

ABSTRACT

NORMAL IS NOT BIBLICAL:

AN EXPLORATORY STUDY OF MINISTRY WITH DEVELOPMENTAL DISABILITIES
IN THE ARKANSAS CONFERENCE OF THE UNITED METHODIST CHURCH

by

Stephen E. Waggoner

In the current context in the United States the inclusion of persons with developmental disabilities, that is an intellectual or functional deficit identified prior to age twenty-one, is considered to be a special project. In the church this is often seen as something beyond the usual expectation of the church. This attitude is a development which comes late in Christian tradition. Inclusion would be expected in the Biblical era and in Christianity up to the time of modernism and the institutionalization of persons lacking many of the competencies required in modern living.

This study analyzes the adaptability of pastors and churches to include persons with special needs in congregational life and ministry. Who is more disabled: the person with special needs or the pastor and congregation which are unable to cope with their needs? Phase One was the collection of data through an on-line survey of Arkansas Conferences United Methodist Churches to identify congregations which included persons with special needs along with the longevity and depth of their involvement. Phase two was phone interviews with pastors or key ministry leaders to confirm the on-line data and to collect additional information about the nature of the relationship of the person(s) identified and the congregation. Phase three involved site visits to representative congregations to visually confirm the information and to obtain an additional depth of understanding.

Congregations with long term relationships and deeper inclusion have longer, more stable pastorates and ministry leadership; were very adaptable in meeting needs of families with special needs; and were typically unaware that there was anything unique about their congregation in this respect. They were simply worship with and in ministry with their friends, their relatives and their neighbors.

DISSERTATION APPROVAL

This is to certify that the dissertation entitled

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IN THE ARKANSAS CONFERENCE OF THE UNITED METHODIST CHURCH

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The praise goes to the Lord God who created such imperfect people as we and loves us forever.

Stephen

CHAPTER 1: NATURE OF THE PROJECT

Overview:

The chapter begins with a passionate puzzle of what our modern time calls disability. For me this is a personal endeavor. Following the autobiographical section is a statement of the problem and research questions that set the parameter for the research. Then is the rationale for the project explaining why this topic is of importance. Next, key terms are defined. Then the delimitations for the project are addressed. The literature review outline is provided followed by the research methodology and then a brief overview of the project.

Autobiographical Introduction:

The Passionate Puzzle

The realization came to me one day that a church to which I was appointed was autistic. I had recently married and with the marriage came an Asperger Syndrome stepson named Tyler. His behaviors were escalating and we were approaching crisis; but the issues with the congregation were strangely similar to the issues we were having with Tyler. He processed information and saw the world differently than I; and so did the congregation for whom I was the pastor. By the time the year was out, I was at a new church and Tyler was living with his grandparents. Yet neither moving Tyler to his grandparents nor myself to a new church helped any of us, and during that year I kept having flashbacks to a member at a previous church.

My flashback was to a member of my first church who excitedly mentioned to me one day that she had discovered she was ADHD. This middle-aged empty nester was prescribed

Ritalin and she described the effects as wonderful. Looking back, having lived ten years with a high functioning autistic, I would describe her as high functioning autistic. She was the middle school teacher you did not want your child to have. A very caring person in many respects, everything had to be done in a precise fashion and life, including her preferred clothing, was black and white. She lacked the ability to see things from another point of view. One afternoon she stopped by the church after school to discuss a proposal to the church council to ask the trustees to put together a building proposal. Truth be known, this was a priority of the District Superintendent and a majority of the membership, but she disagreed. She thought it should be put off several years so that the church could “heal” due to the conflict with the previous pastor. (she and her husband had explained to me a few short weeks after arriving that they had launched a drive to make the previous pastor miserable to get him to request a move when they realized that the congregation was not going to ask that he move). At one point I said to this woman who had launched a drive to chase off every pastor for the past twenty years and had helped keep the average tenure to about 2 ½ years per pastor that “I guess we will just have to agree to disagree.” Her nonverbal reaction made it clear that I was to be the next pastor to be chased off.

Looking back, I wish that I had a checklist at the time, but what I can remember are obvious social behaviors typical of a high functioning autistic. What seemed to me the best approach, directly engaging her over a concrete issue, did nothing but backfire. A more passive approach of ignoring her and appealing to others did not work either because she would simply obsess over the slight and become more infuriated. What she really needed was an emotionally detached engagement to find out what really bothered her. Autistics hate change and frequently the real issue has nothing to do with the presenting problem.

Before we begin this journey together, please understand that the author does not view the inclusion of persons with special needs to be a justice issue, but their absence to be an ecclesiological problem. Segregation and removal of special needs persons is damaging our churches. For me, it is not about them but about us. The process of identifying, labeling and excluding the “disabled” creates a body hard to call “Church” and the process of inclusion, as difficult and as painful as it may be, is one of restoration. I pray that you will see this as we journey together through this labor of love.

No Such Thing as Normal

For eleven years I have been the step-parent of an individual diagnosed as Asperger’s Syndrome and for the past eight years I have been working professionally with children and adults with disabilities and their staff. Working closely with those with severe disabilities has opened my eyes not just to their special needs, but to the ways in which working with those who society calls disabled has informed me dramatically about what it means to be in ministry with the rest of us. Recently I flew to Washington DC with my family. The stewardess had to move a woman to the row shared by my ten year old and me and the woman who moved to our row almost went berserk. After muttering to herself for ten minutes, the rest of the flight was spent with her staring at the wing of the plane. Dressed professionally, she was so rattled that she did not interact at all with my ten year old son next to her or to me. Zach and I would visit and she was in another world. I was not insulted, but fascinated. Some would say that she was not normal; I would rather say that her normal is not mine. In fact, I would argue that there is no such thing as normal.

It was Saturday morning and I dropped into the Boy Scout Camp Mess Hall for a quick

continental breakfast. I sat next to one of the young staff members and we visited. After dealing mainly with two Scouts with severe emotional issues for a week (one diagnosed bi-polar and the other Asperger's Syndrome), I struggled for words and finally used the term "normal." My breakfast friend, a self-professed high-functioning autistic himself, responded, "There is no such thing as normal, just average."

The young man is right. The word "normal" does not appear in the Bible. It does not occur in the King James Version. Its errant use may show up in a more modern translation, but the few occurrences are questionable when you look at the underlying Greek. I have become convinced that one of the causes of conflict in the modern church is that we organize our thoughts and people around this construct. We isolate those we do not consider normal and are unable to recognize that all of us view the world and relate to others very differently. Working with and being immersed in understanding cognitive disabilities has helped me to be more understanding of and better equipped to relate to those who are... ~~normal~~ average.

During the 20th Century our American culture created institutions and specialized program to separate, isolate and "protect" society from those who are different under the guise of providing specialized services. What we have done through segregation is to greatly diminish our ability to understand, relate to and even love those who see the world, process information and live their lives differently. It is my contention that what we call developmental disabilities, in particular cognitive and processing disabilities, is a cover for our desire not to deal with people who think and live differently.

A Missed Opportunity

My twelve year old son has taken to calling anyone who thinks differently (or just seems strange to him) autistic. In doing so, he is simply reflecting a tendency of our culture. Due to

the institutionalization and stigmatization of developmental disabilities, our culture, particularly our churches, lack an understanding of developmental, and in particular cognitive, disabilities.

As will be discussed later, prior to the development of modern science and the rise of specialized, residential institutions, people with disabilities typically did not live long and those who did were cared for by their families and supported by their local community. With the Enlightenment and the rise of modern science, social scientists, like their counterparts in biological studies, sought to categorize and classify humanity. Central to this compulsion is a desire to define deviancy and disorder which pre-supposed that there is such a thing as normal. Institutionalization followed and families either sent their loved ones to an institution or hid them at home.

With the rise of modern science's drive to define deviancy and Darwin's drive to categorize people into races and sub-categories, comes the desire for dominance. Race becomes the lens for social struggle and along with it the need to weed out the less fit in favor of those traits which are superior to others. While I do not completely ignore the philanthropic desire to help, what really fueled the rise of the institutions for both developmental disabilities and mental illness in the late 19th and early 20th centuries was the Darwinist impulse to improve the race by eliminating the undesirable. The solution to the pollution of society by those who were different was their physical removal from the community and from the genetic pool. Those who were significantly different had to be removed and institutionalized at best and at worst euthanized in the horrors of the concentration camps. Socially, this idea still permeates society. Schools do very well with the average child who functions "normally" but break down when dealing with the child who performs well above or well below the mean. In the church this has manifested itself in churches that are unable to know what to do with the low IQ or socially challenged

individual. In large churches, specialized ministries are created for the segregated group so that the larger body may be served. But, Paul tells us that the Body should not be divided.

Normal is not found in the Bible: at least not in the King James or Wycliffe versions which pre-date the Enlightenment. There are two occurrences in the NRSV and in the NIV, but that was due to para-phrasing. Yet, “normal” is a Greek word and was in usage in ancient times. However, “normal” is not a construct found in religious discussion. The hippies of the 60's had it right... modernism is “square.” Normal refers to the right angle, otherwise known as the square angle, and is more applicable to the measurement of objects, not people.

Modern education, sociology, psychology and, I fear, Christian education begins with the concept of normal. In the Church we have divided people into normal and not normal teaching most people in one way and then at a loss on how to minister to the rest.

In what ways does disability re-frame ministry?

Working with disabilities offers us a window to see more clearly ourselves and those around us. Mary came to me one Sunday after church with a frantic look in her eyes, hands shaking, to complain about my children's message. I had used the occasion of the death of a pet to remind us that life was precious and that we should value all life, especially loved ones, in this life. Her daughter, she explained as I watched her trembling figure, was afraid of death. She did not want me to deal with the issue of death and dying. Mary was afraid and projected this fear upon others. Mary suffered from a panic disorder and her anxiety was her lens through which she viewed life.

In this project, I present ways in which we can be in ministry with those with disabilities and through this be transformed ourselves. Like the serpent in the wilderness, disabilities can be a source of life and wholeness. The Israelites were being bitten by serpents and were dying.

Moses constructed the image of a serpent and those who were bitten could come and gaze upon it and be healed and live. Including and embracing those with disabilities is a way the Church and society of our day can discover who we are and re-frame ourselves and our ministry.

This dissertation is an exploration of ministry with disabilities in the Arkansas Conference of the United Methodist Church. This is a time to celebrate life together with each other in unique and exciting ways. At my center, I tell prospective staff that we are taking care of our friends, our relatives and neighbors. In the Church we worship and are in ministry with all of God's creation. In the Christ there is not normal and disabled, but rather friends, relatives and neighbors.

The movement of the dissertation was designed to move into ways in which ministry with what the secular world calls disabilities should re-frame our understanding of ministry. Truth be known -- there is no such thing as normal, just average. Stories and strategies about profound disabilities illuminate the dysfunctional ways in which the normal often function. I would like to use stories of disabilities as windows into our own souls and individual gifts and graces.

Research Questions:

Research Question #1

Which churches in the Arkansas Conference claim a ministry with persons with developmental disabilities?

Research Question #2

Of churches claiming ministry with persons with developmental disabilities, to what extent are these persons integrated into the life and ministry of the congregation and, in contrast, to what extent are they viewed as the subject of ministry?

Research Question #3

Are the churches who integrate persons with developmental disabilities into the life and ministry of the congregation markedly different in their functioning? Has the integration of persons with developmental disabilities made the congregation healthier and more adaptable?

Research Question #4

What are the implications for best practices for congregations to engage families & individuals with developmental disabilities?

There is simply no definitive definition of disability. In the ninth grade I had a teacher who proudly proclaimed that he was ADHD: “it drives some people crazy but I kind of enjoy it,” he said. Generally speaking, disability is a term applied to those who are different and whom the mainstream wants to marginalize. Normal is not in the Bible and the issue of abnormal (or disability) needs to be re-framed into Biblical language and categories. There should be a discussion of creation and just what it means to understand the sacredness of life – all life. While not at all a focus of the dissertation, the question to what extent it is appropriate to use the language of “us” and “them” should be examined.

The question for the church with regards to disabilities should be the ways in which we can be inclusive of those who are different. I will deal with the concept of assessments. The movement toward serving people with disabilities in community settings instead of institutional settings has spawned a great deal of practical literature on needs assessments and client centered planning. A literature review and development of practical ways to understand individual needs is critical for churches wanting to engage those with special needs. Ministry should be designed

around meeting the needs of our brothers and sisters in Christ.

Statement of the Problem

Societal and Church attitudes towards people who have intellectual or adaptive challenges have segregated people from our communities and our churches. Congregations will be identified that show promise of pulling these special people back into church life and the best practices for doing so will be identified.

Purpose of the Project

Through an exploratory study of ministry with developmental disabilities in the Arkansas Conference of the United Methodist Church, congregations that include persons with developmental disabilities will be identified and those with more significant ministry will be selected for additional study to identify best practices for both inclusion and outreach ministries.

Rationale for the Project:

...Or Why Does This Matter?

The purpose of this project is to broaden the Church's understanding of the inclusion of all God's people by identifying successful strategies and programs for inclusion of persons with developmental disabilities. An understanding of persons who do not fit the mold of "normal" often provides important insights for the Church in its own relationships. Those with identified disabilities and how those without identified disabilities relate to them provides insights to other relationships. Jacob and his mother came to Central UMC looking for a church home. Jacob, a non-verbal boy recently diagnosed with autism, would be considered severe by any measure. The Children's Ministry Director wanted his mother to be able to be a part of their young adult ministry and set about finding Jacob a buddy. Bill was a retired college professor who loved children. A large bear of a man, they became quite a sight around Central. He would shadow

Jacob (or perhaps Jacob was his shadow) and he had to learn to read Jacob's mind.

Communication specialists say that 60-80% of our communication is non-verbal. Those who work with the non-verbal must learn to read body language and typically develop the use of sign language, symbols and gestures. We who have been steeped in books and the world of words need to develop this other side of communication. The Christian Education Director who oversaw this process along with the various volunteers had to develop new ways of seeing, listening and adapting. They developed new skills and broadening their capacity to better work with those with less severe needs. While the beginning point of my study will be ministry with people with disabilities, the real point will be to broaden our understanding of ways for the "normal" to learn to better relate to each other! Later Jacob would attend another denomination whose worship his sensory issues could handle. Later, he would return to his home church when they developed an alternate service in a different building that did not overwhelm his senses. Often our congregational leaders simply expect that others should adapt to their leadership and not the other way around.

Often congregations include persons who exhibit characteristics of persons with profound disabilities and the failure to recognize this causes on-going frustrations. The new pastor had a two-point charge. The smaller church was a tight-knit congregation and very friendly. This was tested by the pastor's wife who would "fix" the alter table every Sunday morning. She noticed that the cross was moved to one side of the table and she re-arranged the elements moving the cross to the center and the Bible to one side. An argument ensued with one of the members over what was central. To each of them there was a logical issue. Working with those with profound disabilities leads one to a deeper understanding of the rest of us! Was the argument over theology or was it over the fact that the parishioner was not yet secure with a new pastor's role?

Further, was the issue really over the issue of change (did one or both have an obsessive-compulsive disorder? Those who are used to dealing with persons with developmental disabilities find these sorts of issues to be regular occurrences and have learned to re-direct or adapt. However, those who are not used to adaptive or cognitive deficits with meet these issues head-on and escalate the conflict.

The concrete project of the dissertation is to lay out some simple models which illustrate ministries with developmental disabilities which are fully inclusive. The Church as a whole needs models which are fleshed out in the local congregation to guide program staff and pastors in working with people they may find challenging which include rather than separate. While this researcher certainly wants to break down many of the barriers which exist that separate the church from being in ministry with all people, this research does recognize a legitimate place for specialized and/or segregated programs. Included are a number of extended narratives of some successful ministry examples. The conclusion provides a series of vignettes providing examples of positive ministry models in which the church can really connect with the people involved.

The abstract side of this project will be the progression from story to story which revokes the notion that Christians are defined by their abilities and disabilities. The movement is from examples of marginalization, to deinstitutionalization, to integration, to full community and then to the realization that believers see themselves in the disability. Ultimately, believers grow in grace when in ministry with others. A church which is unwilling and unable to adapt and love one with developmental disabilities does not fit the Acts or Pauline image of what it means to be “Church.” The goal of the Church should be to increase in love of neighbor and to be able to adapt to their needs and their presence.

Definition of Key Terms

The extensive use of terminology and technical language in the field of developmental disabilities and processing deficits is an integral part of the de-humanizing process that my dissertation will argue against. Terminology helps turn people into objects.

Much of the literature in the field of disabilities has actually developed within the last thirty years. As attitudes and legal requirements have changed, terminology and their definitions have changed also.

Developmental Disability refers to cognitive or physical disability which occurs before the age of 19. This usually occurs at birth, but may be a disorder which causes problems with growth or perhaps could be caused by a childhood injury

Institutionalization is the process of accepting the removal from society physically, socially and psychologically of persons deemed unacceptable.

Community Integration is the concept that those with disabilities should be living community settings which integrate them into life in education, work and socialization.

“Normalization” means that these settings are intended to resemble the “normal” person’s life as much as possible.

Intellectual Deficit refers to a person with a measurable IQ which is below a predetermined level (generally below 70 is low, 100 is average and 140 is high

Low Adaptability refers to a person (or group of persons) who, while often possessing a high IQ, may lack the ability to adjust quickly or adequately to a changing environment.

Dual Diagnosis refers to individuals who have been identified with multiple disorders. In the context of this project this if most often manifest in both a psychological disorder and a developmental disorder).

For the society and the church, the technical terminology usually is evolving not because of scientific discoveries but because of societal demands. What used to be known as Mental Retardation is now known as Developmental Disabilities because families have advocated for changes. The problem is that most diagnoses are made for medical billing purposes, not treatment purposes (or because it makes sense). While the diagnosis gives clues to working with the individual, the clinical approach dehumanizes and makes the person an object of ministry and not a participant in the life of the Church. While a review of technical terminology is necessary, it is antithetical this paper's goal. We should focus upon the person, not the diagnosis.

When the term "Person" is used, it is intended in the modern, Western sense of one for whom there is a birth certificate, and in the biblical sense of one to whom God has given soul and a life.

Delimitations: Boundaries of the Study

Handicapping conditions outside of developmental disabilities are not dealt with because these are populations with different histories and functions in society. Usually the person with a handicap is seen as a fully functional member of society who has suffered a trauma or medical condition which now limits their functioning. Conversely, people with developmental disabilities are those who are seen as lacking their full humanity.

The second limitation is geographic. The inquiry is restricted to United Methodist Churches in the Arkansas Conference. In conducting an on-line survey, phone interviews and on-site studies the boundaries of the conference provided a concrete boundary with available contact information.

Review of the Relevant Literature:

This section reviews the ways in which humanity accounts for and relates to persons

whom we today call disabled. This is done through three major divisions:

Historical Foundations of the Construct of the Disabled

1. Labeling & Modernity (normal is not Biblical)
2. Disability in the Old Testament
3. Disability in the New Testament

Theological Constructs of Disabled in the Contemporary Church

1. “Can They Be Saved?”
2. Christian Education & Stages of Faith
3. Modern Christian Thought and the “Disabled”
4. Some Other Issues
 - a. Sensory Criticism
 - b. The Mind of Christ
 - c. Doctrine of Creation
 - d. Doctrine of the Trinity
 - e. Nature and Mission of the Modern Church

Person-Centered Planning and Ecclesiology in the United States

1. Deviants, Imbeciles and the Institutions
2. The Institutions are Targeted by the Civil Rights Movement
3. Person-Centered Planning and Community Integration
4. The Disabled Re-Entering the Church: “Life Together”

According to scripture, the theological basis for the division of labor in the Church is according to spiritual gifts. In American Christianity, churches are organized not around not this model, but that of educational theory which stresses developmental stages. Members typically speak of “Christian Education” in both the academy and the church rather than discipleship. Both educational theory and Christian education theory must relegate the developmentally disabled to a marginalized status lest they admit that their underlying assumption of normality is flawed. From this preface, the paper moves into the progressive political trends with regard to the mentally and physically handicapped from the late 19th century to the 1960’s.

The first major division involves the ways in which the scripture views what moderns call disabled and constructs and orders the life of the synagogue and church.

The second major division provide theological reflections upon humanity from doctrine and church history and how they account for and relate to persons whom we today call disabled.

The third major division is secular literature from the western world, in particular the United States, on mental retardation from the beginning to around the 1970's. This provides a benchmark of attitudes and philosophies regarding developmental disabilities and intellectual deficits which has plagued the thinking of the church. The attitudes ranged from that of relieving families of the burdens of the disabled to protecting society from the mentally deficient to that of improving the gene pool by eliminating the defective. While the latter reached its height in Nazi Germany and in a number of Communist countries, it was not without its followers in the United States.

This final division moves into trends in disability rights beginning in the late 1970's through the present period which shows the rapid evolving of thought leading to the current trend for community integration and normalization.

Included in the listing of sources but not in the literature review is an assortment of literature from the Church regarding programs for developmental disabilities. Many of those who work with developmental disabilities in the secular world, regardless of the secular nature of the service provider, enter and stay in this field because of a spiritual calling. An interesting study would be of the faith perspectives of those in this field.. However, the recent literature regarding churches starting and developing programs is fairly limited. It mostly consists of highlighting specific programs but not the theological logic behind them. There is very little scholarly literature in this area.

The literature review focuses upon more scholarly work, but there are numerous books and articles which are referenced in the bibliography of other works consulted. Oral and written

life stories are perhaps most valuable for those who want to learn and cultivate skills in the field of working with people with special needs. There are numerous testimonials, mostly by family members, speaking of the trials, tribulations and joy of raising one who is challenged. .

Secular literature on mental retardation prior to the 1970's provides vivid examples of attitudes which pervade the church and society even today. That time period was marked by the age of the clinical approach which categorized people and relegated them to the level of care or type of institution. In education and Christian Education, the focus was on what one could not do and major textbooks from this period demonstrate this. Note: a stark contrast comes from the works of Helen Keller and she deserves her own voice and mention.

Secular literature since that time reflects a changing society which is split between the clinical approach and integrative strategies. A rich source for a bibliography is A Disability History of the United States by Dr. Kim E. Nielsen. A fascinating and scholarly read is The Willowbrook Wars by Sheila and Louis Rothman about the lawsuit and subsequent consent decree regarding the nation's largest institution housing 5,400 residents. This period is marked by the creation of funding for alternate services to those provided in state institutions through the Federal Budget Omnibus Bill of 1981 which allowed states to divert funds from traditional Medicaid into community-based services. Some states have completely closed large institutions and increasingly local community organizations are providing individual support staff for persons with developmental disabilities in local communities. This has spawned a great deal of training material and a few college programs which can be mined for contemporary training, behavior management and individual-centered training literature.

There is very little scholarly literature on disabilities and the church. Brett Webb-Mitchell, formerly at Duke Divinity School, is one of the few authors who has written about

disabilities and the church. Webb-Mitchell, who reframed Christian Education into Christian Nurture and Ethics, provided much of the theological framework for this project. This project endeavors to move from his more theoretical works and even his practical application into short stories and illustrations for models that work. Further, this project moves beyond this into the issue of how these models and the inclusion of those who Webb-Mitchell calls “Unexpected Guests” transforms our understanding of Church.

There are many of journal articles in existence about ministry and developmental disabilities, but most are either personal testimonies or descriptive pieces about specific specialized ministries. These provide clues to as places to go for guidance and stories to collect. There are some fascinating programs scattered around the country beyond the limitations of this study which also give voice to those whose stories are seldom heard.. Worship and ministry involve sharing and becoming part of someone else’s story. The institutionalization and segregation of those with disabilities has taken people who were once a part of our congregations and robbed us of their presence. It is time for the “unexpected guests” Brett Webb-Mitchell describes to become cherished members of our households of faith.

Analytic Framework: Data Analysis Plan

One who works with persons with developmental disabilities was asked by a fellow church member if he thought that people with severe intellectual disabilities (they did not use that term) would go to heaven. The question reveals a wide array of underlying assumptions which are pervasive in our society and in the church. First is the assumption that salvation is an intellectual activity in which one learns the correct facts, expresses the correct thoughts and receives the just reward. Second, it reveals an understanding that some persons are less of a person than others. Finally, it puts us as a church on a slippery slope in which we progressively

chose who to include and who to exclude in the family of God.

The theological framework for this Analysis includes the following:

1. All persons are created by God for purpose including those with a whole host of what the secular world calls disabilities and that the Church should not so label.
2. Like King David who grieved and prayed for the life of the first son he fathered with Bethsheba, all are called to treasure and welcome all life no matter the physical condition of the child.
3. The marking and labeling of those who are different has damaged the Church and our culture.
4. The primary task of the Church is to be the Body of Christ which includes all people who desire the community of the people of God.
5. In turn, it is in being the body of Christ that we experience wholeness and grow in grace to Christian Perfection.

Research Methodology

This research involves first surveying and cataloging active ministries with disabilities, but more substantially includes many personal interviews and visits. The Arkansas Conference of the United Methodist Church is surveyed through an on-line survey followed by phone calls to those claiming ministry with persons with special needs to find stories and make visits.. Finally, and perhaps most importantly, characteristics of congregations which include and integrate those with developmental disabilities are examined to see if they function better as a whole. Of interest, and a topic for further study, is if a church better able to work with those with severe needs will also be better able to work through other personality and decision-making differences.

Type of Research

The first type of research used is quantitative research by means of a survey. An on-line survey link was e-mailed by the Bishop's office to all clergy in the conference. The number of responses and most of the questions and responses can be easily tabulated and translated into percentages. The purpose of this phase, however, was not to establish statistical significance of the responses and a detailed regression analysis was not performed. Such analysis as instructed

by Sensing for requires professional assistance and, while interesting, was beyond the scope of what was needed.

The qualitative method was a case study. The on-line survey enabled the researcher to identify ministries based on the numbers involved, length of relationship and breadth of involvement which would then be chosen for a site visit as case study analysis. This data collection method was not scientific sampling but primarily collection of personal narratives of people with disabilities and their families regarding their spiritual walk and their life in the fellowship of the church. Often the stories were told by families and caregivers, but included the story of the one with special needs. The search was for best practices in ministry. Key to this data collection was to focus on a set of congregations with positive results in relating to persons with developmental disabilities and to hear the stories of these persons and their families. Data collected fell under the category of “case study” in which the researcher observes the group in process, hears about their lived lives and looks for patterns and processes (Sensing 140 ff).

The subjects of the research are not those with developmental disabilities, nor their families, but rather the congregations responsible for the nurture and care of those within their congregations. Protections afforded to subjects were afforded to all involved in this research, in particular to those with developmental disabilities and the families of the congregation with which they are affiliated.

Participants, Instrumentation and Data Collection

For practical reasons the study was limited to the Arkansas Conference of the United Methodist Church. This made data collection easier. Additionally the results will be valuable to the Conference since there is no known systematic study of ministry and disabilities in the Arkansas Conference. However, there are several congregations in Arkansas who have been

intentional on targeted ministry with this population and all of these congregations were represented.

Participants in the first step in data collection were those who receive e-mails from the conference (pastors, professional ministry staff and key laity). Phase One was a survey of all congregations in the Arkansas Conference to identify congregations who self-identify as being inclusive of persons with developmental disabilities which significantly impacts these persons' ability to function. The method was an email from the Bishop through the Arkansas Conference E-Mail network (all pastors are required to have conference e-mail) to perform a rough survey of congregations with interventions and ministries involving developmental disabilities. Either a return e-mail or the completion of a very simply survey monkey survey was requested. The questions were originally designed to be as follows:

1. Does your church attendance include people with developmental disabilities? (Individuals with a low IQ , Autistic-spectrum disorders or low adaptability which was diagnosed prior to adulthood)
2. Does your church currently have a ministry for people with developmental disabilities?
3. Who is a contact in your congregation who could tell me about your successes and/or failures in serving people with developmental disabilities?
4. What other UMC congregations have experiences or programs with people with developmental disabilities which should be contacted to learn about their programs and experiences?
5. What is the name of your congregation and how can you be contacted?

The original objective was between an 80 – 90 % response rate. After two tries, a 10% response rate was deemed acceptable. Additional phone calls quickly made it clear that those declining to click on the links represented churches without anyone identified as developmentally disabled.

Participants in Phase Two were the key contact persons provided by the respondents in the first phase representing congregations with two or more individuals involved more than a

year or with extensive involvement in the life and ministry of the congregation. The research involved phone interviews with the contacts. During this phase data collected in phase one was confirmed and the extent of the involvement of the congregation with developmental disabilities assessed through the use of open-ended questions. The number of congregations to study was narrowed to a manageable number for phase 3 and the in-person interviews and site visits. The quantitative (number of people and length of involvement) and qualitative (depth and extent of involvement) data were used to generate a matrix from which to choose congregations for the qualitative study in phase Three.

Table One: Matrix of Congregations for Phase Three

	Limited Interaction	Program or interaction 1-3 Years	Long-term program for 3 plus years
One person in congregation with Developmental Disability			
1-5 individuals in congregation who are integrated into the church ministry			
Church has a specialized, significant ministry for persons with developmental disabilities			

At this phase the table was expected to expand or contract. The plan was to call all of those in columns 2 and 3 and to ask open-ended questions designed to learn the classic information gleaned by asking who? What? Where? When? Why/ How? The plan was to only visit congregations in the far right hand column and to limit the visits to about four in each block with the selection being made to ensure a broad geographic, racial and socio-economic mix.

Phase Three involved site visits and more in-depth interviews. Interviews were designed to be with ministry staff, families of those with developmental disabilities and the person with

developmental disabilities themselves. The purpose in these interviews is to ascertain the following:

1. What is the nature of the congregational involvement of the person with developmental disabilities? Does it involve worship, Sunday School, other programs, ministry team, leadership?
2. What is the nature of the engagement between the subject and congregational life?
3. To what extent does the congregation modify and bend to include the subject in typical congregational life and to what extent is the involvement in a segregated ministry?
4. What could be done to improve the involvement?

The Instrumentation used for the data collection was a written list of pre-determined, open-ended questions for participants and observation of activities in the congregation when possible.

Phase 4 involved evaluating the health of the congregation to look for indicators of a correlation between healthy congregations and congregations that are able flexible and inclusive of those with special needs. This part was not intended to be extensive, but more of an effort to be aware of congregational instability, frequent clergy moves and other indicators. The instrumentation included questions embedded in the phase 2 and phase 3 questions, noting changes in appointments during the study and consulting the conference journal to note the length of tenure of the current pastor. Phase 4 was not intended to be qualitative and represents an effort to indicate a possibility for future research.

Other Issues in the Data Collection:

Confidentiality is of the essence in this project. Actual names and places were not used to protect confidentiality and ensure honest responses. While the real subject of study was the congregation, the stories and subject matter revolve around individuals with low intelligence, impaired cognitive processing or low social adaptability skills who are vulnerable and too often

exploited.

This project is inherently an exploratory study, not an intervention or a quantitative analysis. Therefore, the interview process involved open-ended questions and affirming conversations.

Institutional Review Board and Protection of Subjects: The proposal to the Institutional Review Board went into some depth regarding the interaction with the ministry subjects due to their limited understanding and heightened vulnerability. These issues were fleshed out in more detail for the IRB. Congregational assurances, participant assurances and confidentiality agreements were added.

The original plan or outline for the written project (the summary of the data and conclusion) was originally planned to be mostly biographical in describing persons studied and their interaction with the church. The literature review, project, data collection and analysis changed the manner in which the data was to be presented. The original plan for the summary was to be a litany of case study stories:

Introduction:	Rose's Story: from a wild animal to God's creation No Such Thing as Normal
Section 1:	Life as a Diagnosis: Stories of abuse and living at the margins Greg's Story: Going to Camp for Eight Months
Section 2:	Turning the Corner: Going Home to a Place That Isn't Jim: It's my home, kind of
Section 3:	My Life: Client Centered Planning Kim: I hate purses! And the struggle for my life
Section 4:	My Church Roger's Church Family
Section 5:	Beyond Disabilities Ruth: Everybody knows how she is...
Chapter 6:	No Such Thing as Normal
Me:	Discovering Our Own Story or "What we can learn about ourselves by learning about others"

The final result, while including many vignettes, was more a summary of patterns and characteristics of the congregations.

Schedule of Work (Original)

Fall/Winter, 2014:	Prepare first draft of historical trends and perspectives
December, 2014	Submit proposal to Institutional Review Board
February, 2015	IRB Approval
March, 2015	Survey Monkey & Phase One of overall survey of Arkansas congregations.
March-April, 2015	Phase Two of phone interviews of congregational contacts to narrow the field of possible subject.
Summer, 2015	Visit selected locations and interview people who can tell their stories.

Schedule of Work (Actual)

Fall/Winter, 2014:	Prepare first draft of historical trends and perspectives
December, 2014	Submit proposal to Institutional Review Board
August, 2015	IRB Approval
August, 2015	Survey Monkey & Phase One of overall survey of Arkansas congregations.
Fall, 2016	Phase Two of phone interviews of congregational contacts to narrow the field of possible subject.
Winter, 2016-2017	Site Visits, Focus Groups and Interviews.

Conclusion

In the field of disability studies, low adaptability is one of the traits often measured to determine if one has a disability. Likewise, adaptability is a trait which is needed to work not only with those with special needs, but with all of God's people. In proceeding to study this issue the researcher had to be adaptable. This chapter lays out the plan which was to be tweaked and modified and adapted as it proceeded. However, the original plan, to seek out best practices for ministry together with those with special needs proceeded with its twists and turns following the evidence as it presented itself. Continue this journey through the next chapter for its review

of what both the ancients and contemporary people have thought of those who we moderns foolishly think “disabled,” or much worse.

Chapter Two review the literature and history of disability which has led the American Church to this point including ancient understandings of disability, biblical constructs in the old and new testaments and contemporary American issues. Chapter Three describes the details of the project itself in studying disability and church ministry in the Arkansas Conference of the United Methodist Church. Chapter Four summarizes lays out the raw data and Chapter Five organizes this data into trends and implications.

CHAPTER TWO: LITERATURE REVIEW FOR THE PROJECT

Overview of the Chapter

This review of relevant literature review moves from Biblical understanding of disability to contemporary issues regarding disability in the church and finally into secular trends regarding disability of which the Church should be aware. Prior to the Biblical Foundations section is a discussion on the particular problem of labeling which must be addressed to remove a contemporary bias prior to entering the biblical worldview. The purpose is to understand through scriptural and theological lens the ways in which we view and relate to persons whom are today called disabled. The major divisions in the literature review are as follows:

- A. Labeling and the Christian Community Disconnect
- B. Biblical Foundations of the Construct of the Disabled
 - 1. Disability in the Old Testament
 - 2. Disability in the New Testament
- C. Theological Constructs of Disabled in the Contemporary Church
 - 1. “Can They Be Saved?”
 - 2. Christian Education & Stages of Faith
 - 3. Modern Christian Thought and the “Disabled”
 - 4. Some Other Issues
 - a. Sensory Criticism
 - b. The Mind of Christ
 - c. Doctrine of Creation
 - d. Doctrine of the Trinity
 - e. Nature and Mission of the Modern Church
- D. Disability in the United States and Recent Trends
 - 1. Deviants, Imbeciles and the Institutions
 - 2. The Institutions are Targeted by the Civil Rights Movement
 - 3. Person-Centered Planning and Community Integration
 - 4. The Disabled Re-Entering the Church: “Life Together”

“The Inspiration”:

It was Saturday morning and I had dropped into the Boy Scout Camp Mess Hall for a quick continental breakfast. I sat across the table from one of the younger staff members and we visited. Decompressing after a week of probably the toughest camp I had ever been to: dealing mainly with two Scouts with severe emotional issues (one with bi-polar and the other with

Aspergers), I struggled for words and finally used the term “normal” hesitatingly to make a contrast. My breakfast friend, a self-professed high-functioning autistic himself, responded, “There is no such thing as normal, just average.”

Historical Foundations of the Construct of the Disabled:

The young man is right. The word “normal” does not appear in most translations of the Bible. It does not occur in the King James Version or American Standard Version; once in the Revised Standard Version and New International Version; and three times in the New Revised Standard Version. These occurrences refer not to people, but to measurements of objects and time schedules.

The term “normal” is derived from the Latin “normalis” and carries meanings ranging from rule to pattern (as in a carpenter’s square). Originally used strictly in a geometric sense, it’s meaning gradually extended to other uses “according to rule.” It appears in French as part of the name of a school, “normal school” indicating a school which would be a model to be replicated. Eventually the term “abnormal” appears to indicate deviation. The “carpenter square” measures angles to ensure that they are perpendicular or “square.” (Merriam-Webster Book of Word Histories)

The researcher is convinced that one of the causes of conflict in the modern church is that we organize our thoughts and people around this construct of normal. Christians often isolate those they do not consider normal and are unable to recognize that all people view the world and relate to others very differently. Working with and being immersed in understanding cognitive disabilities helps one to be more understanding of and better equipped to relate to those who are... ~~normal~~ average. Eliminating “normal” in our schools and churches is a good start to getting back to the Word as created by God.

This obsession with normal, as noted by Jay Gould in *The Mis-Measure of Man*, has long been an obsession of modernity and science. He challenges the assumption that determining “normal” and “abnormal” can be an objective project. Says Gould, “Science, since people must do it, is a socially embedded activity. It progresses by hunch, vision, and intuition. ... the most creative theories of imagination are often imaginative visions imposed upon facts.” (Gould 21-22) The medical, psychological and educational disciplines in the United States are obsessed with defining “normal” with the expressed intent of providing services to the disabled. When Alfred Binet was commissioned in 1904 to develop a method of identifying those who needed special education services, he was concerned that “his practical device... could be perverted and used as an indelible label, rather than a guide for identifying children who need help.” (21-22)

Labeling & the Christian Community Disconnect

Normal is not found in the Bible: at least not in the King James or Wycliffe versions which pre-date the Enlightenment. There are two occurrences in the NIV, but that was due to para-phrasing. Yet, “normal” is a Greek word and was in usage in ancient times. It is just that “normal” is not a construct found in religious discussion. The hippies of the 60's had it right... normal is “square.” Normal refers to the right angle, otherwise known as the square angle, and is more applicable to the measurement of objects, not people.

Rich resources exist in disability literature regarding labeling and the damage that it does. Jani Klotz reviews noted theorists such as Robert Edgerton, Robert Brogdon, Steven Taylor David Goode and JJ Gleason. Klotz writes in “Sociocultural Study of Intellectual Disability: Moving Beyond Labelling and Social Constructionist Perspectives.” that “it is upon such social and cultural foundations that our perception of ‘normal’ personhood is built... and it is these

foundations that ultimately need to be challenged if all people with intellectual disabilities are to be accepted and engaged with as inherently social and cultural beings.” (101)

In modern American culture two models for disability prevail: the medical and the social. Jeremy Schipper says it well with regard to the medical model, and I believe his analysis extends well to the social model: “The medical model understands disability as a biological defect located within a person’s body that needs to be cured. By isolating disability in the individual, the medical model downplays the social, political, and architectural structures that also contribute to the disablement of people with disabilities.” (Schipper, Jeremy, Disability Studies and the Hebrew Bible: figuring Mephibosheth in the David Story, p. 206). It is not the disability itself which necessarily marginalizes, but the way in which culture views, labels, and restricts the social mobility of the one with the disability.

A 1997 Master’s Thesis entitled “A New Way of Seeing: Innovative Ministry Through Friendship” illustrates the point. Nancy Post put together a program called “Connectors” for the United Church of Canada to connect recently de-institutionalized individuals to local churches. (70) The fact that this would be considered new, having friendships with people who have been identified as disabled, proves the point that the labeling of our modern society has marginalized a significant portion of humanity.

Of particular concern to those in the disability rights field is the issue of labeling. One problem with labeling is that the label supersedes the person. One becomes “autistic,” “crippled,” “blind,” “deaf,” and is not a person (who happens to possess a particular characteristic). Yet, there is a necessity to identify the characteristic without diminishing the person. Notes Gill and Maynard in their 1995 published study on communicating developmental

disability diagnosis to parents: “many researchers have noted that “mental retardation, autism, emotional disabilities, learning disabilities and related conditions are products of the social system rather than inherent deficiencies.” They argue that labeling should not be seen as one-dimensional: uncaring people who merely turn people into labels, but rather that clinicians and parents reduce their children to labels, instead of using descriptions to name the social and functional issues of their loved one. The subsequent sections of this paper look at 1) the labels used in scripture, 2) their social construct and 3) the implications for the Church today.

While normal does not appear in scripture, many other terms do. Other terms which either have been or are currently in common usage, and not Biblical: include “cripple,” “handicap,” “infirm,” “wretches,” “deviant,” “dependent,” “disabled,” “children,” “imbeciles,” “developmentally delayed,” “low-functioning” and most recently “intellectual deficit.”

The term “handicap” originated from the term “cap in hand” in which those participating in barter turned over earnest money to a third party who held it in the “cap in their hand” to hold and it was forfeited if the transaction fell through. Later, it referred to additional weight put on a horse in a race to slow them down and make the race more even so that no rider or wager would have an advantage. In recent years, it came to be used to indicate that a person has a characteristic which hurts their ability to function in society (Merriam-Webster Book of Word Histories).

Rebecca Raphael in Representations of Disability in Hebrew Biblical Literature describes a distinction between impairment and disability: “Impairment is just physical... disability refers to the result of a misfit between physical impairment and social environment.” (6) In other words, the demands of our modern world create disability by making life more difficult for people with particular impairments.

Much of the movement in the early 1970's in disability in the United States came as a result of civil rights attorneys who moved from the field of racial inequality into the arena of disability rights. (For a first hand discussion of this see David J. Rothman and Sheila M. Rothman's account in *The Willowbrook Wars* regarding the de-institutionalization of 5,400 adults with disabilities warehoused in an institution in New York City). They drew upon theories of oppression as outlined by Raphael, "physical difference provides the pretext, but the oppression serves a hegemonic strategy." (7) Liberation and feminist theology can likewise provide a rich well of images and understandings for those working to challenges attitudes and culture relating to those with identified disabilities.

At this point the literature review moves into biblical foundations. In contrast with the labeling dominate in contemporary culture, there is the contrast of a blessing for those with disabilities. In our American culture those with special needs are taught to depend upon government; but not according to the Psalmist.

Psalm 146

Praise the LORD!

Praise the LORD, O my soul!

I will praise the LORD as long as I live;

I will sing praises to my God all my life long.

Do not put your trust in princes,

in mortals, in whom there is no help.

When their breath departs, they return to the earth;

on that very day their plans perish.

Happy are those whose help is the God of Jacob,

whose hope is in the LORD their God,

who made heaven and earth,

the sea, and all that is in them;

who keeps faith forever;

who executes justice for the oppressed;

who gives food to the hungry.

The LORD sets the prisoners free;

the LORD opens the eyes of the blind.

The LORD lifts up those who are bowed down;

the LORD loves the righteous.

The LORD watches over the strangers;

*he upholds the orphan and the widow,
but the way of the wicked he brings to ruin.
The LORD will reign forever,
your God, O Zion, for all generations.
Praise the LORD! (NRSV)*

Camrun, a five year-old in a wheelchair, walks with the help of braces. He is a miracle who was almost declared dead at birth and has gone through numerous heart surgeries. He loves balloons. When given a balloon, he plays with it awhile and then insists on taking it outside where he releases it, “to give it to the God who let me live.” (As told by Monica Barfield). Rather than an object of pity, these “disabled,” “marginalized persons” have a special relationship with God.

Camrun represents one of the classic types of the defective character in scripture. His disability shows the power of God. Says Raphael, “being chosen by God disables precisely because human beings must show God to be powerful” (132). Being disabled in some fashion seems a requirement for greatness:

“Strangely, perhaps, the near requirement of disability does not mean that these patriarchal and matriarchal figures cannot also be dynamic and active; they are.” (132) For Raphael, disability in humanity is a way to show the power of God. Invariably, the great figures of scripture have some defect.

Oylan cites Psalm 146: 7-9 as an expression of YHWH which lists “vulnerable categories of persons” in which these persons become an example of the care and protection of God (3) All of Psalm 146 is quoted on the previous page to show how those with disabilities are blessed because of their special relationship with God. This contrast moves from labeling to the scriptural models.

Biblical Foundations

Disability in the Old Testament

There is no Hebrew word which carries with it the modern sense of “disability.” Oylan looks for a Hebrew Bible definition of disability but does not find one. He does, however, find a social construct similar to the concept we have of disability. He, like most disability scholars, says that “disability, like gender, is a social construction rather than something ‘natural and timeless.’” Oylan identifies those with “physical defects” (*mumim*) such as the “blind” and “lame” diseases, and the “deaf” and “mute” (3) as falling into the same general construct as we have today.

For Oylan the major category in Levitical Law which is similar is “Defective” or “with blemish” (*mumim*) (3). Brown-Driver-Briggs notes that the Hebrew instances have to do with “disfiguring” of either a person or an animal in relationship to priestly functions (548c). Other labels are afflicted, polluting (*sara’at*), deaf, mute and blind. Elsewhere, words for physical disabilities and mental disabilities are used as “synonyms for “poor,” suggesting a close association between disability and impoverishment. (Oylan, 7)

The term “*mumim*” translated “defective” or “blemish” is used almost exclusively in the cultic materials in Leviticus and Deuteronomy. (Oylan, 27). Activities which occur within the sacrificial system are expected to involve sacrifices without blemish offered by priests without blemish. Interestingly, a priest who is blemished or otherwise imperfect may not perform the high sacred duties, but is still a priest, is still entitled to the benefits of the priesthood. Moreover, he may be reinstated should the condition improve. The origin of the stigmatization of persons with “defects” seems to lie in a desire to purify the temple and worship (along with quarantining contagious conditions). Leviticus 21:22 makes it clear that the defective priest is still a priest

and entitled to food, housing, temple and priestly duties (only restricted from the sanctuary and the offerings).

There are texts which associate “ignorance and bad judgment” with the physical traits of blindness, deafness, and similar traits (Oylan, p. 35). This association is a theme of Isaiah and later appears prominent in the New Testament stories of Jesus. In other words, it is often automatically assumed that those with physical disabilities also have a low IQ, processing deficits or mental conditions. (Note: While immediately concluding these associations is not warranted, it should be noted that these traits do often come in clusters leading to what the profession refers to as “dual diagnosis.”)

Megan Burnett, in Disabled Ancients: Societal Positions of Disabled Persons in the New Testament World, puts forth the following: “Jewish thought linked illness/disability directly to sin... a patient’s recovery was therefore seen as a sign of God’s forgiveness.” (37) While some extend examples of this link and generalize it to all cases of illness / disability, a reading of Job seems a refutation. After reading Job, one gets the feeling that one of the primary purposes of the work is to refute the idea that all suffering, or even most, is the result of sin. Job’s friends, notes James Crenshaw in A Whirlpool of Torment, “not only flaunted their sound bodies, but also drew the natural conclusion that Job’s own pitiful condition bore conclusive testimony to his own guilt” (70). Considering the fact that both Job and his friends are excoriated by God for their rash conclusions by the Almighty hardly seems to be justification for making the link of suffering and sin automatic.

Further, for biblical writers to observe that one had an ailment or physical defect does not necessarily mean that the person is being marginalized by society or the religious structures. (However, there is one glaring physical trait for which explicit stigmatization is required in the

Old Testament: that of the lack of “circumcision” (36-37). The sign of the covenant, the failure to perform circumcision is a breach of the covenant).

A major theme of wisdom literature is of theodicy, or the study of the nature of God in the context of evil and suffering. Most famously, the Book of Job is a dialog in which Job and his friends attribute physical impairment, among other life issues, to be punitive. These punishments are often attributed directly to God or to his agents. Interestingly, the Book of Job does not resolve this problem except to reject the notion that suffering is caused by God or by our sin.

Fiorello studied both biblical and extra-biblical sources and writes in “Physically Disabled in Ancient Israel According to the Old Testament and Ancient Near Eastern Sources,” about for labels and their implications as applied to the physically disabled. He came to several conclusions:

1. “No legislation could be found that explicitly relegated the disabled to an inferior class status of disenfranchised them.”
 2. Those with disabilities were “integrated into society.”
 3. “The king was divinely charged to protect the oppressed and disadvantaged.”
 4. The disabled were to be treated as equal members of the community of faith.”
 5. “Texts suggest that a moral imperative existed that supported decent treatment of the disabled”
- (Fiorello, 301-2)

While these conclusions were made based both on the Old Testament and extra-biblical sources, Oylan notes that it is Hebrew literature which makes the additional move of using “disability language metaphorically.” He notes that the current trend in modern scholarship, with which he disagrees, argues that the physically disabled are either a “disenfranchised group” or were, as characters, “inserted into ancient literature with a representational function” (Oylan, 301).

Lynn Holden provides an extensive listing of “forms of disability” cataloging, describing and discussing the implications of each. In *Forms of Disability*, Holden executes an incredible feat of listing and cataloging physical deformities from ancient biblical and extra-biblical sources in a four hundred page work. The listing looks remarkably similar to the modern medical diagnosis and billing codes also known as the ICD 10. Holden lists dozens of abnormalities and divides them generally into three categories in the table of contents:

- a. Abnormality as a result
- b. Abnormality as a means
- c. Abnormality as a symbol

While there is a lack of definition of the class which contemporary culture calls “disabled,” the various categories are frequently found in juxtaposition with the Hebrew word “*ot*” which is generally translated as “sign.” Mark David Schutzius studied this term and its meaning and purpose. The wide range of what we call disabilities in scripture serve as an opportunity to juxtapose the frailty of humanity with the power of God. While “*ot*” is not used in instances of human defect, the use of “*ot*” to show God’s power and the juxtaposition of disability with the perfection of God does an interesting parallel. It is our weakness which shows God’s power. Mark David Schutzius II’s dissertation, “An Analysis of the Old Testament Usage of ‘ot with Particular Emphasis on Isaiah 7:14, lays out this theme of contrasting God’s power with our frailty.

Hector Avalos proposes sensory criticism as an alternate approach to reading scripture. This is appealing in part due to the heightened awareness in recent years of autism spectrum disorder and the key issue of sensory processing. Says Avalos, “Sensory criticism is premised on the idea that concepts and expressions involving the body and its senses are valuable features for study” (47). A case in point for this is the by different cultures of exactly what constitutes a

“sense” which can vary in listing and interpretation from culture to culture. In disability studies, particularly autism, a key to the classification of disability is the variance in processing of sensory stimuli and variations in what is considered to be socially appropriate responses. Avalos focuses upon two senses in particular: hearing and vision. He notes: that “to hear” and “to see” are ranked 44th and 37th overall of the most repeated words in the Hebrew Bible (50). Avalos performs a cursory review of Deuteronomistic history versus the theodicy of Job in comparing and contrasting the use of sight and sound in understanding and experiencing God. I believe, however, that there is another depth of discussion which should be made. His analysis assumes that all hearing and seeing are the same senses for everyone. Modern disability studies, in particular in the area of autism, focuses not simply upon whether one can see or hear, but how the brain processes the data collected by these senses. Much of occupational therapy, for example, is preoccupied not with whether the sense is collecting data, but rather the nature of the data and how it is processed. Key to understanding autism is to understand that the same data (e.g. a sound or a touch), is processed quite differently for different people. To illustrate, drag your fingernail across a chalkboard and see the different reactions!

By the same token, understanding the differences in processing provides a very different reading of Psalm 115. [Note: the researcher is the father of one who is high-functioning autistic with numerous sensory issues and has concluded that the “idols” mentioned must be autistic!] Psalm 115 has a laundry list of communication disabilities which shows the idols of those surrounding Israel as being disabled:

Psalm 115: 3-8
 Our God is in the heavens;
 he does whatever he pleases.
 Their idols are silver and gold,
 the work of human hands.
 They have mouths, but do not speak;
 eyes, but do not see.

They have ears, but do not hear;
 noses, but do not smell.
 They have hands, but do not feel;
 feet, but do not walk;
 they make no sound in their throats.
 Those who make them are like them;
 so are all who trust in them. (NRSV)

These metaphorical uses comparing other gods to the foolish in wisdom literature are common. Some of the metaphorical uses in prophetic works are Isaiah 43:8 “Bring forth the people who are blind, yet have eyes, who are deaf, yet have ears;” and also in Jeremiah 5:21 “Hear this O foolish and senseless people who have eyes, but do not see, who have ears, but do not hear.” (NRSV) The rebuke, if taken literally does not make sense. Why should the blind be expected to see? The rebuke seems to be addressed to those who hear the words and see the evidence of God, but who do not take it to heart. The prophet is not calling the disabled, dumb; but the able bodied, foolish.

The story of Mephibosheth is one of the more interesting pericopes. It consists of 2 Samuel 4:4; 2 Samuel 9:1-13; 2 Samuel 16:1-4; 2 Samuel 19:24-30; and 2 Samuel 21:1-14. Jeremy Schipper notes that in recent years the “social model of disabilities” has “reconfigured people with disabilities as an oppressed social group” (17). His primary contribution is to focus first upon the person, Mephibosheth, and then on what the biblical presentation says about the role and status of persons with disabilities in that time period. The question within this research context, is as follows: Is Mephibosheth presented as a cripple representing a class or people or is he a person who happens to have a deformity?

Samuel introduces the story of a child who is crippled due to a fall fleeing battle and, almost as an afterthought, we are told that his name is Mephibosheth. While he is not a major character in 2 Samuel, it is significant that he makes five different appearances. To tell the story of Mephibosheth as a person is to flesh out what it means for him to be the grandson of King

Saul and the son of King David's best friend. Further, it recognizes him as an orphan raised, not by his family, but in the biblical equivalent of a foster home. He is there when King David, almost as an afterthought, thinks to ask if there is anyone of Jonathan's house left to which to show kindness. Chapter 9 demonstrates David's desire to show kindness to Saul's house, in particular the descendants of Jonathan, and the fact that he is crippled seems not to matter at all. In chapter 16, King David is told by Ziba, the servant assigned by David to care for Jonathan's estate, that Mephibosheth is trying to regain the kingdom from King David. In this instance there is no reference to Mephibosheth being a cripple (in fact, the claim that Mephibosheth could retake the kingdom is treated as a possible, not an absurdity).

It is not until 2 Samuel 19:24-30 that King David and Mephibosheth speak. Mephibosheth swears allegiance to King David and gives his side of the story. The interesting thing is that it is here that Mephibosheth, and no one else, cites his disability as a limitation. Later, in Chapter 21, when David turns over descendants of Saul's over to the Gibeonites for punishment, it is Mephibosheth who is spared not due to his disability, but to David's loyalty to Jonathan. Throughout the Mephibosheth story it is his ancestry and actions, not his being crippled, which drives the story.

A central theme of this dissertation is that the modern, American compulsion to classify persons according to disability is contrary to the Christian theological heritage. That this understanding is not congruent with the Hebrew Bible understanding becomes evident when Oylan notes frustration with the difficulty in identifying a classification schema in scripture (124-126). This researcher argues that any attempt to superimpose categories as being biblical goes against our tradition and is simply a modern invention. The Hebrew understanding of inclusion is carried forward into fuller reality in the New Testament witness.

Disability in the New Testament

A study of disability in the New Testament should begin with a look at the understanding of deformity and disability in the Roman-Greco world. Nicole Kelley asserts that this period, like that of the Hebrew Bible, does not have a comparable term for disability or deformity, nor that concept of a category of “disabled individuals belonging to a separate and identifiable class” (33). Kelly notes that a physical characteristic such as blindness, deafness or other abnormal body characteristics did not necessarily make one “fall short of bodily or aesthetic ideals” but rather it was only if the impact of the difference made it difficult to function in family and society that they were considered to be what we call disabled (34).

Megan Burnett, in her study of disabled persons in the New Testament world, has a curious finding: “there were few (if any) true examples of mental retardation discovered in the literature.” (83). Martha Edwards notes that disability is defined not by one’s condition but by the position or role they hold in the community as is influenced by their physical and/or mental functioning (35).

Melanie Howard writes of the father who brought his son to Jesus for healing and encourages us to view “through the bifocal lens of ability and disability.” She acknowledges that this language is not explicitly used, but that it is descriptive of the New Testament view in “Jesus Loves the Little Children” (276). Howard uses this story to encourage parents to be advocates in obtaining and pushing for resources for their children. The story highlights several aspects of impairments (physical, mental emotional) of that day. First, the family is the primary caretaker. Second, it is not the disorder itself, but the manner in which the defect impairs social functioning that is most problematic. The inability of the disciples (and through extension the priests and rabbis of the day) to deal with the needs of the family is noteworthy when compared to the

church of today. Howard notes that everyone in the story--- the father, the disciples, the son; are disabled. It is Jesus who teaches all of them of the power of God. This pericope presents an episode which resembles a seizure disorder almost perfectly. Depending upon its severity, most seizure disorders can be fairly manageable. Reading this story and Howard's interpretation reminds parents and friends of the necessity of being an advocate both in our society and before God.

Kelley looks at two case studies of mythical figures who inform those of the Graco-Roman age about disability: Hephaestus, the Greek god of fire and artisans and the blind Thebian prophet Teiresias. Hephaestus is the Greek god of fire and artisans and is deformed. He is described as having "crooked feet." At times stories refer to the other gods mocking him. Kelly tends to think that he is included in the pantheon simply because the inclusion of one with physical defect is reflective of the culture of the day. His mother rejects him as a baby due to the deformity. The interesting question, says Kelley, is whether the rejection of the child with a congenital defect by the parent would be seen by the Greeks as a good thing or be considered revulsive. Kelley does not have a good answer (37-40).

The prophet Teiresias is also presented as an example of one who has a defect, blindness in this case, but this is the result of punishment. There is no question that in the ancient world mutilation of an enemy or criminal was a common form of punishment. Teiresias is blinded by another god as punishment. Kelley cites blindness as the most frequently mentioned physical handicap in ancient Greek texts. Causes can range from accidents, battle wounds, intentional infliction and natural causes. A number of specific stories abound in Greek myths in addition to biblical stories. The interesting part is that numerous stories exist of those who were blind and as a consequence developed special creative abilities (poetry, song, enchantment). This makes

sense on a practical level, people must develop other senses to compensate for the loss of sight, but more so, it speaks to the idea that blindness leads to special gifts being prominent in ancient Greek times and during the times of the New Testament Church. (Kelley, 41-45)

The issue of blindness is a major theme in the New Testament. Notes Felix Just who focuses on it, there is only one example of a blind person in the Old Testament (King Zedekiah) and yet there are numerous in the New Testament. Just examines the stories in the gospels with particular emphasis on the story from the point of view of the blind person, their social position in society and what this tells us about Jesus. While others have written about blindness in the ancient world and others extensively about the healing Jesus, few have written about Jesus from the perspective of the marginalized blind person (9-10).

Theological Constructs of the Disabled in the Contemporary World:

Can They Be Saved?

Recently, an accountant at a community-based center for children and adults with disabilities was asked by a friend at church whether or not “those people” (ones with low IQ’s), would be able to go to heaven. It shocked him; not that someone wondered it, but that it would be said so plainly.

Mark 2: 1-12 is typical of modern religious thought regarding disability. First, for the crowd, the paralyzed man is defined by his defect. To the contemporary reader, he is in fact, first a paralytic, rather than a man. It is his friends who bring him, the caretakers, for whom he is first a human being who has a need. Second, it is Jesus who is concerned about his spirit (or soul). Whereas the crowd sees a paralytic, they see a disability. Jesus, seeing the spirit within, announces that his sins are forgiven. There are those who associate the sin and the disability, but

Jesus and Markan writer do not: Jesus pronounces forgiveness and then, as a secondary event, heals the paralysis (Hentrich. 86-87).

Jesus' pronouncement has two scandals. First, the scribes question the divinity of Jesus and his ability to forgive sins (notice that Jesus does not say, "I forgive your sins," but rather, "your sins are forgiven"). The second scandal is that he pronounces forgiveness rather than healing. In his day, as in ours, the physical difference is seen as the problem. What really disables him socially is not the physical impairment, but the way in which society treats him because of it. Jesus uses the moment to make several points: 1) he can forgive sin, 2) he can heal bodies and 3) the impaired are important to God. Wherever Jesus goes, he heals the physical impairments he encounters. In Levitical law, the physically impaired are not allowed to enter sacred space before a flawless God. In the New Testament, the flawless God enters the space of the physically impaired and removes their physical imperfections.

Christian Education & Stages of Faith:

A classical theory of from Jean Piaget who argued that "at different points in their growth, children acquire new systems of cognitive operations... that radically alter the form of learning of which they are capable." The idea for the educator was that they would assess exactly what stage of development a person was at and then design the education best suited for that stage. Piagetian theory provided a theoretical framework for different teaching methods. (Case. 219)

Later educational theories would build on and modify Piagetian theory. However, the understanding that development occurs in stages and the idea that there are basic patterns of learning, or as Case calls it, "general sequence of attainments that could be expected. (229)

James Fowler, in *Stages of Faith: the Psychology of Human Development and the Quest for Meaning* takes this concept of stages of development along a predictable path and applies it to the development of religious faith. Working with those with special needs, in particular intellectual deficits and processing disorders, provides a harsh critique of developmental theory not only in education but more definitively in religion.

Contemporary American culture knows only developmental theory to teach writing. The older generation was first taught to recognize letters, then to print letters and, to go on to learn to write cursive (for the younger generation many are not taught cursive but rather typing). The researcher struggled to learn to print-- not because he did not know what they were supposed to look like, but due to a fine motor disorder that today would qualify for pediatric occupational therapy. What he did was to teach himself how to write cursive. His teacher, seeing this, finally gave up and taught him cursive. In special education stages can become irrelevant and often steps are skipped to focus on what a person can do. Conversely, many education plans focus not on one's strengths and advance learning in these areas, but rather most of the time is focused on the missing developmental stage (which may explain why emotional disturbances are common in special education classrooms).

What Fowler has done is to provide normative (normal) steps to faith development. Working with special needs calls this into question. Chuck was close to his support staff person Henry. Henry had worked with Chuck, who had Cerebral Palsy and lived alone, for years. Henry was in his fifties and one day had a stroke which led to another until a few months later a massive stroke ended his life. The staff was devastated and went to comfort Chuck. Chuck was matter-of-fact: "Henry is in heaven now," he said. While staff was distraught, it became clear that Chuck was at peace and he knew Henry was too. Chuck operated on about a second grade

level academically, but his spiritual perspective was that of a mature Christian. He became the minister to a staff in mourning.

Often there is a bias toward using educators to work with special needs persons in the church. One should be cautioned that using their skills can be helpful, but this background should not be seen as the most important qualification. The most important qualification is not learning educational or religious theory but rather having the ability to love, learn about that person and their abilities and have a genuine Christian fellowship with them.

Some Other Issues to Consider:

Sensory Criticism: With the rise of diagnosis of autism spectrum disorders and the acknowledgement of disability in scripture comes another angle through which to examine scripture: that of a sensory approach. Rather than lie flat on the page, the narratives and images of the biblical story come to life not only through story but through the senses. Hector Avalos notes that while most cultures share the same listing of senses, sight, hearing, smell, taste and touch: there are others which add to or merge some on this list. Further, the emphases of these within cultural/ religious perspectives vary (47-49).

Recently one of the “non-denominational mega-churches” opened a satellite in a community. A client of a community based center working with developmental disabilities, a rather high-functioning young woman who is a member of a local civic club and works part-time at a local bookstore, decided to visit. She had to leave early for she could not handle the loud music and the dramatic visual effects. They were sensory overload. For many on the autistic spectrum, processing what seems pleasing to others is very difficult. Whether it be mass media or modern worship, churches tend to appeal to a particular set of senses with little regard for the many who cannot handle what the majority prefer. Some want to stand and shout to God. Others want to be still and experience God in the stillness of the moment. In the world of

disability, still others are physically unable to handle a particular experience due to sensory interference.

Avalos examines in some depth the issues of hearing (audio-centricity) and sight (visio-centricity). Hearing is critical in the deuteronomistic period and this is made obvious through the frequent stories in which God is proclaimed and experienced orally. Avalos is uncertain of the reason precisely (54). He speculates that it is important for a non-literate period. There are many processing disorders, in addition to people with difficulty reading, which limit understanding unless the information is presented orally. Jeremy was a youth in a small church who dropped out of school. He participated in youth group and bible study and the pastor who met regularly with the youth never knew that he was a special education student and attended school in a self-contained environment. He could read fluently, but did not have a clue what he had read. However, if he heard it read, he was able to process the information, understand and explain. He had a processing disorder which prevented him from processing visual input yet he could process the same information through hearing. For him, understanding required hearing, not reading.

In Job, says Avalos, there is a focus on visual input. Job and his friends are focused on what they can see. Scripture and church history are replete with visual examples from the visual representations of God in the Exodus through the visual experience in temple worship to the experience of miracles in the New Testament and into the worship symbols and architecture throughout church history.

The Mind of Christ: For congregations, there is a necessity to have the mind of Christ in congregational life and missional outlook. Timothy Wesley Mahler lists examples in which Christ expressed compassion on others:

- a. Feeding stories
 - b. Healing stories
 - c. Stories of those with emotional needs
 - d. Stories of those with physical needs
 - e. Mental disorders
 - f. Social needs
- (Mahler, pp. 43-57)

This list provides guidance for the congregation seeking to emulate Christ. In the later chapters in which congregational ministry with those with special needs is discussed, the congregations exemplify this list. They are engaged with those with a variety of medical, emotional, mental and developmental needs and do so through social, spiritual physical means. And yes, feeding is usually involved.

Doctrine of Creation

James Wm McClendon speaks of creation in three categories: 1) Gift and Blessing, 2) Creation as Travail and 3) Creation as Promise. In dealing with creation, McClendon moves straight to suffering (being present in the delivery room makes clear that the usual pattern is to we move from birth to crying quite quickly). McClendon sees five main points:

1. God is the origin and source of all else
2. Creation is perceived as God's ongoing blessing
3. The creative divine rule is nevertheless under constant attack
4. God's rule is both displayed and enhanced by creation
5. Creation has a terminus or a goal. (146-189)

One of the problems with labeling others as "disabled" is that it makes us feel that we are not. We either remove ourselves from being part of the attack upon creation (being without defect) or we remove the disabled from the creation (lacking the blessing of being a creation of God). While we are all part of God's created order, including the part where the Lord spoke and said that it was good, we all are also part of the travail and turmoil of the created order. In each

one of our creation, there is both difficulty and promise. This researcher's bookshelf is littered with wonderful volumes containing the personal testimonies of parents, family and friends of people who have been labeled disabled by society and even the church but to their family and friends, they are blessed and a blessing. We, and the "they," are each part of the created order.

Doctrine of the Trinity

Myroslaw Tataryn and Maria Truchan-Tataryn have a well-developed approach in applying the Doctrine of the Trinity to what they call "a Theology for Embracing Difference" in *Discovering Trinity in Disability*. In their book, they merge the fields of theology and humanities along with personal family experience with disabilities and the Church. They write:

"Today, when we regard someone as "special" or with "special needs," we albeit unconsciously, push them away from "all" of humanity, diminishing their roles as equally divinized human. At the same time, we distance ourselves from Christ. How? Our refusal to be open to the "foreignness" of another closes us off to the complex realities of our own selves. Without encountering our human realities, we avoid encountering Christ. God's power is manifest in the fleshly dependencies of a person whose refusal to conform to socio-cultural norms results in alienation, degradation, and a criminal's death. Christ embodies human frailty together with the bold strength of human love. Through Christ we know God." (61).

The Doctrine of the Trinity reminds us of the necessity of living in community. The early church knew that in Acts and the monastics of the early church established a model which still endures. The Community Integration movement in the United States has, for the last several decades, been moving adults with disabilities out of institutions and into community based

settings of which many are either church-based or overtly Christian. Tataryn outlines a model for independent living of persons with disabilities based upon this model (72-83).

Nature and Mission of the Modern Church

Fiorello, in noting that the physically disabled in ancient Israel were neither excluded nor marginalized, states my concern well that current efforts to develop specialized ministry will simply promote labeling and marginalization:

“The motivation and effort in modern scholarship to eliminate the barriers and categorizations endured by the physically disabled and to replace their exclusion with inclusion is laudable. However, juxtaposing different physiological phenomena in literary contexts, even though symbolic and broadened beyond physical features, only serves to further disability and to validate differentness as a basis for their stigmatization...few distinguish themselves by rising above their limitations and risk potential depreciation for doing so” (303).

Walls discusses the place of persons with disabling conditions in *The Origins of the Disabled Body: Disability in Ancient Mesopotamia*, and brings forth the model sought by most advocates in the United States today:

“Whatever social stigma was attached to physical or mental disability, people with abnormal physical or cognitive conditions were assigned jobs as they were able... severely disabled children and adults were cared for at home over long periods of time... apart from a very few prescriptions of infanticide or euthanasia and sparse references to the social exclusion of people with leprosy or dropsy, we see little clear evidence for the social rejection of disabled people based upon physical forms.” (30)

Nancy L. Eisland, writing an article for a collection on medical ethics, says that it should be the task of people of faith to “(i) acknowledge our complicity with the inhumane views and treatment related to people with disabilities and (ii) to uncover this hidden history and to make it available for contemporary reflection” (587). While this research does not go as far as Eisland does in attributing the Church to be a cause of inequitable treatment in labeling and marginalizing, the tendency of the Church to emulate culture in first applying labels and then separating people as disabled, even with good intentions, will tend to marginalize. The problem in our culture is that the very act of labeling and creating specialized ministry serves more to create a divide in culture and the church rather than to build community which bridges the divide which exists.

Fiorello argues that the function of Israel’s law code was to establish Israel’s spiritual while narrative functioned to reinforce it.” (305) The legal code required that the disadvantaged be treated as equals and included not as what we call outreach ministry to the “other,” but as an integral part of Israel’s identity as the people of God. “The ethical, equitable, and moral standards embodied in covenant law were practical and at the same time ideal... in the practicing of them the nation’s identity was made known.” (307)

An item which will be examined in the next section is the response of the United Methodist Church, to the Disability Rights Movement. John Pridemore’s study analyzes General Conferences from 1968 to 2004 and the manner in which “the United Methodist Church has generally exhibited similar levels of resistance and discrimination toward members of the disability community as other religious denominations or groups” (5).

Eisland points out that Jesus in his resurrection appearances (example, Luke 24: 36-39) comes complete with the scars of the crucifixion. God appears to his Disciples complete with

the scars of humanity. The perfect God of the Old Testament becomes the Disabled God proclaimed as Savior by the New Testament Church.

The final section of this chapter examines the historical and contemporary status of persons with developmental disabilities in the United States from the secular disability studies perspective to provide a context for this issue in the contemporary church. A variety of literature exists both from the ministry perspective and from the disability studies perspective. See for example Christopher Thomas Blair in “The Use of Religious Coping and Perceptions of Family Functioning of Parents Who Have a Child with a Developmental Disability.”

While ministry and disabilities has been a popular topic of late, the real question is whether the ministry and programs being developed are theologically sound and informed by good research into the most appropriate ways to be both inclusive and relevant to those with whom we wish to be in ministry.

Disability in the United States and Recent Trends

While the Biblical and Theological perspectives are those which should guide Christian thought, there is also the current environment, its origins and its directions. Since the 1950's, there has been a steady march propelled by parents, courts, academics and public policy makers away from the vast divide between institutionalization and seclusion toward community based services and inclusion into society at large. This is represented in recent literature in the field of disabilities representing the movement toward community integration and “normalization” of those with what society calls disabling conditions into the mainstream of culture. The research phase revealed both those who were extremely knowledgeable about these trends and those who were woefully uninformed. For the contemporary church, there is an opportunity to contribute to

this debate a theological, moral perspective drawn from a much richer perspective than that of the legalistic argument or even of the family advocate. In fact, many of the advocates in education, medicine and social services are Christian and invariably their advocacy springs from theological roots. It is this project's assertion that a biblical model which sees all humanity as people first and then seeks to find a place in the community of faith for all who come to Christ regardless of society's labels is a preferable model. The movement of some churches toward focusing primarily upon specialized ministry for people with disabilities is one which will simply continue the marginalization and, worse yet, rob the broader church of a vital part of our humanity.

Deviants, Imbeciles and the Institutions

One of the few comprehensive volumes on the subject of disability in the United States is Kim Nielson's 2012 work, *Disability History of the United States*. There are currently only two Universities in the United States offering doctoral programs in the area of disability studies. Dr. Nielsen writes as one who holds a PhD in history and as the parent of one with a disability. On the other hand, there are numerous scholarly articles documenting specific stages of the development of this field in the United States.

At the time of the settlement of the New World, both the Native Americans and the arriving Europeans expected everyone to contribute to their communities' survival. In furtherance of that goal, they worked to integrate everyone into society and to ensure that everyone had a job which helped their society. "Though individuals might experience impairment, disability would only come if they were unable to participate in community reciprocity." In other words, as long as they are able to contribute their gift to the community,

they do not have a disability (Nielson 3).

European settlers likewise worried not about one's physical characteristics, but more importantly about their ability to contribute to the survival of the settlement. "One-armed men and women, or those with slight palsies or limps, or those who could not hear, and on and on, could plant fields, mind children, sail, build a barrel" (Nielsen 9). They were concerned, however, with the "Idiot or distracted person" (Nielsen 21). It was when their mental functioning was lacking that they became a problem. Massachusetts law, cites Nielsen, divided persons as follows:

1. "Idiots... incapable (sic) to provide for him or herself... idiots were generally born idiots"
2. "Lunatick or distracted person... for whom perceived mental instability occurred later"

"Idiots" and "lunaticks" were protected from punishment for breaking laws they did not understand and, while families bore primary financial responsibility, were to be supported by the community (however, standards were required of the community to protect them). (see Nielson 22 ff).

For a humorous contemporary story about a lawsuit between two Vermont towns over who bore financial responsibility for an incompetent person see Tales of a Vermont Country Lawyer. In it the subject of the lawsuit had alternately lived in both towns and they were in court trying to avoid responsibility for his care and upkeep in his later years. He attended court sessions with considerable interest and in the end proclaimed that the community saddled with the bill for his care "won."

With the development of modern science, including the fields of medicine, psychology and sociology, the desire arose to determine everyone's classification and to determine just where they fit in not because of how they functioned in society, but based upon genetic or

scientific classification. Rather than the pre-modern understanding which might acknowledge physical defect but only see disability if it interfered with societal functioning, the new paradigm was eager to label and even segregate at an earlier and younger age.

In 1817 the first institution specifically for disabilities was founded in Hartford, Connecticut. During the 1800's an extensive network of societies and institutions in the United States specializing in disabilities was developed. With this proliferation came experts and attempts to better define causes and pathology of disorders. Kim Nielson provides an extensive chronicling of this development.

Nielsen defines the period of 1890 – 1927 as the “Progressive Era: Three Generations of Imbeciles Are Enough” (100). It is during this period that institutionalization, segregation and sterilization became the preferred solutions. Whether it was Native Americans or the Scotch-Irish hill folk, families learned quickly that they either cared for their family member at home or they would lose them into to state run institution.

The early 20th Century is marked in the United States and Europe by the rise of Progressivism, Marxism, Communism and science. Whether they went hand in hand this research will leave to others, but in the case of developmental disabilities we see science and medicine used to manage the problem of the “defectives.” Martin S. Pernick writes in “Defining the Defective: Eugenics, Aesthetics and Mass Culture in Early Twentieth Century America” that a Chicago surgeon made headlines by “allowing the deaths of at least six infants he diagnosed as ‘defectives.’” Further, he actually sought “publicity for his efforts to eliminate those he considered to be ‘unfit’” (89). Pernick goes on to document the movement to define “unfit” not by functioning in society but by aesthetics in particular beauty. Those not meeting the ideal were considered to be disabled. Pernick writes that during the period 1910-1930 the topic of

eliminating the unfit through euthanasia essentially did not disappear as a practice but did disappear from the public dialog as “unfit to discuss in public” (100).

In the American colonies, later the states, the responsibility for support of the families fell upon local governments. It is only with the New Deal in the 1930’s that this responsibility moved further away from the family and community to the state and national government and for them these special people were no longer friends, relatives and neighbors but a diagnosis, a cost and another body to warehouse. In Arkansas, the institutions never reached the size and scope of other states, but here still the trend was toward that regrettable choice of institutionalization or no help from the government at all.

The Institutions are Targeted by the Civil Rights Movement

David and Sheila Rothman wrote what is almost a blockbuster novel titled The Willowbrook Wars about the legal fight over the Willowbrook Institute, a New York Institution for persons with developmental disabilities that by 1970 was housing over 5,400 persons in a single location. Opened following World War II, Willowbrook steadily grew in population which the standard of care followed an inverse relationship. At one time, Robert Kennedy, along with many other advocates for those with disabilities, advocated to better care. During the 1960’s what is known as “The Parent’s Movement” advocated for more money and better with no real results. Much as the Civil Rights Movement began with lobbying and demonstrations and eventually moved in to federal court, civil rights attorneys took up the cause and filed suit against the State of New York in federal court in 1972. After several years of hearing, a consent decree was signed in which the State of New York agreed to reduce the size of Willowbrook to a few hundred persons and move the rest into community-based or other more appropriate settings. The national movement toward de-institutionalization had received legal precedence. (Rothman,

pp. 16-124)

Likewise, in education the passage of the Individuals with Disabilities in Education Act created civil rights protections for students and their families. States and local school districts were required to provide services and protections for those with special needs where previously service level varied widely.

In recent years a change in the understanding of autistic spectrum disorder, or Asperger's Syndrome, has prompted a higher degree of awareness of developmental disabilities and in particular behavioral disorders. The article by Houtrow et al in *Pediatrics* analyzes recent trends in diagnosis and finds that there is a "21% increase in disabilities related to neurodevelopmental or mental health disorders... with the most pronounced increase among advantaged families" (535-536). The researcher is suspicious that the increase in diagnosis among advantaged families may be indicative of less fear about labeling or possible seeking a diagnosis in order to access more services or better legal protections.

Person-Centered Planning and Community Integration

The standard model today for persons with developmental disabilities, as least on paper, is person centered planning or equivalent. The American Geriatrics Society describes person-centered planning as care in which "individuals' values and preferences are elicited and, once expressed, guide all aspects of their health care, supporting their realistic health and life goals. Person-centered care is achieved through a dynamic relationship among individuals, others who are important to them, and all relevant providers" (15).

In Arkansas, the Making Action Plans (MAPS) process is used to create Individual Education Plans (IEP). Wells & Sheehey write "including parents of children with disabilities in educational decision making has been a core value since the passage of the Education for All

Handicapped Children Act in 1975.” (33) Questions for the MAPS meeting, which includes parents, teachers, therapists, the student and others invited by the parent, should include the following:

- What is the person’s history
 - What is your dream for the individual?
 - What is your nightmare?
 - Who is the person?
 - What are the person’s strength, gifts and abilities?
 - What are the person’s needs?
 - What would the ideal day look like?
 - What must be done to make it happen?
- (Wells & Sheehey 34)

In the disability field, person-centered planning extends beyond educational services of an academic nature to living arrangements, vocational training, work and social settings. In “Person-Centered Planning for Transition-Aged Youth with Autism Spectrum Disorders,” Hagner et al discussed both the concept of person centered planning and how it can be modified to fit specific persons. “Person-centered planning has emerged in recent years as an approach that involves consumers and families in the planning process more centrally than traditional planning approaches.” (Hagner et al 3) The planning process is less formal and more individualistic including planning at the pace of the client, discussing issues in a manner understandable to them and, in the case of this study involving autism, presenting issues in a more visual fashion. “The individual, family, vocational and other adult service representative... collaboratively plan the assessments and other services... for a smooth transition.” (Hagner 5)

Person centered planning is more of a mind-set than a formal process. Often organizations will “go through the steps” so to speak but not follow the spirit of the process. The Minnesota Department of Human Services help fund a manual explaining this process which lists the values of person-centered as being to:

- *craft a desirable lifestyle
 - *design an unlimited number of desirable experiences
 - *find new possibilities for each person
 - *focus on quality of life
 - *emphasize dreams, desires, and meaningful experience
 - *Organize to respond to people
- (Amado and McBride 4)

On an international level, the Centre for Research into Disability and Society in Australia produced a study entitled “The Individual Supported Living (ISL) Manual: A Planning and Review Instrument for Individual Supported Living Arrangements for Adults with Intellectual and Developmental Disabilities.” This was a study of a Manual being used to do person-centered planning for adults with developmental disabilities living in community arrangements. The development of person centered plans is an international trend. (Cocks et al 614-624)

In 2014, the Centers for Medicare and Medicaid Services, an agency of the US Department of Health and Human Services, released a much anticipated rule commonly known as the “Definition of Community.” It defined what living in the community means and required that services provided outside of institutions must meet this description. Coupled with a stated preference, both for monetary and civil rights reasons, to keep individuals out of institutions, this definition provided guidance for states in establishing requirements for home and community based services for geriatric, mental health and developmentally disabled populations. This rule is the culmination of decades of family advocacy (aka “the parents’ movement”), legislation and court decisions. Understanding this background is critical for churches and pastors to relate to and be in ministry with persons with disabilities in these areas. (At the time of the final edit of this paper, implementation of this rule has been suspended with a new administration in Washington, but most states pretty much follow its guidelines already.)

A primary challenge for those living in supported living and congregate living is what

Reid and Parsons refer to as “challenging behaviors.” One of the fundamental ways of turning these “challenging behaviors” into positive behaviors is “frequent participation of consumers in meaningful and enjoyable activities.” (9) Supportive living and congregate living facilities are looking for activities in which their clients can engage which are positive. Church participation, whether worship, class meetings, activities or outreach, are identified as “therapeutic” to transform a bored, problem client into a happy, valued member of the community. (Reid and Parsons, 69)

Much of the focus in recent years has been upon children and developmental disabilities. Due to better medical care, more and more individuals with special needs are living longer and often fall into the category of what the profession calls “dual diagnosis.” Smith and Carey write about a care plan for such a dual diagnosed client who has both an intellectual deficit and physical disabilities. Dual diagnosis could also be mental health and low intellect and in my personal experience adults are usually some sort of dual diagnosis. Their case study highlights the need for individualizing care plans for the person, not one particular disorder. (Smith and Carey 21-23)

The Disabled Re-Entering the Church: “Life Together”

David Anderson writes in *Toward a Theology of Special Education*, “In the case of persons with obvious disability, the tendency is to focus first on the limitation rather than the giftedness of the persons.” (149) He writes this within the context of arguing for inclusion of persons as opposed to “ghettoization.” For many, a discussion of ministry involving those with disability begins with a discussion of diagnosis and disability and a focus upon the person’s weakness. It begs the question: how would you like it if your life revolves around everyone

talking about and focusing upon your weaknesses? His book is a needed corrective to the fields of education, psychology and medicine which focus on classification and identification of disorders as opposed to our common God given humanity.

Churches need to understand that in government and society inclusion, person-centered planning and modifications have become the norm. They expect you to learn about their family, their loved one and their specific needs. In fact they expect it. Congregational leaders also need to understand that there is a lack of trust. There is a history of being lied to, loved ones disappearing into the system and lack of care or even worse abuse.

Research Design Literature

There is no existing research in the Arkansas Conference of the United Methodist Church on the scope and nature of ministry with developmental disabilities in its congregations. In fact, a review of the scholarly databases only revealed one dissertation on disabilities and it was an exploratory study of discussions of disabilities in sessions of the General Conference performed by John Pridemore in 2010. Beyond the United Methodist Church, no scholarly literature regarding ministry and developmental disabilities was discovered. However, numerous case stories have been written along with a number of articles, books and websites about how to put together a program.

Two options for this study were possible. One involved choosing a particular congregation to study and the other an exploratory study of a geographic collection of churches. Due to confidentiality issues, the researcher leaned toward an exploratory survey of a geographic area. The availability of the conference email network lent itself to this geographic boundary. The lack of existing research and therefore models of how to research this particular issue,

suggested that an exploratory survey would both generate issue specific results and perhaps provide a model for others wishing a similar study.

Tim Sensing quotes the Association of Theological Schools (ATS) in his introduction as saying, “The project should be of sufficient quality that it contributes to the practice of ministry as judged by professional standards and has the potential for application in other contexts of ministry.”

The multi-methods approach, say Sensing, “allows various perspectives to engage in a critical dialog that leads to several sets of rich data. (54) He goes on to advocate “an orientation to inquiry rather than a particular method.” Sensing discusses a variety of action research models in which the researcher becomes a “co-participant with the community in the process of gathering and interpreting data.” (63) This approach essentially involves testing an intervention and then analyzing the data from that intervention.

The case study, by contrast, is one in which there is a “snapshot” of a moment in time in which the researcher makes an “intentional, proactive intervention.” (Sensing, p. 144) For this methodology to yield valuable data, there must be valid data of what exists before and after the intervention so that changes can be measured. While Sensing dismisses the descriptive case study as a model for Doctor of Ministry projects, he cites others in the social sciences field who see this as a valid project.

Summary

The field of developmental disabilities encompasses a variety of disciplines and combining this with ministry even more. Pre-modern social structures for those born or who develop disability in their youth are quite different than those of modern culture. In many ways, the trend in contemporary culture toward inclusion and integration is simply a movement back

toward religious and cultural roots. In Arkansas the three primary pre-modern cultures, native American, Scot-Irish and African are all very tribal oriented and all have an expectation of individual's contributing to their community.

Labeling and marginalization are themes dominate in modernity and both the Old and New Testament portraying a God who is an advocate for the marginalized. The present struggle to re-integrate persons with what the Old Testament writers called "defects" presents a wonderful opportunity for prophetic preaching in our current age with poignant texts in both testaments.

Part of the challenge today with disability, in particular intellectual and functional deficits, is that institutionalization has robbed the modern United States context of the experience of interaction with persons who function very differently. Due to the lack of their involvement in schools, churches and the marketplace, many today are nervous and less adaptable themselves about how to engage persons with special needs.

The Church today is poorer for their absence and less able to experience the richness of different perspectives and life experiences. The journey to rediscovering God's plan for our community continues as the researcher lays out the study of one corner of God's kingdom, the Arkansas Conference of the United Methodist Church.

CHAPTER 3: PROJECT DESCRIPTION

There is not currently a comprehensive study or even a survey of congregations in the Arkansas Conference of the United Methodist of ministry with people with developmental disabilities (i.e. a significant impairment of one's ability to function in society diagnosed before age 19). This study focuses on ministry with this target population within this specific set of congregations. The purpose of this exploratory study of ministry with developmental disabilities in the Arkansas Conference of the United Methodist Church is to identify congregations which include persons with developmental disabilities and those with more significant ministry to the disabled will be selected for additional study to identify best practices for both inclusion and outreach ministries.

The subjects of this research are not those with developmental disabilities, nor their families, but rather the congregations responsible for the nurture and care of these persons and families within their congregations. The identity of congregations, families and individuals will be protected through anonymity and the use of common stories.

Research Question #1 Which churches in the Arkansas Conference claim a ministry with persons with developmental disabilities?

(Addressed in phase one)

Research Question #2 In a survey of churches claiming ministry with persons with developmental disabilities, to what extent are these persons integrated into the life and ministry of the congregation and, in contrast, to what extent are they viewed as the subject of ministry?

(Addressed in phase two)

Research Question #3 Are the churches who integrate persons with developmental disabilities into the life and ministry of the congregations markedly different in their

functioning? i.e. has the integration of persons with developmental disabilities made the congregation healthier and more adaptable?

(Addressed in phase three)

Research Question #4? What are the implications for best practices for congregations to engage families & individuals with developmental disabilities?

(Addressed in phase two and phase three)

The conference studied is a southern, family oriented culture with a high opinion of reason and education. Respect and decorum are a high priority and this often serves as an impediment to including people who have difficulty functioning socially. Suspected is that the decorum of worship and structure of congregational life in most of the congregations excludes many with developmental disabilities. The focus on reason and education often means that congregants (and leaders) assume that one with a low IQ and education will not “get anything out of church” and that their behaviors will be considered problematic.

By contrast, the family oriented culture can be a benefit for those with developmental disabilities. In the south, “we take care of our own” is a common expression. The advocacy of families has propelled the disability rights movement in the United States. It is suspected that the attitude of advocacy and the expectation of modifications is a value which will be expected by families from the church.

PHASE ONE (On-Line Survey):

Phase one was a survey of pastors or other key ministry staff of all congregations within the Conference through the use of an on-line survey tool (See Appendix A). The method was to use the Arkansas Conference E-Mail network (all pastors are required to have conference e-mail) to perform a ten-question survey of all congregations to identify those with interventions and

ministries involving developmental disabilities. Either a return e-mail or the completion of a very simply survey was requested. Due to confidentiality issues, a number of disclaimers were added by the Institutional Review Board which may have discouraged participation by some respondents.

Survey Monkey Consent:

1. A forced choice was in the informed consent statement which will only allow the respondent to continue to the questions if they agree with the terms and conditions stated.
2. The statement “please feel free to skip any questions you do not wish to answer” was included.
3. The statement that this is third party software and that it is not secure along with the request not to provide confidential and sensitive information in this pre-study collection of data was included
4. The statement “continuing on a answering this survey implies consent to participate in the study of congregations in the Arkansas Conference” was included.
5. The fact that follow-up phone calls would be limited to those reporting a ministry involvement with families of those with developmental disabilities and that only about a dozen congregations will be chosen for an on-site visit was included.

The questions were as follows:

1. If you agree to these conditions, please chose yes. If not, chose no.
(item one begins with conditions & disclaimers to which the respondent must agree in a forced choice routing items that only allows those who agree to continue to the remainder of the questions).
2. How does your worship / program attendance include people with developmental disabilities? (persons with a low IQ , Autistic-spectrum disorders or other low functioning issues which began in childhood)
3. Does your congregation have persons with developmental disabilities who attend worship, Sunday School or other program integrated with non-disabled persons?
4. Does your congregation have persons with developmental disabilities who are helping to lead or carry out the ministry of your congregation?
5. Does your congregation currently have a self-contained ministry for people with developmental disabilities? *(In other words, a special Sunday School class, week-day program, etc.)*
6. Has your congregation completed a serious study on accessibility barriers?
7. What discussion has taken place in your congregation about ways to remove barriers for those with a low IQ or low social functioning?
8. What is the name or the person completing this survey?
9. Who is the best person to contact for follow-up questions?
What is a good phone number?

10. What is the name of your congregation?

Each of these questions had some suggested common answers along with the opportunity to provide other information. The researcher maintained a chart on which he recorded which congregations had responded (to identify duplicate responses from a single congregation). The minimum goal was a 60% response rate with a goal of an 80% response rate and to use follow-up e-mail and phone calls to ensure this.

The results were used to generate statistical numbers to measure the extent to which congregations are engaging people with developmental disabilities. The rationale for this large response rate was to be able to identify congregations to participate in phase 2 and 3. There was concern that there would be so few positive results that there would be a lack of subjects for phase 2 and 3.

PHASE TWO (Phone Interviews):

The second step involved phone interviews with the contacts generated by phase one. During this phase the extent of the involvement of the congregation with developmental disabilities was assessed. Then, the number of congregations was narrowed down to a manageable number for phase 3 which involves be in-person interviews and site visits.

The data collection for this phase was performed through phone calls to the identified contact person. Ideally the study group at this stage was about 30-50 congregation. Questions 1-4 were repeated to ensure that the concepts are clear and to re-state these questions in an open-ended fashion to obtain more descriptive information.

The objective was to look for positive examples in which persons with developmental disabilities appear to be well integrated into the life and ministry of the congregation. Signs of this were made evident in the phone interview:

1. How long has this individual(s) been active in the congregation?
2. How willing is the congregation to adapt to the special needs and sometimes quirky behavior which often comes with developmental disabilities?
3. Do the individual(s) in question and the congregation claim each other in the bond of Christ or is the individual only seen as a receiver of outreach?
4. Have special efforts been made to ensure that the individual and their family are fully integrated and not simply put into a specialized setting?

These indicators were expected to be present before making a site visit. Those clearing this hurdle were placed into a matrix designed as follows: The Horizontal axis charted the degree and duration of involvement: 1) limited interaction between the individual with a developmental disability and / or less than a year, 2) consistent interaction for one to three years and 3) three years or more of consistent involvement. The vertical axis charted the number of persons involved: 1) single individual, 2) two to five persons and 3) a large, specialized ministry (all of those having a specialized ministry also had more than 5 integrated into the life of the congregation).

The researcher intended to chart the results as follows:

	Limited Interaction	Program or interaction 1-3 Years	Long-term program for 3 plus years
One person in congregation with Developmental Disability			3-4 congregations
1-5 individuals in congregation who are integrated into the church ministry			3-4 congregations
Church has a specialized, significant ministry for persons with developmental disabilities			3-4 congregations

At this phase, the table may expand or contract. Natural breaks and groupings of responses indicate clusters from which to draw samples although the goal was to focus on 3-4 respondents in each of the three blocks in the right hand column in the above table. An effort is

made to select congregations of various sizes and socio-economic representations if at all possible.

The questions were open-ended and designed to learn the classic information gleaned by asking Who? What? Where? When? Why/ How? Depending on the number of churches and the information gleaned, phase 3 would be modified to ensure that it was representative of what is going on in congregations in Arkansas Methodism. This phase was designed to take the quantitative data (numbers of churches and levels of involvement) and move into qualitative collection consisting of collecting a better description and understanding of ministry and practices.

It is from this chart and collection that the congregations are selected for phase 3. Ultimately, the goal for phase 3 was to include personal stories from individuals with developmental disabilities about their spiritual walk and their life in the fellowship of the church. Often the stories were told by families and caregivers as their narratives of life in the community of faith. The key to the data collection in phase 2 was to focus in on a set of congregations which demonstrate positive results in relating to persons with developmental disabilities and then in phase 3 hearing the stories of these persons and their families.

PHASE THREE (Site Visits):

Phase three involved site visits and more in-depth interviews. The people interviewed included ministry staff, families of those with developmental disabilities and the person with developmental disabilities themselves when possible. This is the most intensive stage and the one involving the most sensitive issues involving confidentiality and subject risk.

The hope for each site visit was to be able to spend 3-6 hours on site for a significant program event or perhaps a focus group. A 2-3 page overview of the purpose, confidentiality issues and questions to be asked were sent to the appropriate ministry leader(s) of the congregation. They were asked to arrange for a gathering for a visit so that there will be proper notification and advance planning. The questions were asked and, in most cases, observations of programs and worship were made.

Use of Pastor / Staff Person as Gatekeeper:

The church pastor was generally the gatekeeper through whom all arrangements for the site visit was made. The procedure was as follows :

1. The pastor spoke to the key persons involved in these exemplary ministry examples and determined an appropriate setting for interviews. Key persons included anyone who is interviewed in the site visit (the pastor, other staff persons working with persons with developmental disabilities and their families, significant laity involved in this ministry, families of persons with developmental disabilities and lastly the person(s) with a developmental disability).
2. The pastor set aside physical space in which ministry occurs for the visit.
3. The setting be as natural and relaxed as possible for those involved.
4. That adequate time was available for a leisurely visit.
5. That the pastor relay the attachments about the purpose of the study, confidentiality assurances and release documents.

All arrangements and selection of participants were made by the pastor or their designee.

In only one case were follow-up questions made to a participant. A number of questionnaires with the questions used were left, but only two of these were received.

Informed consent was essential in this process. Participants were provided an Informed Consent Letter for Participants (Appendix C) and a Purpose Statement & Confidentiality Assurances (Appendix E). Pastors were provided an Informed Consent Letter for Congregational Involvement (Appendix D) in addition to the documents provided to participants.

The purpose in these site visits, interviews and focus groups was to ascertain the following:

1. What is the nature of the congregational involvement of the person with developmental disabilities? Does it involve worship, Sunday School, other programs, ministry team, leadership?
2. What is the nature of the engagement between the subject and congregational life?
3. To what extent does the congregation modify and bend to include the subject in typical congregational life and to what extent is the involvement in a segregated ministry?
4. What could be done to improve the involvement?

Phase 4 involved evaluating the health of the congregation in general with the suspicion that there is a correlation between healthy congregations and congregations that are able flexible and inclusive of those with special needs.

Ethical Considerations:

Confidentiality was of the essence in this project. While attribution would be nice, this would be limited to situations in which written was obtained and even then should rarely be used. Most of the subjects are those with low intelligence, impaired cognitive processing or low social adaptability skills and identifiers of churches and places would also identify individuals.

This project was inherently an exploratory study which will included some descriptive case studies, not an intervention. Therefore, the interview process involved open-ended questions and affirming conversations to elicit practices which work.

The end result should be four basic sets of stories or case studies.

1. Stories of individual involvement in congregations which went well.
2. Stories of individuals involved in congregations which did not go well.
3. Stories of specialized ministries which went well.
4. Stories of specialized ministries which did not go well.

From these case studies indicators of congregational health emerged and correlations were made. Indicators of congregational health include long-term pastorates, stable or growing

attendance and families who feel that the church is responsive to their needs. There should be a correlation between a healthy congregation (as evidenced by long-tenure pastors, stable and/or growing attendance, and active lay involvement) and a positive relationship to the families of persons with developmental disabilities.

Confidentiality:

- 1) The informed consent form provided by Asbury IRB for individuals interviewed in the site visits was be used.
- 2) A sound recording (not video) device in the small group interviews and focus groups to enable me to later transcribe and review the discussions was referenced but never used.
- 3) The raw data involving names of individuals and congregations was not be shared, but composite stories and statistical information was be the thrust of the project and was to be the topic of analysis and discussion.
- 4) Data sharing is statistical in nature and will be shared with leadership of the Arkansas Conference.
- 5) While many persons with disabilities have communication limitations, a focus of the site visits was to include persons with developmental disabilities in the discussions when possible.
- 6) While names and contact information to enable follow-up questions and clarification was available, data regarding individuals was been shielded using pseudonyms.
- 7) Of critical importance was the recognition that, regardless of whether or not the person(s) with disabilities are minors, the potential for harm exists if their relationships with their church its ministry is harmed. The researcher's job was to listen and learn their perspective, not to interject their own.

CHAPTER 4: EVIDENCE FOR THE PROJECT

Introduction:

This exploratory study was divided into three phases. Phase One was completed in the early fall of 2015 and consisted of a request through the Arkansas Conference Office for pastors and / or key staff to complete a survey monkey regarding the involvement of persons with developmental disabilities in the life and ministry of their congregation. The first request was made in June 2015 and a second request in August 2015. After a delay of a year, pastors reporting the involvement of persons with developmental disabilities beyond just having such a person present in services were contacted by phone. These calls were conducted between October 2016 and January 2017. The third phase took place during January and February and consisted of site visits to locations identified as having a significant ministry. The focus was upon churches with a ministry involvement of persons with developmental disabilities which demonstrates characteristics of congregations.

Research Question #1 (Phase One):

Which churches in the Arkansas Conference claim a ministry with persons with developmental disabilities?

This was an initial assessment of ministry connecting with persons with developmental disabilities (a disability which significantly impairs one's ability to function in society first diagnosed prior to age 18) and a congregation in the Arkansas Conference of the United Methodist Church. Phase One of this study involved the collection of data from congregational leaders (primarily pastors) via an on-line survey. This survey was intended to be short and collect only rudimentary information regarding whether 1) the congregation includes a person(s) with developmental disability, 2) the extent of that involvement and 3) contact information to

obtain additional information. Due to the potential for violation of confidentiality, this stage specifically was designed not to capture sensitive information.

The Arkansas Conference Office sent out an e-mail with a link to the survey. After several months, a second attempt was made. Of the total of 467 charges (either a station or multipoint assignment), there were 124 individual log-ins on the survey monkey during part one:

- 16 Declined to respond to anything
- 1 was from out of state and beyond the scope of the study
- 19 were repeat responses from the same location (duplicates or triplicates)
- 3 did not indicate a district or congregation

Eighty-five unique responses which can be identified by district, congregation and contact were identified. Overall, there were responses for 18% of the congregations in the conference. Based on several e-mails and phone calls received, it appeared that many did not respond because they do not perceive that their congregation has an involvement with a person with developmental disabilities and did not bother to click on the link and complete the questionnaire. It is also possible that technical limitations prevented some from responding.

The purpose of this stage was to identify congregations to contact for a more in-depth phone interview and, in some cases, a site visit for an exploratory study. This study was not attempting to determine precisely what percentage of congregations in the Annual Conference had a particular level of involvement. To do so, would necessitate a phone survey of congregations from whom there was not response and that is beyond the scope of this study. Rather, the purpose was to detect patterns or trends and study these. This would suggest other possible avenues of exploration. But, to establish the degree of reliability, the responses needed to reflect congregations with a broad distribution in geography, size, and population density, socio-economic and racial diversity.

While there was some difference in geographic distribution (by district), the difference was not statistically significant. By District, identifiable responses were as follows:

Table Two: Breakdown of Responses by District

	Charge/ Churches	Responses	No Response	Return Rate
Central	87	15	72	17%
Northeast	106	25	81	24%
Northwest	100	21	79	21%
Southeast	73	9	64	12%
Southwest	101	15	86	15%
Total	467	85	382	18%

Table Three: Distribution of Responses by Congregation Size (Average Attendance)

Under 50	37%
51-100	28%
101-250	14%
Over 250	22%

For the Arkansas Conference, this distribution was skewed toward the larger congregations. Urban areas were represented in the sample (Little Rock, North Little Rock, Jonesboro, Northwest Arkansas, Fort Smith, Pine Bluff, West Memphis and Texarkana. Small towns were also well represented as were rural communities of fewer than 3,000 populations. Exact percentages were not analyzed, but were at least 20 responses in each of these categories. The broad geographic, population density and congregation size did ensure a wide cross section of socio-economic patterns. The sample included one ethnic minority congregation and one

campus ministry. Due to the small number of ethnic minority congregations, there was not the ability to generalize based on ethnic variations.

Of the respondents, 70% reported having someone with developmental disabilities who attended worship, Sunday School or other programs. The 70% were broken down in the following grid:

Table Four: Matrix of Nature of Involvement

Number of Participants with Developmental Disabilities	Regular in Worship or Programs	Assists in Leadership or Implementation of Worship or Programs	Specialized Ministry Beyond Participation and/ or Leadership
One Person	30	1	
2-5 Persons	14		
Significant Presence of Over 5 Persons	2		9

Of the congregations reporting involvement of one person, there were thirty reporting just one person with a developmental disability who was regular in worship or program with one congregation reporting an involvement beyond just attendance. Of the congregations reporting 2-5 individuals involved in worship or programs, fourteen reported only attendance with seven reporting involvement beyond just attendance. Eight respondents reported that the church had a significant presence of more than five persons and that they had either a specialized ministry or that they had an intentional program of integrating persons with developmental disabilities. All of those reporting a specialized ministry also looked for opportunities to include participants with developmental disabilities in leadership and service in their ministries.

The first request for the completion of an on-line survey took place just prior to Annual Conference; the second two months following Annual Conference; and phone calls occurred following the subsequent Annual Conference. One would expect a large changeover in pastoral appointment, but of the 56 respondents, only five had moved. One of these was a Senior Pastor

not involved in this ministry but whose Associate was involved and did not move. In the four cases in which there was a change, there was also a significant change in the ministry related to developmental disabilities (they quit attending).

Research Question #2 (Phase Two):

In a survey of churches claiming ministry with persons with developmental disabilities, to what extent are these persons integrated into the life and ministry of the congregation and, in contrast, to what extent are they viewed as the subject of ministry?

The next phase of this study was to call congregations reporting a specialized or intentional ministry and those reporting involvement beyond just attendance. Calls and phone interviews with the respondents (usually the pastor) were made to the nine congregations reporting a specialized or intentional ministry and the sixteen respondents reporting individuals involved to a level beyond just regular attendance. Calls and phone interviews averaging 15-20 minutes were made to twenty-five congregational respondents.

The purpose of the phone interview with the pastor or designated ministry contact was to determine the numbers of persons, length of involvement and the nature of their involvement in the life and ministry of the congregation along with a description of the personality and functioning of the congregation.

Of those citing involvement beyond attendance, six of these had changed status and quit attending. In one case the parent of the individual was a staff member, three moved frequently and did not stay long and two had quit attending and provided no reason. This left nineteen congregations meeting the criterion of having involvement of persons with developmental

disabilities who are involved beyond passive Sunday attendance over a period of more than two years.

Of most interest were congregations with clusters of two or more persons with developmental disabilities and those with individuals involved beyond just attendance and congregations with specialized ministries.

Table Five: Specialized Ministries Reported by Congregations:

One congregation has Outreach program conducted monthly at a state institution for adults with developmental disabilities and offers a specialized Sunday School program for persons with developmental disabilities.
One congregation has a monthly parent's night out program for children with developmental disabilities and their siblings and has a part-time coordinator who coordinates aides for children with severe developmental disabilities.
One congregation has a monthly parent's night out program for children with developmental disabilities and their siblings and recruits aides for children with severe developmental disabilities.
Three congregations with specialized Sunday School classes designed specifically for persons with developmental disabilities.
*An additional three churches report assigning a volunteer or paid staff to serve as an aide to enable inclusion of person with developmental disability into a class.

The on-line survey was intended to obtain broad statistics on inclusion and to get contact information for follow-up questions regarding the nature of the disabilities, the extent of involvement, and characteristics of the congregation. Calls were also made to congregations reporting regular attendance of more than one person with a developmental disability to gain more information regarding the quality and length of involvement. An additional forty phone interviews were conducted with respondents not reporting a specialized, self-contained ministry or one which assigned aides to help with specific individuals who were mainstreamed. These calls had the purpose first of confirming the initial responses on the on-line survey and then

ascertaining additional through open-ended questions and dialogue. These conversations averaged ten to thirty minutes each and involved listening to the story about the person, their involvement in the congregation, and how the congregation functions in this involvement.

One of the purposes of this data collection was to determine if those with disability were considered objects of ministry or if this was seen as a collaborative effort. The label and language used by respondents as well as the construct of ministry interactions indicated the relationships. First, the churches with only two to four involved exclusively integrated these individuals. In most cases, the child or adult was born into the congregation or had been part of the fellowship for years. The language used was that of a family including its own. In the larger congregations with children, the recruitment of paid or volunteer aides to provide either one-on-one assistance or extra help was treated as a given. The extra assistance was viewed as a natural thing to do. Families interviewed saw this as an expression of love and support. The only cases where language of “them” was used had to do with those beyond the walls and, most interestingly, in the two cases where the individuals with disability had disappeared. This will be discussed in the next section on research question #3.

Research Question #3 (Phase Four)

Are the churches who integrate persons with developmental disabilities into the life and ministry of the congregations markedly different in their functioning? i.e. has the integration of persons with developmental disabilities made the congregation healthier and more adaptable?

This phase involved reviewing the questionnaires, phone interviews, field notes and comparing them to appointment sheets and service records. Conducting regression analysis of staff tenure would have been interesting, but was simply beyond the time frame allowed. However, several patterns readily emerged. All of the congregations with self-contained

ministries and all of the large congregations with five or more individuals involved have a pattern of long term appointments. In fact, they typically have the same senior pastor for a decade or more. The only two exceptions were the two congregations which had a change of pastor and the new one could not identify the individuals mentioned by the previous pastor in the on-line survey. (Note: in one case there was a change of the Senior Pastor, but most of the associates and senior program staff were long term)

Of the congregations reporting 2-5 persons involved, less than ten percent had a change of pastor's during the time of the study and the tenure of most pastors was in the 4-10 year range.

Further, during the phone conversations and site visits, there was not a single instance in which a pastor, program staff, volunteer or congregant uttered a single word of criticism about their pastor or their congregation as a whole. While there was mention of a conflict or of a desire to do better in an area, it never rose to the level of negativity.

Research Question #4 (Phase Three)

What are the implications for best practices for congregations to engage families & individuals with developmental disabilities?

The final phase, site visits, involved interviews (ideally focus groups) to discuss the nature of ministry in the congregation and in particular ministry which includes persons with special needs. The objective is to document and report best practices which lead to meaningful, long term congregational ministry which includes persons with developmental disabilities.

First Church Bigtown is the only congregation in the Arkansas Conference with a ministry which reaches literally beyond its walls and targets a population of adults with developmental disabilities. Led by a volunteer who is a local school teacher, for four years a

ministry group consisting of a pastor and volunteers have been putting on a program in the lunchroom of an inpatient institution for persons with intellectual and functional deficits. These are individuals who by definition have some of the more severe delays and who are not integrated into the community at large. Residents, usually around 30 in number, choose to go to the cafeteria for the program which consists of crafts, snack, prayers, music, Bible time and communion. Volunteers from the church man the different activity centers as well as accompany the participants who have been divided into groups. Residents are able to express their perspectives in a variety of artistic modes through the activities as well as relate their personal experiences. The volunteers, some of whom travel some distance to participate, have turned this into a meaningful priority for themselves. The program started when a church member, who was working at the institution at the time, arranged for the church to do some activities and it has expanded from there. The steps for its development were 1) Unicorns and Rainbows for crafts and activities; 2) then the residents started sharing and bringing their problems; and 3) “the next thing we knew we were in the mud,” says the leader of the ministry. “These are our brothers and sisters and we are all a minute of O2 away from joining them,” she says. A fear of First Church Somewhere is that the government would shut them down bringing the love of Christ into a state institution. This was an issue for them and a precondition of my visit not to bring too much attention to this program.

First Church Somewhere also has a self-contained ministry through a Sunday School class for adults with developmental disabilities. Prior to the research visit it was reported that many of those from the institution, along with others from some area group homes, came for worship and Sunday School at the main campus on Sunday morning. Some of these adults would gather to visit and greet the congregation at large in the church breakfast nook as people

arrive. The Sunday School class consists of 20-25 individuals (note: attendance does fluctuate at times due to staffing shortages which impede the ability to transport clients). Most participants are fairly new. Although there are a few individuals related to large term members who have been around for a long time and participate in other ways in the church. Currently the class consists only of adults, and they have limited interaction with the rest of the congregation (a separate building with its own entrance – they come and go in that building with limited interaction with the congregation at large). The pastor and others do report that at times the group has been very social in the main foyer area. This program began when a church member, who was also a manager at a small institution (in Arkansas there are a number of private institutions called ICFMR's which can house up to ten persons), began bringing residents to church. She later changed jobs and began working at the state institution and began bringing clients from there.

First Church Somewhere also has an intentional ministry of finding aides to help with children who are mainstreamed. This is done through the church education staff and is very much separate from the other programs which are considered outreach.

First Church Somewhere is very outreach oriented. It has taken on the project of revitalized a congregation in a declining part of town and has active outreach in addiction/Recovery, underserved school children, medical assistance and other associated outreach ministries. For decades, staff members, clergy and lay, serve for extended years; frequently until retirement.

Central Church is the largest congregation in the state and is in its third year of a Parent's Night Out program. Directed by the church's part time disability coordinator, once a month families with children with developmental disabilities are able to drop off their disabled and non-

disabled children for the evening. A group of volunteers, almost exclusively college students from the nearby college, play with, entertain, and mostly keep up with the very energetic group of a dozen or so children. The program generally follows a model laid out by a local non-profit (started by the parents of a child with profound disabilities) in which communications, scheduling, training, and a photo gallery are facilitated through a secured website. The stated purpose is to provide parents respite, but it is clear that for the volunteers it is a welcome change from classes and a way to feel good about contributing to society and those with special needs. While some volunteers are in related endeavors, most are studying in fields totally unconnected with disability ministries. There are crafts, games, activities, and movies. Parents dropping off children bring them in and then scurry out the door except for one. For several months she has been using the time to complete paperwork in preparation for psychological and educational testing of her child (“they keep changing the paperwork and I keep having to fill it out again,” she groans).

Central Church has a storied tradition of starting new churches and in recent years has been particularly active in reaching out to street people, blue collar families and now families with disabilities. Known for long tenure staff, the Pastor responsible for programs sees not the uniqueness of their program but rather its inadequacy to meet the needs. For years, there has been a practice of recruiting aides from the congregation to assist one on one with children who requires assistance to function. In the mid-90’s Andrew, a non-verbal child, attended, and a retired college professor accompanied him. Today, there are three similar children who attend Sunday School regularly, and each have a one-on-one aide recruited and trained by the disability coordinator.

For decades, Central Church has had a history of long term full time staff who serve for a decade or more and usually retire from there. The exception tends to be many of the program staff who are part time and frequently college undergraduate or graduate students.

TV Church was operating a parent's night out program, but it has been suspended until they can find a new coordinator. This was an expansion of programming for disabilities which goes back more than a decade with a Sunday School class which started out for teens with disabilities who are now adults and still meeting. The congregation includes two dozen or more individuals with developmental disabilities of all ages, most of whom are integrated into various programs and aspects of the congregation.

Lake View UMC has no specialized ministry, but for years the congregation finds niches for persons with special needs. "It is in the DNA," says the pastor who explains that this pattern of acceptance and flexibility appears to have been set by leaders years ago. It is one of a number of churches who responded to the questions about specialized ministry by explaining that they believe in mainstreaming and integrating, not segregating.

Western UMC, average attendance 35 has the early service on the charge which begins with breakfast, features a variety of worship styles and inter-generational participation. This rural congregation is about 25% developmentally disabled. Mostly adopted by one extended family group, they function as an extended family. It began when one couple adopted four children (two special needs) and continued when both of their daughters adopt more including four more special needs children. Add to that a couple of others, and the congregation is proud to say that they are not normal. Most of the special needs teenagers and adult pride themselves not on their needs but rather how they minister to others. Often potlucks end with the filling up of take home containers as the church fans out to deliver them to the homes of nearby elderly and

impoverished. Their church building was purchased from a new church start which collapsed and was intended for a congregation many times their size. The gym provides basketball practice and indoor walking track space for the community and numerous groups use their fellowship hall.

The key traits a congregation needs, says its lay leaders, are flexibility, a love of helping people and deep traditions of fellowship. Morning worship is followed by breakfast together and Sunday School. They change clergy fairly regularly. Says the church leadership about their pastors, “we break them in and they are promoted up.” Asked how they handle emotional breakdown so common with the developmentally delayed, they are confused. “That does not happen here.” Their focus is upon loving the person and accepting their traits and going with the flow which eliminates the trigger for most melt-downs. Asked how they handle people who have difficulty handling people who are different, their advice was to just ignore them. Of course no one at Western UMC looks down upon anyone who is different.

Beyond the scope of this study, but worth mentioning is Camp Aldersgate, Inc., an agency related to the Women’s Division of the Board of Global Ministries of the United Methodist Church. Originally begun in the 1940’s by the Women’s Missionary Society of the Methodist Church, in the 1960 the focus shifted toward children with special needs. For decades, Camp Aldersgate has been running summer medical camps (a separate week for each of a myriad of childhood medical conditions or developmental delays) and weekend Respite Camps serving children with medical needs or functional deficits. During these years, the program model has utilized a handful of full-time staff, part-time counselors (personal care aides) and a large number of high school and college age volunteers. The source of these staff and volunteers has been colleges (Hendrix College, another United Methodist related institution is a favorite)

and United Methodist Churches. This study has been directed specifically toward congregational life, but this ministry is worthy of note and is a significant resource for congregations in Arkansas.

Synthesis of Essential Discoveries

There are terms and descriptors which keep being used by respondents in focus groups and individual interviews which deserve specific notation. It is not a specific program that is different about these congregations, but rather they have a different set of traits. In chapter 5 this will be discussed more, but what follows is a list of traits which they have in common:

--Flexibility: Flexibility is viewed as the ability to change. The rule of thumb is that it is not the job of the person with the disability or their family to change but rather that of the congregation and its members. On the walls where I work we have posters which proclaim, "The only person you can change is yourself" (Unknown author). Most of those with developmental disabilities have low adaptability and are unable to participate not because of a gross motor or intelligence deficit, but rather because they cannot adapt to sensory or environmental conditions. Congregations and leaders with a high degree of immunity to change are not flexible.

--Creativity: A favorite term in the field of disabilities is "thinking outside the box." What seems to some as a problem is to others a glorious opportunity to come up with a new idea. Artistic creativity is one example, but more than that creativity involves constantly coming up with solutions. Creativity within the congregation means leaders and congregations who delight in innovation and individualization.

-Acceptance of Others (or non-judgmental): Families are constantly on edge and, for them, life is difficult enough without seeing or hearing criticism. Most communication is non-

verbal, and it is the non-verbal rejection of which they speak. Greeting, engaging, and encouraging the family member is incredibly appreciated. Most developmental disabilities are not obvious physical but become manifest in behaviors.

-The ability to listen (and believe what one is told): The expert on the disorder of the child is generally the parent. Most developmental disabilities come in clusters, interact with the personality of the individual, and are shaped by the family environment. It is tiring for parents to hear strangers “informing them” about the disability of their loved one.

-Sense of Humor: Families love their child / adult family member and learn to laugh about their “***isms.” Some “Billyisms” may include his strange terminology, dietary habits and obsessions. We tend to laugh and cry about the same things and if we don’t learn to laugh a lot, we will cry.

-Love of others: Love is characterized first and foremost by sacrifice. Our Christian model is that of Christ who died for our sins and in that we see Christ’s love. Love means that we as God’s people will do whatever we have to do for those we love. The single mom who shows up with a sensory sensitive autistic nine year old will know whether or not you love her child.

-Recognition that we are not that different: Intelligence and adaptable testing shows a continuum of scores: we are all on that scale somewhere. The more one gets to know those with what the world calls developmental disabilities the more we realize that we share many of the same traits.

To paraphrase a volunteer in one of the self-contained ministries,” We are all just five minutes of oxygen from being like one of these in the institution,” said a volunteer.

Listing of Major Findings

Only about 10% of United Methodist Congregations in Arkansas Claim a Ministry with developmental disabilities.

1. The congregations claiming ministry with developmental disabilities are more flexible, adaptable and have longer pastor/program staff tenure.
2. A ministry of inclusion is the most common form of ministry with developmental disabilities.
3. The limited number of self-contained ministries in the Arkansas Conference are operated by larger churches. Summaries of the best practices gleaned from these programs are presented in chapter 5.
4. Congregations engaged in ministry with developmental disabilities are characterized by a set of traits rather than a particular set of programs.

CHAPTER 5: MINISTRY RESEARCH FINDINGS

This project began with the puzzle: How does ministry with persons the world identifies as disabled re-frame our understanding of ministry and leadership in the church? The assertion of this project is that there really is no such thing as normal in scripture and nor should there be a place for this concept in our leadership in the church today. In the review of relevant literature, the Hebrew Bible, the Christian New Testament, and Early Christian writings were examined for clues as to their perception of disability and, by extension, “normal” functioning. Then, a study was designed to survey a defined group, in this case the Arkansas Conference of the United Methodist Church, to ascertain the level and nature of ministry with persons with developmental disabilities. Then, more in-depth visits were made to a sampling of these congregations to determine the scope and nature of these ministries. Finally, the evidence collected was analyzed to determine best practices for ministry with persons with special needs and their families. In many ways, the study went full circle to the scriptural roots. In the Scriptures, as in the early church, people are identified first as individuals with varying characteristics. There is no particular term or category for disability not is there a concept for what we today call normal. The congregations who best integrated individuals with special needs first developed relationships and customized their approach to each person. The few churches with specialized ministry (a class or respite program) did so mostly as outreach to develop relationships but also were intentional about integrating families who were viewed as part of the body. Before moving to the project findings, a quick review of the theological roots is helpful.

Conclusions from the Review of the Literature:

The findings from the literature review regarding Biblical Understandings of disability included the following:

- There is no biblical concept of “normal” or “normalacy”
- The Bible does not label persons as disabled, but rather identifies particular characteristics which interfere with the ability to function. When characteristics are identified, they are very specific. The only prohibition or restrictions upon these persons relates to their ability to serve as priests in sacramental settings.
- Scripture repeatedly pronounces special blessings or protections for those with various forms of disability.
- While there are examples in which a disability is identified as the result of sin, the idea that disability is evidence of sin is rarely to be found (in fact Job can be seen in part as a treatise against this idea).
- The identification of a person as possessing a physical defect does not necessarily mean that one is marginalized by society or religious structures (with the exception of the lack of circumcision in the Hebrew scripture).
- Findings by Michael D Fiorella on disabilities in ancient Israel deserve to be repeated:

“No legislation could be found that explicitly relegated the disabled to an inferior class status of disenfranchised them.”

 1. Those with disabilities were “integrated into society.” The disabled were to be treated as equal members of the community of faith.”
 2. The king was divinely charged to protect the oppressed and disadvantaged.”
 3. “The disabled were to be treated as equal members of the community of faith.”
 4. “Texts suggest that a moral imperative existed that supported decent treatment of the disabled”

(Fiorello, pp. 301-2)

- Psalm 115 identifies other gods and their idols as bearing physical characteristics of disability.
- The story of Mephibosheth in 2 Samuel provides a powerful narrative and example.
- In the New Testament family and friends are seen as advocates for persons with disability.
- Extra-biblical literature in the Graco-Roman world includes a disabled god and numerous stories of persons with disabilities who develop special creative skills in other ways.
- Jesus repeatedly ministers to the persons first and does not characterize them by their disability.

The literature review of disability studies and historical trends in the United States reveals the movement of disabled from community to institution and more recently the movement back into communities with the ideal of inclusion.

The project included an on-line survey of the 467 congregational appointments in the Arkansas Conference. There were discrete responses representing 85 of these congregations. Of these, there were 44 congregations reporting the regular involvement of one or two persons with developmental disabilities and 12 reported more extensive involvement such as the provision of aides, blended Sunday School classes, a parent's night out (respite), specialized Sunday School class and even one outreach to an institution.

There were a number of consistent patterns which emerged from the literature review and the survey process. Successful, long-term relationships involve looking past the disability to the person, customizing the ministry involvement and relationship to the person and the ability of the congregation and pastor to adapt to the needs and desires of those with special needs.

Major Findings

1. Only about 10% of United Methodist Congregations in Arkansas Claim a Ministry with developmental disabilities.

Table Six: Number of Congregations by Category of Involvement

No Involvement of Persons with Developmental Disabilities	One or Two persons active in congregational life	Provides Supports such as Aides for Integrated	Blended Sunday School Classes	Specialized Sunday School Classes	Parent's Night Out Program	Outreach Beyond the Walls
29	44	5	3	1	2	1

Twelve congregations were identified as having a ministry beyond attendance only with persons with developmental disabilities. One congregation reported a ministry to persons with developmental disabilities reaching specifically beyond the walls of the congregation to those residing in an institution. This same congregation has a special Sunday School class for adults with developmental disabilities in addition to working to integrate several children into age appropriate classes. Three have Sunday School classes in which there is a blend of members with developmental disabilities and other individuals. Two conduct monthly parent's night out programs and most report an intentional ministry of mainstreaming individuals with supports (primarily paid or volunteer aides). Beyond these nine congregations reporting specialized and intentional ministry are two congregations with five or more persons with developmental disabilities. In addition, one congregation has a musician who helps in worship with developmental disabilities. There are another forty-four congregations with one or two people who are regular in attendance in worship or other programs with non-developmentally disabled. This is not to minimize those with only one or two present; often this involves significant work in providing transportation, accommodation in programs and special efforts in inclusion. One congregation has a part-time employee specifically assigned to coordinate special needs.

A link was emailed from the Arkansas Conference office to every pastor in the Conference and then a second link was emailed several months later. In several cases, more than one response was received from the congregation and in most cases it was a congregation claiming a ministry connection with developmental disabilities. After eliminating duplicates, there were 85 unique responses out of 467 appointive settings for a response rate of 18%. Due to the unique nature of this ministry, I tend to think that those who did not response had no such connection and did not bother to even begin the survey and that I probably captured most of those who would have reported some ministry. Lacking phone calls to non-responsive pastors, I tend to think that this is a fairly accurate representation.

In the Arkansas Conference the vast majority of churches are small membership congregations who either have a part-time pastor or share a pastor with other churches on a circuit. The results are skewed toward larger congregations, but there is still a wide range of church sizes represented. Once those who claim a ministry with special needs were identified, the process moved to the next phase of determining the type of ministry. The history within the last two centuries in the United States of either institutionalizing those with pervasive special needs or families caring for these persons with little supports means that the majority of these persons are not involved in community activities including church life. The finding that only 56 of the almost 700 congregations would report the inclusion of a person(s) with developmental disabilities would be consistent with the lifestyle patterns of these persons. Even allowing for a few congregations which include persons with developmental disabilities, it is hard to imagine that more than 10% have the active involvement of a person with developmental disabilities.

2. The congregations claiming ministry with developmental disabilities are more flexible, adaptable and have longer pastor/program staff tenure.

For the Arkansas Conference, the distribution of those responding was skewed toward the larger congregations, but this is probably due to 1) better computer technology of pastors in larger churches and 2) that pastors having more persons with developmental disabilities were more motivated to respond. Communications and technology is a problem in the conference with regard to pastors of small membership congregations.

There were fifty-six congregations reporting the inclusion of individuals with developmental disabilities. The research crossed two appointment cycles. The on-line survey links were sent in May and September with the follow-up not taking place until the September-December of the following year. From the period of the on-line surveys to the follow-up phone interviews, there were six pastoral moves during this period within the fifty-six target congregations. Two involved the senior pastor (but with little change in program level staff), one a wholesale change in ministry staff, one retirement and the other two circumstances were not reported. In fact, what the congregations with persons with developmental disabilities had in common was a history of long term, stable appointments. In depth phone interviews with pastors & key staff persons representing half of these congregations were conducted. The interviewee tended to be familiar the families of those with developmental disabilities and comfortable in relating their stories due to their long tenure. None of them told stories about struggles or fights over inclusion within their congregation. In fact, in the one exception, the congregation in which there is a fairly routine mass turnover in staff experienced what can only be described as the disappearance of 5-6 persons with developmental disabilities. The new pastor was not aware that they had any such persons. This congregation was not studied in phase three due to the fact that they had “lost” their special needs congregants.

Another factor is that those with specialized ministries involving developmental disabilities had church members who initiated this actual ministry. It was not the pastors or a planning team which initiated the programs, but rather church members who stepped forward. The only ministry beyond the walls to an institution was initiated by a member of the church work was also an employee at an institution for adults with severe developmental disabilities (generally individuals who are not integrated into a community setting). Supported by the ministerial staff, the program is planned and implemented by a dedicated group of volunteers. One of the “parent’s night out” programs is directed by a part-time paid staff member, but the staffing for the program comes from a variety of church, college and community volunteers. The other parent’s night out program is staffed and operated entirely by volunteers and was “temporarily” suspended due to the unavailability of a key volunteer. Sunday School self-contained classes and integrated settings all involve volunteers with the interesting exception that three churches hire individuals to serve as companions for some children who require a one-to-one aide to function in the Sunday morning setting.

One of the follow-up phone call questions was to ask what modifications or accommodations the church had made and the pastors often struggled to explain or describe what their congregation did to provide for persons with special needs. Often the response was that they were just loving, welcoming and inclusive but did nothing special. Yet, in the conversation it became clear that there were numerous accommodations but that they did not even think of them as such. In the smaller congregations various techniques such as intergenerational classes and including the individual (acolyte, usher, etc.) in worship were utilized. In several cases church members would provide transportation to an adult without the means. With the exception of the few churches engaged in offsite outreach or parent’s night out, almost all of the families

and individuals being served by larger congregations were being mainstreamed into the congregational life. These churches with specialized ministries also offered one-on-one aides for families of children who had low adaptability skills and required a companion to be able to function in an integrated setting. At the time of the study, I did not find a church providing a segregated setting to an individual(s) unable to be included at all in an integrated setting. All of the congregations studied were intentional about customizing the inclusion of persons with developmental disabilities by making needed modifications. In interviews with families, the adaptability of the congregation in making modifications to include their loved one is virtually a pre-requisite to their involvement. The larger question has to do with congregations who do not have anyone with special needs in their congregation and why?

The story of Mephibosheth found in 2 Samuel 9 is a case in point. Mephibosheth was of the house of Saul, and when it fell, he moved to and was a part of the house of Makir, son of Ammiel in Lo Debar. It is from there that David calls him to come live in his house. It was expected, and this is typical in other cultures and places, that persons with disabilities would be a part of a family group that could care for them. It is only in our modern, western culture that the expectation develops that they should be cared for in specialized, segregated settings. More often than not (this should have been something I tracked) the respondent was regretful or even apologetic that “our church is not big enough to have a specialized ministry.” Yet, the most common, and the one yielding the best results, was the integration of persons with special needs into the life and ministry of the congregations with the supports that they need.

3. A ministry of inclusion is the most common form of ministry with developmental disabilities.

A major issue for families of individuals with developmental disabilities, and I believe for the church itself, is that of labeling and subsequent issues of inclusion. As discussed in the literature review, labeling is problematic because of the impact both upon the person who is of a different functioning level, but also on those who label them. Dietrich Bonhoeffer, in *Life Together*, speaks of ministry as the journey together or working in service with each other. An analysis of the manner in which ministries include those with developmental disabilities indicates whether these persons are the target of ministry or whether the church is working to make them a part of ministry. Several variables were examined:

1. Does the language used indicate an “us” and “them” attitude?
2. Are the participants referred to by name or by disability?
3. Is the setting designed to segregate or include?

Site visits or phone interviews were conducted on all of the nine churches reporting a specialized or intentional ministry beyond attendance and sixteen of the other respondents from the other congregations were interviewed by phone. With rare exception, the individuals with developmental disabilities had a long term connection to the congregation. In fact, the language often used was that they were born into the congregation. In other words, they are “one of ours.”

One of the specific research parameters was the privacy of participants. When asking questions, an inquiry as to the diagnosis or nature of the disability would be made. Most often than not, the respondent, usually the pastor, could not name the disability, but could name the person. There was usually great sensitivity to language regarding disability as most pastors were careful to discuss the person and their wants and needs as opposed to the disability.

Only a handful of segregated settings were identified which existed by necessity: outreach to an institution, respite care (parent’s night out) or a designated Sunday School Class.

Much more often the identified individual was included in general church settings with some supports as needed. The interesting parallel from chapter two is that there is not a category for disabled, much less that of institutionalized, to be found in scripture. First, those with a disability are referred to as a person with a specific condition, e.g. paralytic, not as a class of people. Second, segregated settings are not established to separate these persons with special needs from the family, church or society. Further, only in more recent modern times has this pattern of classification and segregation becomes the norm. The vast majority of persons with developmental disabilities in Arkansas Conference congregations are integrated into their church settings, not served in specialized ministry. Finally, most of the pastors had difficulty describing the nature of the disability. They knew these individuals first as people who mattered in the life of their congregation and were not familiar with a diagnosis because it did not matter.

4. The limited number of self-contained ministries are operated by larger churches.

There were three examples of self-contained ministries: A monthly program at a state-run institution; two respite programs for children and their siblings; and at least two Sunday School classes. These vary widely in structure and function. The program at the state institution is definitely Christian with religious music, crafts, refreshments, prayers and even communion. The volunteers are all church members and participation is voluntary. One of the respite programs is overtly secular, includes no religious instruction or elements of worship and the volunteers are drawn partly from the church but mainly from a nearby college. The first provides chaplaincy to the institutionalized and the latter respite to families outside the church. Being a larger congregation, there are more resources, but that did not seem to be the reason that only the self-contained ministries are in the larger church. The real reason was that these were

laity initiated programs and the laity happened to be located in larger churches. These programs could have just as easily taken place in medium sized or even smaller congregations.

A common response from pastors regarding ministry with special needs was that “we are not big enough.” This began with e-mail responses to the on-line survey, continued with some of the open-ended responses within the on-line survey and into the phone conversations. There seems to be an erroneous understanding that one cannot be in ministry with the developmentally delayed outside of a self-contained environment or that special skills were are required. This is in keeping with the literature review findings that the culture has re-shaped our understanding of community and disability and that “those people” must be served only in segregated settings.

5. Congregations engaged in ministry with developmental disabilities are characterized by a set of traits rather than a particular set of programs.

began with a bias toward emphasizing what does work. There are churches in the Arkansas Conference who have years of experience involving individuals with developmental disabilities. None of these experiences involve segregated, specialized ministries. The few specialized ministries which target this population are relatively new. It is the integrated settings which have the longest history because they are personal

Implication #1: Their name is...

Repeatedly pastors told me about an individual, not a disability. Due to privacy considerations, the research protocol masked names; but yet it is the name, the person, which really matters. Usually pastors were not really sure about the nature of the disability, but they knew about the person. “Jack grew up in this church, his parents are now dead but every Sunday, or if we have a special event, Roger and Ruth, two of our church leaders, pick him up

from his apartment and bring him to church.” Or perhaps it is “Kellie who is twelve and has problems but she loves to sing and helps light the candles.... She was born into this congregation and everyone considers her to be one of their own.” Perhaps it is Tom who “is eleven and doesn’t talk yet and usually is in church until the children’s message and they keep him in children’s church afterwards even though he is really too old.” The pastor who married and brought a new bride and stepson into a congregation is somehow typical. The wife joined the choir so 9 year old Tyler would sit with LJ and Earleen until after the children’s message at which time he would happily trot off with the 3-4 year olds to the nursery and no one thought anything of it. Most ministry in the Arkansas Conference occurs because churches treat those with disabilities as their own, not worrying about the name of the disability. They just know the name of the person, love them and include them as if they were their own.

Implication #2: They are our family...

Frequently the family is part of the congregation before the person with the developmental issues enters the picture. Repeatedly the respondent said that the congregation, like the family, has known this individual since birth. The ritual for church membership is baptism and United Methodists practice infant baptism. In baptism all are members of the body of Christ and these congregations who are successful in this ministry take that commitment seriously. When asked how their congregation adapted to take care of special needs, pastors would instinctively say that there really were no adaptations. Digging further, they would mention forms of adaptation and would tell how the church had adapted in many ways but simply did not see it in these terms. They had become used to the young lady singing off key in the choir or the young man who insisted on handing out bulletins or the adult who would laugh or cry or blurt out comments or verbal tics at inappropriate times. The adaptability of the

congregation, like the adaptability of the family, was seen as something natural that you did for a member of the family. These adaptable congregations had over the years accommodated a number of times for persons with special needs. Several times I heard the phrase, “it is in the congregational DNA,” used to describe their ability to modify as if it were the most normal thing in the world.

Implication #3: Not my family...

The reverse was also true. There were half a dozen congregations who, between the time of the on-line survey and the follow-up study, lost the individuals with developmental disabilities. In two congregations about 4 to 5 persons each actively involved in congregational life mysteriously disappeared during a fifteen month period covering two appointment cycles. In one case the Christian Education Director who had a child with developmental disabilities left and a support group along with a specialized Sunday School class vanished. In another case the new Senior Pastor could not identify anyone with developmental disabilities even though the predecessor had reported 4-5 individuals active in the congregation. These families too disappeared without a trace. In other settings the explanations were readily available: One young man was off to a trade school in another part of the state and in another church a couple who had been part of the congregation temporarily had migrated to another community.

Implication #4: In search of a church home...

Some of the individuals with disabilities are adults who found and became part of a congregation on their own. In one congregation a member who worked in a local facility (housing 5-10 clients) began inviting clients to church. Quickly all ten clients were excitedly loading the vans to go to church. In another setting, a pastor reported that a local group home had begun bringing residents to church. She isn't sure why their church was chosen. This brings

up an issue and an opportunity for congregations: the mandate in recent years by courts, federal bureaucrats and state agencies has been to both move adults with developmental disabilities out of institutions and into communities, but also to encourage their integration into communities. Integration means downsizing or eliminating institutions and spreading housing opportunities throughout communities. In addition, the desire is for persons with developmental disabilities to have “friends who are not paid to be their friends” (Source unknown). One of obvious settings for this is in the church. Agencies that work with developmental disabilities, and quite frankly many of their clients, are desperately looking for places in which special people can simply be welcome. There is no reason not to be locating and inviting these adults to church. Often, the worry or objection is that they are in state care or in care paid for by the state, but that only means that no one can force or coerce them to participate. They are not in prison (and even there they have the right to religious expression and participation). The issue for the state or for the caretakers is one of choice. There are literally thousands of adults with developmental disabilities living in supportive living in our communities and most would love to have a place to go where they can be accepted, be loved and learn about Jesus.

Implication #1: Offer Them Christ:

It is the last point which needs to be emphasized. Those with developmental disabilities, often low intellectual or low adaptability, expect to encounter Jesus at church. In fact, in my years working in this field, some of the most passionate testimonies have come from these very special people. In my field visits, midst of the conversation, and the focus of the study, has been upon the nature of the congregations and the ministry not upon the persons with developmental disabilities. The researcher had difficulty asking the special needs persons themselves what they liked about this congregation. Responses had to do with food, programs and theology: they

loved Jesus. There are those who, because of the low IQ of those involved, are inclined to remove religious content from the outreach. Those with special needs have the right and what is more they expect to hear about God and Jesus in the church.

Ministry Implications of the Findings

Specialized Ministry

The specialized ministries studied consisted of 1) outreach to an institution, 2) parent's night out (respite care) or 3) self-contained Sunday School. While some may find this intimidating, all congregations have a model on how to do this: vacation bible school. One of my favorite quotes came from the leader of one such program: "they started with unicorns and butterflies (arts & crafts), got dirty (sharing prayer concerns & meeting practical needs) and pretty soon they were playing in the mud (sharing and caring in ministry together)." Numerous how-to-guides exist for special needs programs in the forms of books and websites. The specialized ministries I studied were a popular and rewarding venue for volunteers.

A missed opportunity for churches is that of outreach to day programs and institutions operated by the government and non-profits. None of these churches reported that they have put together special events or even helped with activities for day programs in their community. Only one church, at the initiative of one member, had actually reached out to invite residents of institutions or group home to attend anything. In one case, it was the group home residents themselves who had actually initiated going to a church. The key issue for those operating these residential and day activity programs is that it is the client's choice. Most of these programs are excited at the prospect of having a community organization, including churches, putting together programs. Certainly, a narrow doctrinal focus would be problematic, but a grace-filled program that is culturally sensitive and is voluntarily is not a problem, and it demonstrates that the government funded program is encouraging community participation. A Changing Environment: Governmental & Societal Changes

The following issues, while not directly related to the research questions, are issues which arose during the research which are deserving of consideration and additional research. A

changing external environment includes public policy, societal expectations for worship and religious programs along with better medical understandings of disability suggest additional considerations for congregations and their leaders.

January 16, 2014 the Centers for Medicare and Medicaid Service issued the “Final Rule for Home and Community Based Services” which included a definition of community which both asserted standards for community care for individuals with developmental disabilities funded by Medicaid but also reflected a trend which has been building for years. Living in community has more to do with how one functions than it does with where one is located. Persons living in Medicaid funded settings are to have the same access to work, housing, education, and social settings as persons who are not disabled and do not live in Medicaid funded settings. Current law requires that service providers integrate their clients into the community and that includes church participation. Providers are looking for ways to integrate people to meet these new requirements (Centers for Medicare and Medicaid Services 2948 ff).

Those with developmental disabilities who are living in personal residences with supports, group homes, congregate living facilities and institutions are for the most part starved for opportunities to be with other people, go places, do things, and experience the wholeness which comes from being with the family of God. There is no legal requirement that religion be denied from them and in fact to restrict them only to secular interactions would be a violation of their civil rights. There is fertile ground to create special programs to go to their facilities or to bring them to the church. In addition, many of these people are desperately seeking meaning and purpose in their lives. The opportunity to attend worship, light candles, hand out bulletins, fold bulletins, fill food baskets or flood buckets are all things most want to do and be a part of.

The most common ministry with persons with developmental disabilities involves children (or adults) who attend church with their families. It is hard to define who is impacted most by this ministry: the church, the family or the individual with the identified disability. All are blessed and changed by the encounter. Families are asking primarily for acceptance and understanding from their church family. Most developmental disabilities manifest themselves in behaviors which are not considered the social norm, and thus the disability is not readily apparent. Families, which include an individual with developmental disability, are at high risk for divorce, substance abuse, financial instability and abuse. When this person with developmental disabilities is an adolescent who is going through the hormonal spikes and accompanying exaggerated behaviors, it is particularly frustrating and embarrassing. These families desperately need understanding, emotional support, and spiritual guidance. The identified patient, the one with the developmental disability, likewise needs and may desire acceptance and inclusion. When possible, the person with the disability was asked what they liked about this church. Usually the answer would be theological, "I love Jesus." It is through their encounter with the church that Jesus is encountered and the love of God experienced. Verbal or not, everyone understands and is blessed by love and acceptance. Lost in the discussion is that ministry with developmental disabilities both requires an adaptable and loving church and helps to create one. The presence of one of these special persons should be treated as a glorious opportunity for the church to exercise its faith. First, there are those who love nothing more than to come to church and to be a companion for someone needing this assistance. This is a valid ministry and will forever change the life of the caretaker. In one case, it was a retired professor who became the caretaker for a non-verbal boy. Likewise, a congregation in general can develop additional capacity to love, adapt and accept. Repeatedly during the course of

interviews, respondents were unable to identify that ways in which their congregation adapted to a person's special needs, "well we really have not had to..." Later in the conversation, it would become clear that they had but did not realize it.

Sunday Morning Inclusion:

The provision of aides Sunday morning is the most common formal intervention in churches. This is by far the best route for churches trying to keep families involved. It gives the family a break of sorts plus the confidence that their loved one is being included and is safe. Some churches may worry about "Safe Sanctuary policies," but these can be followed with some tweaking. First, quiet rooms and safe places can be established which are easily observable and yet still provide a quiet, sensory friendly space. A combination of basic background checks, reference checks, quality training, and most importantly, understanding the needs of the people involved, can bless everyone involved.

Like aides, another important factor in these churches is an advocate or "go to" person. In Acts we hear Jesus promise to send an advocate, a *paraclete*. Families with special needs need an advocate. This is the person who people can go running to when disaster strikes and more importantly can be a mentor, trainer, and confidant. Depending on the size and configuration of the congregation this may be an important church member, staff person or pastor.

He Doesn't Have a Clue:

Mary went to her pastor, a former District Superintendent and Senior Pastor of one of the largest churches in the conference. She poured out her heart about her son who required one to one assistance. She spoke of their struggles, needs, and the ways that their church could be in ministry with families like hers. He finally responded with, "This has been really hard for you,

hasn't it." She confided later to her mentor in the church who actually worked with her child, "He doesn't have a clue." For families of these very special children life often consists of nothing but caring for and looking after these children's needs. It is about day to day survival. For many, just being able to go to Wendy's to eat and shop afterward at Wal-Mart for groceries without disaster is triumph and a special occasion. Active listening does not equate to understanding. For the family of a special needs child, taking care of that child is their life in a way that even those with normally developing children have difficulty understanding.

A Loving Heart and an Open Mind:

These families repeatedly ask that people have a loving heart and an open mind. Disapproving looks, much less comments, are noticed and are often one of the main reasons families stay away. These families do not need well intentioned advice nor clippings about the latest theory about their child's disorder. Special accommodations are not requested to make life easier but to make their presence in church possible. Andy loves people. In his twenties, he still has lots of energy and says "hi" to everyone... three times. He remembers everyone's name and approaches new people for their name. A person with excellent eyesight and vision, he can see or hear you easily from a hundred feet away and will yell "hi" from across the room. Ask him how is doing or try to engage in conversation and he does not respond. He is a joy to be around if your mind is open and your heart is loving.

Living into our baptism

Mary and Bill began worrying about their son Will when they noticed that he was not progressing developmentally the same as their neighbor's child, Anna. As the years passed, visits to the pediatrician turned into visits to Children's Hospital and child care became developmental day treatment. What was termed Pervasive Developmental Delay eventually took on a laundry

list of diagnoses by psychologists, physicians and special education professionals. But, as for Will, he was exploring his rapidly expanding world. Part of his world was his church family. Bill and Mary were members of a congregation that loved him from the start. As he grew, they accepted him as Will, not a child with a disability. If he walked a little slow, they modified so that he could keep up. If he functioned better in a Sunday School class not his own, they let him go where he functioned best. When he swelled with pride handing out bulletins, he became the regular greeter. Will loves to help set up for potluck, so they will wait until he arrives to begin moving tables and chairs. The youth group has learned to adapt to his quirks and keeps up with him on their trips and activities.

Bringing Our Friends to Jesus

The four friends brought their friend to Jesus. It is interesting that in neither the Matthew nor the Mark version, assuming that both are relating the same incident, are we told the reason they brought him to Jesus. In our worldview, we assume that it is for physical healing, but neither the gospel writer, nor any of those in the story, tells us this (Matthew 9.1-8, Mark 2.1-12). Nor are we told specifically anything about the physical, spiritual or mental condition of the disabled friend. We are not told the nature of the friend's issues but we are told simply that they wanted to bring their friend to Jesus. He sees not the disability, but a person who needs forgiveness. The healing comes almost as an after-thought. Those with special needs are not a client or a subject of our mercy, but our friends. The Human Resource Director works with a staff of some 140 who care for over 200 children and adults with a variety of developmental delays and functional limitations. One of the standard statements to applicants and during their training is to tell them that "these are our friends, our relatives and our neighbors." And then, "we will find out if you do not treat them right." This should be the attitude of our church.

I Love Jesus:

“I love Jesus,” she responded to the question about what she likes about the church in which we were sitting. There was difficulty in this study interviewing individuals with developmental disabilities. Re-phasing the question on several occasions did not work... but the young lady had provided the answer. Why she came to church and what she liked about the church both had to do with Jesus. The site visit was on the day of a Valentine’s Day party. The class was celebrating Valentine’s Day and this was their Valentine’s Day Party. The scripture was about love. The lesson was about love. The craft was about love. The food was meatballs, cheese dip, veggies, chips and cookies. Afterward one of the teachers was apologetic, “usually everything follows a theme but this week the food did not.” But good food is love. They were sharing love.

“Give me a Break; I’m Autistic”

Jill recalls the occasional looks and shrugs over her son’s socially inappropriate behaviors. The occasional verbal tic or the obsession or this subject or that would elicit smiles and and occasional comment. After one particularly obvious expression of disapproval he gave voice to what his mother would not, “give me a break, I’m autistic.” His mom saw the immediate look of surprise on the woman who obviously was disapproving and was amazed at the change of personality. The recipient of her son’s comment became more friendly and even encouraging. What they thought was merely rude behavior now had an explanation and, yes, they did begin to give Will “a break.” What is more, Will and the woman began to work to develop a relationship.

“A sensory appropriate church setting”

Walking down the hallway, the room drew a double-take for the visitor. It was a sensory room for the congregation's special needs program. "A physical therapist designed it for us," a volunteer proudly exclaimed. In the same church a walk past the children's program from which emitted loud music from within and, where any passerby could see, there were numerous "loud" visual colors, shapes and play objects. With the extreme of creating a children's space that would be impossible to manage for children with sensory issues... they would need the safe space. In fact, many of those without diagnosed sensory issues might have to go to the safe space of the sensory room if we were in the children's area very long. Most people do not understand sensory issues unless it is their issue. For the uninitiated, imagine a person as a car. Some gauges work and some do not. Some are wired to the wrong sensor. Some switches are wired to the wrong device: to spray washer fluid you push the horn and the car honks every time you turn left. Many developmental disorders, including perhaps most notable autism spectrum disorders, involve sensory issue which are primarily processing disorders. The brain is wired in some odd ways. Their fallacy of designing a special sensory room for all children with disabilities is that the "mis-wiring" of each person, while there may be some common patterns, is different.

Bobby was a high school Junior and bright at that. Making good grades, everyone who grew up with him just knew him to be a little odd. "A picky eater" his doctor advised his parents that he would eat if he got hungry enough. The doctor was wrong. He never felt hungry enough to eat items that violated his unique sensory inputs. When his youth group went to Veritas, an Arkansas Conference youth rally attended by thousands of youth, his parents sent him with a couple of rolls of quarter for vending machines knowing that he would not eat the catered "youth-style" food. The problem was that the vending machines were only taking dollar bills.

He said nothing and after thirty-six hours of not eating he fainted during Sunday worship.

Timothy, likewise, has issues with food not to his palate and, when asked, will always say that he is not hungry. More accurately, he does not feel hungry even though his blood sugar is dropping.

The first indication that something is wrong is his behavior which grows uglier and more belligerent the longer he goes without food. Ask him if he is hungry and he simply says “no.” Encourage him, much less insist, that he eat and his oppositional-defiant mood kicks in. The best option is to make available food that he likes, and let nature take its course.

The most important issue for a church regarding sensory issues is to trust what you are told. When told that something bothers someone, please believe them. Rose visited one of the new mega-churches and found the loud music, computer graphics and excitement to be chaotic and disconcerting. For many with sensory issues, a little church is usually quiet and more calming. Large churches need safe settings for those, diagnosed disabled or not, who are disconcerted or overwhelmed by noise, light, sounds, and crowds. The drive toward contemporary worship, whether driven by a desire to be “relevant” or by a consumer driven approach, needs to take into consideration that there is a need for a safe space. Sanctuaries, classrooms, fellowship halls, and even hallways can be a major source of problems.

Joe was bothered by the drums. It wasn’t the fact that they were there or the skill of the drummer, but the uncontrolled volume. He would shudder at times with a particularly hard hit, and the family finally went to another church whose band had electric drums (and a sound technician who would control them). A physical environment which allows one to get up and move about when anxious--- cushioned chairs instead of wooden pews, sound dampening, and less chaos--- tends to be easier on those with sensory issues. Interestingly, many of these complaints are familiar to us all. Much of the debates congregations have over architecture,

furnishings, and service format revolve around what we call “taste” and those familiar with special needs call sensory issues.

All churches need safe spaces for people with special needs and helpful distractions which are tailored to these special friends of God. Just as parents with babies need crying rooms, changing tables, and other accommodations, leaders in the congregation should make sure that someone in authority gets to know these families well and arranges to meet their needs. A child who squirms and fusses in the pew make function well in the worship space seated at a table or desk. The availability of appropriate food, drink, or candy may make an impossible situation bearable.

Finally, these issues create suspicions that many of the strategies being employed to make churches more attractive to the masses are creating more disabilities. Large, crowded spaces, rotating Sunday School classrooms, manipulating lighting and creative, exciting worship are all disconcerting to people who crave routine. Much of the resistance to change in church is not because people hate change, visitors, or outreach but because these changes are disconcerting to the senses and/or the psyche. A pastor proposed to a board meeting that the back two rows of pews be removed to free up gathering space at the back of the sanctuary and a man sadly asked, “Then where would I sit.” It is not just those diagnosed with special needs who have sensory needs.

Unexpected Observations:

There were a number of complications in conducting this study provided indicators of issues deserving further study. The following are some of these complications to be considered to better address the study questions with which I began.

It became apparent that this study would be an exploratory study due to the lack of information in the Arkansas Conference. When first contacting the conference office about doing a study on developmental disabilities, I was told that the conference had a study committee. When I inquired further about this committee, I learned that the reference was to the conference committee on disability (relating to clergy members who were unable to serve due to short-term or long-term disability). At this time there are no formal or informal groups meeting which connect those congregations involved in ministries with developmental disabilities. This study is exploratory by nature and the conclusions are based on the limited information collected in this process.

Attempts were made to conduct phone interview with respondents from all of the fifty-six congregations reporting ministry over a period of several months. Phone conversations were only conducted with about half of them due to the lack of returned calls. Most of those who were interviewed required numerous phone calls. Generally messages were left, although some of the respondents did not even have voice mail. Those not interviewed, with rare exception, simply did not answer the phone when I called nor did they return a phone call. Attempts were made to visit a dozen congregations, but visits were only made to five due also to the inability to get phone calls returned.

One of the more interesting complications had to do with the simple question of who is the subject of this investigation. The Institutional Review Board (IRB) required several modifications and additions to this study design due essentially to a debate over the question of who exactly is the subject of the study. At its heart, the design considered the subject of the study to be the congregation and, to a lesser extent, its pastor. The IRB considered the subject of the investigation to be the person with a developmental disability. One of the goals, which were

rarely realized, was to ask questions of the individual with special needs about their church, but that was to their perspective regarding the nature of the congregation. Often these individuals either were not verbal or lacked the comfort level to visit with me. However, most of the interviews were with the pastor, staff member, volunteer or family member. The questions were about the church, its ministry with special needs, and its adaptability and responsiveness to those who are different (which includes a wide range of needs beyond developmental disabilities). Only cursory information was collected about special needs individuals and then just to have an idea of the general nature of the disability to which the congregation was adapting. The IRB was focused on the person with special needs as the identified patient. The disclaimers required went beyond that of privacy and at times discouraged participation because they implied that a great deal of personal information was being collected about the person with the developmental disability as opposed to the collection of information regarding the general nature of the congregation of which they were a part.

Future Directions

Disability, in its purest definition, is a trait or characteristic which limits an individual's ability to function in a particular setting. Currently, most government assistance or civil protections refers to either a low IQ or a functional deficit. The argument made here is that modernity has created additional disabilities. For the church the question is as follows: To what extent is the way we do church creating disability? More recent trends, rotation Sunday School and bands in contemporary worship, create a plethora of sensory and processing problems for many on the autistic spectrum in the same way that steps create disability for one in a wheelchair. Is the increase in recognition and diagnosis of autism really due to a change in its incidence (are there more people with these characteristics) or is the increase due to changes in

our culture which create disability? Likewise, the question for the church is whether some of our changes in worship and Christian Education, while intended to market the church to the modern world, are also having the unintended consequence of creating disability for people who could otherwise function well in the traditions of a previous era.

My personal experience in living with and, to what extent can one really can, raising an autistic child along with ten years of working with and training staff who care for those with developmental disabilities has made me far more aware of the ways in which we all have similar deficits. Too often we forget that there really is no such thing as normal. What our modern world calls “normal” does not really exist. Working with those who are obviously disabled makes me more sensitive and aware of the ways in which we all have our unique needs, perceptions and pathologies. In disability studies the issue of adaptability, or the lack thereof, is an important topic. The relationship between adaptability and effectiveness needs further study. The congregations with an effective ministry seem to be the most adaptable.

Concluding Remarks:

There is a need for workshops, presentations and networking involving those who are interested in this topic on the Arkansas Conference and, I am sure, that this is transferable to other conferences as well. What is important is not so much a workshop here or there about how to do a specialized ministry, but rather there is a need to better teach and communicate the skills involving becoming more adaptable in ministry generally. The resources are almost limitless.

APENDIXES

A. On-Line Survey Questions

Q1 If you agree to these conditions, please chose yes. If not, chose no.

(in response to conditions of conducting the on-line survey)

Q2 How does your congregation include persons with developmental disabilities (low IQ, autistic-spectrum, or other low functioning issues which began in childhood)?

(several choices ranging from no involvement to leadership or service role)

Q3 Does your congregation have persons with developmental disabilities who attend worship, Sunday School or other program integrated with non-disabled persons? Yes or No

If so, How many?

Q4 Does your congregation have persons with developmental disabilities who are helping to lead, implement or assist with ministries? Yes or No

Q5 Does your congregation currently have a self-contained ministry for persons with developmental disabilities?

Q6 Has your congregation performed a serious study of accessibility issues in the last five years?

Q7 What discussion has taken place in your congregation about ways to remove barriers for those with a low IQ or low social functioning?

(several choices ranging from none to a special study)

Q8 Who completed this survey?

Q9 In what district is your congregation?

Q10 Who is the best person for follow-up questions?

Q11 What is the average attendance of your congregation?

B. Follow Up Questions

1. Does your worship / program attendance include people with developmental disabilities? (persons with a low IQ , Autistic-spectrum disorders or other low functioning issues which began in childhood)

Follow-up: How many people are attending your church?

Follow-up: Describe the disabilities and tell be about them:

2. Does your congregation currently have a self-contained ministry for people with developmental disabilities? (In other words, a special Sunday School class, week-day program, etc)

Follow-up: I work at a center for children and adults with disabilities and I would love to know more about your programs. Please tell me about what you are doing:

3. Does your congregation have persons with developmental disabilities who attend worship, Sunday School or other programs along non-disabled persons?

Follow-up: Could you tell me more about these congregants?

Follow-up: How long have they been participating?

4. Does your congregation have persons with developmental disabilities who are helping to lead or carry out the ministry of your congregation?

Follow-Up: I would love to know how you have included them in your church. Could you tell me about them?

C. Informed Consent Letter for Participants

An Exploratory Study of Ministry with People with Developmental Disabilities in the Arkansas Conference of the United Methodist Church

You are invited to be in a research study being done by **Stephen Waggoner** from the Asbury Theological Seminary. You are invited because of your involvement in ministry with families of persons with developmental disabilities.

If you agree to be in the study, you will be asked to participate in small group interviews and focus group discussions of your congregation, ministry and developmental disabilities. The purpose of this study is to describe what works well and what does not work well in ministry involving developmental disabilities. **While the researcher will maintain confidentiality of what is shared, it is not necessarily confidential from each other.**

This involvement will occur in a single session of 1-2 hours with the possibility of a follow-up phone call for clarification. In addition, Stephen Waggoner will make some observations of congregation life in a public setting.

Your family will know that you are in the study. If anyone else is given information about you, they will not know your name. A number or initials will be used instead of your name.

If something makes you feel bad while you are in the study, please tell Stephen Waggoner. If you decide at any time you do not want to finish the study, you may stop whenever you want.

You can ask **Stephen Waggoner** questions any time about anything in this study. You can also ask your parent or ministry leader any questions you might have about this study.

Signing this paper means that you have read this or had it read to you, and that you want to be in the study. If you do not want to be in the study, do not sign the paper. Being in the study is up to you, and no one will be mad if you do not sign this paper or even if you change your mind later. You agree that you have been told about this study and why it is being done and what to do. Permission is granted to the researcher to audio-tape the interviews so that the researcher will be able to re-play and better remember exactly what is said. Tapes will be destroyed once the research is completed and final paper written.

Interviews for this study should be in a safe place where everyone feels comfortable in sharing the joys and struggles of life together in the Church community and we should only share things that we are comfortable in sharing. If anyone cannot read and sign the consent, they can assent to participation under these terms and a responsible person should sign the consent form

Signature of Person Agreeing to be in the Study

Date Signed

Signature of Parent or Guardian (if applicable)

Date Signed

D. Informed Consent Letter for Congregational Involvement

An Exploratory Study of Ministry with People with Developmental Disabilities in the Arkansas Conference of the United Methodist Church

You are invited to be in a research study being done by **Stephen Waggoner** from the Asbury Theological Seminary. You are invited because of your congregational involvement in ministry with families of persons with developmental disabilities. If you agree to be in the study, you will be asked to host and arrange for participants in small group interviews and focus group discussions of your congregation, ministry and developmental disabilities. The purpose of this study is to describe what works well and what does not work well in ministry involving developmental disabilities.

This involvement will occur in a single session of 1-2 hours with the possibility of a follow-up phone call for clarification. In addition, Stephen Waggoner will make some observations of congregation life in a public setting.

While there will be an acknowledgement of congregations involved in this study, there will not be specific information published about your congregation or congregational members. The study will present composite information involving a number of congregations being studied.

This study or site visit can be stopped at any time if there is a concern. If something bothers you about this study, please tell Stephen Waggoner. If you decide at any time you do not want to finish the study, you may stop whenever you want. You can ask the researcher, **Stephen Waggoner**, questions any time about anything in this study.

Signing this paper means that you have read this and that you want your congregation to be in the study. If you do not want to be in the study, do not sign the paper. Being in the study is up to you, and no one will be mad if you do not sign this paper or even if you change your mind later. You agree that you have been told about this study and why it is being done and what to do.

Signature of Pastor

Date Signed

Signature of Key Lay Representative

Date Signed

Signature of Researcher

Date Signed

E. Purpose Statement & Confidentiality Assurances

Purpose Statement: Rev. Stephen Waggoner (the Researcher) is conducting an exploratory study of ministry with persons with developmental disabilities in congregations of the Arkansas Conference of the United Methodist Church. This study is being done for two reasons: 1) to meet requirement for a Doctor of Ministry from Asbury Theological Seminary and 2) to provide leaders of the Arkansas Conference with information regarding how congregations within the conference are engaged in ministry with this important population in our state. Before deciding what congregations to visit, a survey was performed to determine what churches report having members and participants in their congregations with developmental disabilities (that is a disability which significantly limits one's ability to function independently in society). This congregation was chosen for an in-depth interview so that the researcher can learn what is working in your life and in your congregation.

Nature of Publication:

The results of this study will be summarized as one chapter in a hour chapter dissertation about church ministry and persons with developmental disabilities. This dissertation will be presented to a review Committee at Asbury Theological Seminary and available through the Seminary library to researchers from other institutions. In addition, the final dissertation will be provided to leadership

The dissertation will acknowledge the churches who provided interviews and data for the project. However, the researcher is primarily interested in discovering patterns in health ministry models for being in ministry with the families of persons with developmental disabilities. The stories and experiences will be turned into composite sketches and stories which illustrate ways that other congregations can follow. In short, the product will be templates for effective ministry.

Should the possibility arise of turning the dissertation into a work for broader publication, additional care will be given to ensure that there are no specific identifiers of individuals or congregations.

Confidentiality:

Due to the vulnerable nature of many of those interviewed and the personal nature of the stories we will be sharing, nothing will be published or dissemination which can easily be traced back to specific individuals. Only the researcher will have access to audio recordings, notes and releases which identify specific names. The researcher works professionally in a field which complies with Health Information Privacy and Protection Act (HIPPA) standards and intends to apply these same standards to this study.

Special Statement Regarding Audio Recording, Written Notes & Personal Identifiers: **What data is being collected?**

There are four specific sets of data being collected. First, there will be a listing of congregations and whether they report any type of ministry with families of persons with developmental disabilities and the basic nature of that ministry. Second, there will be notes of follow-up phone calls to representatives of churches reporting such a ministry. These will be used to report basic statistics about congregations of the Arkansas Conference of the United Methodist Church and the instance of inclusion and ministry involving developmental disabilities. Third, there will be site visits in which interviews will take place with families and significant ministry staff detailing family histories and details about congregational and ministry involvement. Finally, there will be audio recording of the interviews to supplement and supplant the site visit notes.

Who has access to the data?

Only the researcher will use and have access to the raw data which specifically identifies congregations and the names of those involved in the identified ministries.

How will the privacy of those who are interview be concealed?

The characteristics of families, individuals and congregations will be used to develop composite stories. These composites will serve to blend various stories and experiences into templates for those new to the issues involving developmental disabilities to be able to better understand and relate to those in their own communities and congregations.

How and when will records be destroyed?

Upon acceptance of the final dissertation, person specific data which ties notes to individuals will be destroyed. Data not connected to specific identifiers will be retained for up to two years in the event of broader publication.

Stephen E. Waggoner, Researcher

F. Phase Two Phone Interview Questions

The wording for the phone call consent is as follows:

My name is Stephen Waggoner and I am following up on a survey completed by _____ (usually the person whom I am calling) in which you were identified as a contact person who can provide additional information. I am collecting information about congregations who have a ministry involvement of families including person with a developmental disability (this could be a person with a developmental disability living independently). Before I move into the questions, please understand that I will be collecting information that may be sensitive. At this stage, I am only interested in general information and not specific names, circumstances and details personal case histories. Should I wish to visit your congregation and interview these families and those in ministry with them, I will go through the pastor or designated staff to set up and arrange the visit. All of those involved in the visit will need to consent to being interviewed. In the dissertation and any subsequent writings, special care will be taken to conceal identities. You can feel free to answer as many or as few of the questions that I have. Can I continue with the questions under these conditions? (allow time for questions about this consent)

The questions are as follows:

1. Does your worship / program attendance include people with developmental disabilities? (persons with a low IQ , Autistic-spectrum disorders or other low functioning issues which began in childhood)

Follow-up: How many people are attending your church?

Follow-up: Describe the disabilities and tell be about them:

2. Does your congregation currently have a self-contained ministry for people with developmental disabilities? (In other words, a special Sunday School class, week-day program, etc...)

Follow-up: I work at a center for children and adults with disabilities and I would love to know more about your programs. Please tell me about what you are doing:

3. Does your congregation have persons with developmental disabilities who attend worship, Sunday School or other programs along non-disabled persons?

Follow-up: Could you tell me more about these congregants?

Follow-up: How long have they been participating?

4. Does your congregation have persons with developmental disabilities who are helping to lead or carry out the ministry of your congregation?

Follow-Up: I would love to know how you have included them in your church. Could you tell me about them?

G. Phase Three Interview Questions

These questions are to be used during the site visit phase of the research project. In this phase, congregations selected during phase 2 will be visited for the purpose of understanding 1) the nature of the ministry of the congregation with families of persons with developmental disabilities, 2) the families of persons with developmental disabilities both in their personal histories and faith journeys and 3) the characteristics which enable a healthy ministry and congregational life involving persons with developmental disabilities, their families and the congregation. As such, there are three sections of questions:

1. Nature of the ministry with disabilities
2. History of the persons involved
3. Characteristics of the congregation

I. Nature of the Ministry (info about specific ministry with disabilities):

- Q Tell me about your church?
- Q What does your church so that is special to you?
- Q Does your church do special things for people who are different?
- Q What is the best thing about your church?
- Q How do you fit into this church?
- Q What could your church do better?

(much of the questions and discussion are going to vary depending upon whether the congregation has a specialized ministry, whether those with disabilities are integrated or a combination of the two).

II. History of the Persons Involved:

- Q Tell me about your family?
- Q What Makes your family special?
- Q What are the challenges that your family faces that makes life difficult?
- Q How did you become involved in this congregation?
- Q What are your experiences in other churches?

III. Characteristics of the Congregation (the congregation as a whole):

- Q How long has this congregation included people with developmental disabilities?
- Q How many pastoral / staff changes has this congregation had in the past ten years?
- Q What is the average worship attendance?
- Q What are the church's major ministries?
- Q Tell me about the personality of the congregation?
- Q Tell me some stories about your church?

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