may also have disabilities.

Community and Connection

- “If they were going to offer anything, it would probably be to accommodate service and Bible study . . . You don’t want to segregate your kids . . . you don’t want your child in that box, but it is hard not to do that and meet their needs.”
- “As a matter of fact, Robyn this fall is going to be a help for a little boy with Down syndrome. It will be the first time in the church that this kind of thing has been done. Actually be a mentor of another child with Down syndrome, he is six and she is going to help him sit still and do arts and crafts. So hopefully that will start something.”
- “We tried a few churches after we moved in here, but nothing ever felt right, no where we were able to connect there, the bible study groups, they were not particularly welcoming, no problem because we wanted Joyce to have a spiritual experience and Young Life (Capernaum) became it and the Catholic church would not baptize her, they would not recognize her as a human.”

The parents of adolescents with disabilities in this study wanted their children to know God and experience the fellowship of other believers to the best of their child’s ability. The participants interviewed in this study were amazingly gracious toward those whom they identified as neither ministering to nor teaching their child as they did for others connected with the church. In fact, several families expressed an apologetic perspective on behalf of those who fell short, further shouldering the weight of passing on faith to their own child and protecting those who did not or could not be supportive in this effort.

Positive Encounters with Ministry

- “You know choir worked, we took her to choir. There was an adult who was patient enough to hold the music and then help her, whereas the kids, you couldn’t really count on them to do that. And the youth group is not staffed . . . at school there was a person to be there for her, but the youth group is not staffed like that. It wasn’t appropriate for parents to be there, nor did I care to be at youth group all the time. And so she found a niche where she fit, and it was choir because she could sing. She sang at school, she sang at choir. That gave her a leadership role on Sundays where she was in the morning, where the whole family went.”

There were those parents and guardians who had positive experiences. While these examples represented the minority of the responses offered, they did exist and helped to shed light on what can occur in a positive way. Some of these experiences were couched as positives within an otherwise negative experience. In particular, two experiences were named repeatedly as positive. The first was the idea of a peer “buddy” system, in which a youth with a disability is paired with a peer without disabilities or, in one case, where a youth with a disability was given the opportunity to be a buddy to a younger child with Down syndrome. The second was the experience that adolescents, and concurrently families, had with Capernaum (a Young Life ministry involving youth with disabilities). Capernaum offers teenagers with disabilities a safe space to be themselves while experiencing the love of Jesus in community and through education. Activities, lessons, and the entirety of the ministry intentionally maintain a safe, developmentally appropriate approach while offering the reality of Christ and God’s word. Awareness is raised with leaders and training is offered not only in teaching and ministering but also in the special needs of the particular students being served. Beyond even the lessons being taught in an accessible way, the welcome and acceptance each teenager and his or her family experienced taught volumes of the theology this ministry offers. Again, it is important to note that religious education can and does take place in more than one way.

Negative Encounters with Ministry

- “The Sunday school teacher’s nephew actually said that she (the Sunday School teacher) would not teach if she had Robert in her class and I just remember really feeling hurt, and instead of saying can we get someone else to help him, we would like to support you, . . . so we ended up just stopping going to Sunday school, we did not have a place for him, Sunday school was not a particularly welcoming place with regard to youth group Sunday school . . . actually if someone would have come alongside and

said we would love to have him in Sunday school even if he does not understand, I will be his buddy he would have been fine and he learned a lot, he really is a high functioning guy so we kinda stopped going to Sunday school because there was not a place for him during that hour and we would just keep him in church with us and that is what we have done.”

- “Church does not have a lot to offer for her.”
- “I look at her Bible, it is a youth Bible, but it is still very hard for her to understand. I look at the worksheets and other homeworky things they send home and it is still very hard for her . . . there needs to be something more appropriate that way . . . not watered down, but simplified. There is no accommodation for that at all.”
- “And then when it got to youth group in seventh grade she went when they did things that she could do. When they went out to places, that meant that we had to go because we had the transportation. We went if we were able and if it was too much she just didn’t go, she didn’t participate. And then when she got into high school she participated less and less.”
- “There’s a challenge when you’re from a low church, believer’s baptism tradition, as opposed to liturgical infant baptism tradition. Because it does raise a problem if you’re in a baptistic tradition there’s a point at which a child will accept Jesus and they’ll get baptized and at least in some measure be a part of their volition and development. And with a clearly disabled kid it becomes problematic. Now if you’re Catholic or Episcopalian it’s not quite so bad because you’ve got the whole liturgical tradition, baptizing infants—you know what I’m saying. So for most church baptistic traditions those kind of issues do become problematic. Jorge’s teacher, who goes to our church, has a now adult 22-year-old daughter who has hardly any mental capacity. Partly at the urging of a family friend, we had a baptism service. And of course, everyone was okay with it, but the fact is she can’t do the things that you normally would do. A profession of faith, an explanation, she can’t do any of that. So there’s a certain awkwardness and defensiveness, and it was more private too. It wasn’t done in the church, it was done in the home. So for those traditions there are a separate set of problems that come up because of theological understandings and liturgical understandings.”

Unfortunately, the positive experiences of adolescents and their families were far outweighed by negative ones. Parent after parent expressed the heartbreak of their attempts to find a ministry in which their child could be ideally embraced and taught the doctrines and practices of the Christian faith. Many parents accepted that their child may not be taught and expressed a longing for their child to be accepted and for those in ministry to model the incarnation.

What Youth with Disabilities Offer to a Community

- “Robyn prays, I mean she really prays . . . I think an additional benefit is the kids that are in Bible study get to see and experience Robyn . . . and learn and accept and learn . . . what a great lesson right there, God made us all different, no one is any better than anyone else . . . And to facilitate that relationship building between the kids and Robyn.”
- “Cristin doesn’t question much, looking at herself, she has a sense of needy people . . . She is very compassionate . . . You go into a room, and if there will be a child with special needs, she’ll go over and try to make friends. Or kids that are of a different ethnic background that feel out of place. So in some sense that has been a place of faith, seeing how God works . . . She has a great gift of hospitality, and she just wants to make people so welcome and cared for.”

Not surprisingly, many parents and guardians recognize the blessing their child is and can be. They spoke of the depth of relationships their child is able to maintain. This element of relationship speaks to the incarnation, the presence of Christ in the lives of those in a Christian community. It speaks to that which is beyond religious education, reflecting instead internalization. Martina Holder-Franz says that “a relational perspective on the human person means they are not defined by ability, but rather by availability for relationships” (Swinton & Brock, 2007, p. 61).

Words of Wisdom from Families

The final question asked of each parent was, if they could offer any words of wisdom for ministry, for teaching their child about faith and Jesus, what would it look like? The following are a few of their responses.

- “They should offer me peace of mind that my child is number one physically safe, in a safe place with safe people and that she is doing bible study. That she is learning and hearing the message. That is number two, she is safe and she is hearing the message . . .”
- “If the person in charge of youth ministry were to make an effort to sit down with the parents and with the child, and say, “We’re crafting a program. We would eagerly hope to have you included as much as possible. What are some of the things you can do and like to do; some of the things you can’t do or won’t do.”
- “If you could say that once a month, or twice a month there will be something specifically organized for the inclusion of this person. I think that would be a great step forward. I would not expect people at our church

- to have crafted the ministry program specifically for Sheena's needs, any more than I would expect to craft it around any kid's needs."
- "I've always thought about this. I think that if the churches could offer a Sunday School class for kids with special needs whether it's two or three kids . . . But they do not have a class for special needs, which they could be taught the same thing but in a different level, either with pictures, or just a lower level, like in kindergarten, there would be no difference. And I really wish they would offer that in churches, and to educate. To go that far, just have a place. That would be nice."

Parents and guardians of special needs teenagers are aware of the realities that come with their child. They are also deeply committed to their child's well being. It seems that many youth workers are either unaware or choose to remain uninvolved because of the perceived difficulties and liabilities surrounding a teenager with special needs. Youth workers need not be afraid of making a mistake. At some point a mistake will be made, but it is forgivable and becomes a teachable moment. The effort alone will be appreciated. There is a temptation to "dumb down" a lesson for all to comprehend. As with all good teaching, youth workers must "know their audience," but the content does not need to disappear. Adolescents with special needs have the same questions, concerns, and interests as their typical friends regarding family, dating, God, and what comes next in life. Just as with all teens, they are receiving messages from the world. Religious education has a remarkable opportunity to speak truth and grace into the lives of those often ignored or belittled.

DISCUSSION

A number of concrete steps emerged from these interviews that may facilitate youth ministry development. Many of these steps are fairly simple, but often get overlooked by many congregations.

- Remember that teenagers with disabilities are first and foremost teenagers, *not* a disability who happens to be a teenager.
- Do a little research and learn how many teenagers with disabilities live in your community.
- Put yourself and others in the position to develop relationships with youth with disabilities.
- Do not be afraid to ask youth with disabilities questions about themselves.
- Ask parents about their child, their child's disability, and their own lives.
- Talk with special education teachers and read anything you can find on specific disabilities as you meet youth with those disabilities.

- Safety is a first priority for any parent and youth.
- Become an advocate for teenagers with disabilities and their families.
- Expect things to take longer and plan accordingly.
- Use a peer support or “buddy” system for teenagers with a disability.
- Utilize small groups to facilitate meaningful participation and promote interactions.
- Do not worry or be afraid of how much a teenager with intellectual disability is or is not getting your message about Jesus. Your job is to share Jesus, not to determine what they are or are not getting.
- Adapt your programming and activities to truly include youth with disabilities. Do not just allow them to observe and call it participation.
- Educate your leaders, volunteers, and entire youth group on issues regarding teenagers with disabilities.

These suggestions represent starting points only. As when working with any youth, wisdom and much prayer are needed when working with youth with disabilities. Additional education, in particular regarding issues of safety, is required. However, the task is not impossible and is more achievable than most think.

Limitations and Future Research

This research was somewhat narrow in scope in that it considered only the perspective of a parent or guardian and not that of the teenager, the youth leader, or any others who may be involved in youth ministry. It could be considered broad in a different way in that there was no single answer being sought. Although an initial attempt was made to categorize responses, many of the quotes could easily fall into more than one category. This is a limitation of this exploratory research study. Through analyzing the interview responses, several additional research topics were identified that should be explored in greater depth. First, research is needed that explores the impact of intentional ministry on the spiritual lives of youth with disabilities as well as the impact on the spiritual lives of families who have experienced such intentional ministries. Second, further study needs to be done on the impact of a special needs child on the marriages of Christian couples. Third, barriers, present and imaginary, in the life of a church considering ministry for teens with special needs, as well as success stories and lessons to be learned from churches and ministries currently ministering to teens with special needs should be investigated. Then, potential approaches and methodologies for sharing the gospel with teenagers with disabilities, and physical adaptations to make youth ministry more accessible for this group might be explored. Finally, the impact on the spiritual life of youth workers involved in intentional ministry for teens with special needs would perhaps prove an interesting area of study.

CONCLUSION

There is a clear desire on the part of the families of youth with disabilities for inclusive religious education. There is also a clear awareness of the barriers to just such a hope. For those of us in youth ministry, we must begin an ongoing conversation of contextualizing with our students. Youth culture is dynamic and so too must we be as we seek to pass on the truths and traditions found within Christianity. A recognition that adolescents with disabilities are first and foremost teenagers, a part of the community to which youth ministers have been called, is the first step in a long journey which needs to take place. This is not a naïve cry that calling and willingness will cover all training that would be needed. Rather, a call to youth ministers to contextualize, to reach out and to teach adolescents with disabilities just as they would any other teen in their church or community.

Although there are challenges to including teenagers with disabilities, the cost of not including them may be higher. Youth workers strive to educate their students on compassion, on slowing down to spend time with God, on His grace and presence in their lives, and on His love for all to imitate. For many students, these become words with no meaning or no impact in their lives. When youth workers invite and authentically include a teenager with a disability in their ministry, they are opening opportunities for everyone to learn from that person. It is indeed a two-way street. The lessons many adults can only talk about are better learned in experience and by example from an adolescent with a disability. Although there are struggles in being open to those with a disability, these youth have just as much as to give as any other person present.

Much work is being done to address the spiritual needs of those with disabilities. Much, however, is not enough. This community of teenagers is sorely underrepresented in churches and Christian communities. Training and education, fear of doing more harm than good, depletion of financial and other resources and lack of community support are real barriers. They are, however, barriers that can and should be overcome if we are to truly live out God's call to pass on faith to the next generation.

REFERENCES

- Arzola, F. (2008). *Toward a prophetic youth ministry*. Downers Grove, IL: InterVarsity.
- Cohn, D. (2002, July 5) US counts one in 12 children as disabled: Census reflects increase of handicapped youth. *Washington Post*, p. B01.
- Glaser, B. (1994). *More grounded theory methodology: A reader*. Mill Valley, CA: Sociology.
- Hoeksema, T. (1995). Supporting the free exercise of religion in the group home context. *Mental Retardation*, 33, 289–295.

- Jacober, A. (2007). Ostensibly welcome: Exploratory research on the youth ministry experience with families with teens with disabilities. *Journal of Youth Ministry*, 6(1), 67–92.
- Lambert, D. (2004). *Teaching that makes a difference: How to teach for holistic impact*. Grand Rapids, MI: Zondervan.
- Keefer, M. (Ed.) (2004). *Special needs, special ministry: For children's ministry*. Loveland, CO: Group.
- Mark, R. (1996). *Research made simple: A handbook for social workers*. Thousand Oaks, CA: Sage.
- Osgood, E. W., Foster, E. M., Flanagan, C., & Ruth, G. R. (Eds.) (2005). *On your own without a net: The transition to adulthood for vulnerable populations*. Chicago: University of Chicago Press.
- Osmer, R. (2005). *The teaching ministry of congregations*. Louisville, KY: Westminster John Knox.
- Pierson, J. (2002). *Exceptional teaching: A comprehensive guide for including students with disabilities*. Cincinnati, OH: Standard.
- Sisneros, C. (August 14, 2006). *Executive summary to mission wide committee of Capernaum*. Colorado Springs, CO: Young Life.
- Stern, S. (2003). *Counting people with disabilities: How survey methodology influences estimates in Census 2000 and the Census 2000 supplemental survey*. Washington DC: U.S. Census Bureau, Poverty and Health Statistics Branch. Retrieved July 21, 2007 from <http://www.census.gov/hhes/www/disability/finalstern.pdf>
- Swinton, J., & Brock, B. (Eds.) (2007). *Theology, disability and the new genetics: Why science needs the church*. New York: T & T Clark.
- Swinton, J., & Mowat, H. (2006). *Practical theology and qualitative research*. London: SCM.
- Vogt, W. P. (1999). *Dictionary of statistics and methodology: A nontechnical guide for the social sciences*. Thousand Oaks, CA: Sage.

APPENDIX

Research Questions

- 1) What is your experience as parents of a special needs child?
- 2) What is the family experience of having one member with special needs?
- 3) What faith issues have come up for your family?
- 4) What have your experiences been with church, church programs, or youth ministry programs?
 - 4a) Any specific positive experiences?
 - 4b) Any specific negative experiences?
- 5) What should churches offer you, as parents of a special needs child?
- 6) If you could design a youth ministry specifically for your special needs child, what would it look like?
 - 6a) What suggestions would you give to church leaders?
 - 6b) What are some keys that should be included?