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LEADERSHIP ROLES: CREATING INCLUSIVENESS WITHIN A WORSHIP ENVIRONMENT

Presented in Partial Fulfillment of the Requirements for the Degree of Doctor of Occupational Therapy

Eastern Kentucky University College of Health Sciences Department of Occupational Science and Occupational Therapy

> Susan Morreau 2017

LEADERSHIP ROLES: CREATING INCLUSIVENESS

EASTERN KENTUCKY UNIVERSITY COLLEGE OF HEALTH SCIENCES DEPARTMENT OF OCCUPATIONAL SCIENCE AND OCCUPATIONAL THERAPY

Certification

We hereby certify that this Capstone project, submitted by Susan Morreau, conforms to acceptable standards and is fully adequate in scope and quality to fulfill the project requirement for the Doctor of Occupational Therapy degree.

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LEADERSHIP ROLES: CREATING INCLUSIVENESS

EASTERN KENTUCKY UNIVERSITY COLLEGE OF HEALTH SCIENCES DEPARTMENT OF OCCUPATIONAL SCIENCE AND OCCUPATIONAL THERAPY

This project, written by Susan Morreau under direction of Shirley O'Brien, Faculty Mentor, and approved by members of the project committee, has been presented and accepted in partial fulfillment of requirements for the degree of

DOCTOR OF OCCUPATIONAL THERAPY

CAPSTONE COMMITTEE

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Executive Summary

This Capstone Project sought to investigate and measure the process of social change in the community setting of a Christian church. A committee of stakeholders came together with a common passion to engage and integrate individuals of varying disabilities at all levels of church participation. As a new committee, stakeholders agreed to use the cyclical process of Participatory Action Research (PAR) to guide them in creating an action plan for promoting this congregational change. The occupational therapist served on the committee as both a cofacilitator and researcher.

While the primary purpose of the project was to objectively measure the degree of progress made towards creating a more inclusive environment, a secondary purpose was to gain a better understanding of how to promote participation and engagement for disabled individuals within a faith-based community. The lessons learned from engaging in PAR may also provide the field of occupational therapy more information about conducting this type of research in faith based community settings.

The philosophical underpinnings of this Capstone Project were rooted in both Christian philosophy and the values promoted by the field of occupational therapy. Both of these entities agree that spiritual engagement is unique to each individual and should be available to all. A Grassroots Theory of Change and the theory of Participatory Action Research were also used as a framework for the organization of this project. These theories contend that groups of people unified by one goal have the power to promote social change. PAR promotes the idea that those who make up the group should be the individuals who experience the problem being addressed. This is because their personal experience offers insight in identifying and addressing the issues. Stakeholders also learn more about advocacy by engaging in the change process and can feel empowered as a result.

Multiple forms of data collection were used to measure the degree of social change in this Capstone Project. Most of the information was qualitative, but aggregate counts were also collected and then a deeper analysis occurred through the use of a Concept (Systems) Map. The process of PAR was also analyzed at the end of the project, to reflect on what lessons were learned and what strategies were helpful. Results indicated that the stakeholders were successful in initiating social change in their worship environment, but the degree of social change did not satisfy the committee at the end of the 18-month project. The committee learned through the PAR process that social change requires time and patience. It also involves many inter-related components within the organizational system to be effective and sustainable.

Acknowledgements

I would like to thank Dr. Shirley O'Brien for her gentle guidance in helping me sort through the multiple facets of this Capstone Project. She has also been a source of ongoing support and motivation throughout my OTD coursework. A genuine thank you is also extended to Dr. Kelly Leigers, who offered several valuable resources and feedback during the proposal and re-writing phases of this project. This research would not have happened without the support of the committee members of *ALL God's People*. I have grown quite attached to the friendships we have created and truly believe that the work we are doing goes well beyond my personal needs in accomplishing my OTD. Finally, I want to formally thank my family, friends and co-workers for their patience and support over the last two years. Thank you for allowing me to have moments of absence in my role as a partner, a mother, and a friend as I pursued this degree so late in life. Your support in my personal goals is a testimony to me and I appreciate what you had to sacrifice in order for me to accomplish them.

EASTERN KENTUCKY UNIVERSITY COLLEGE OF HEALTH SCIENCES DEPARTMENT OF OCCUPATIONAL SCIENCE AND OCCUPATIONAL THERAPY

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Submitted to: Shirley O'Brien Student's Name: Susan Morreau Title of Submission: Leadership Roles: Creating Inclusiveness Within a Worship Environment

Certification of Authorship: I hereby certify that I am the author of this document and that any assistance I received in its preparation is fully acknowledged and disclosed in the document. I have also cited all sources from which I obtained data, ideas, or words that are copied directly or paraphrased in the document. Sources are properly credited according to accepted standards for professional publications. I also certify that this paper was prepared by me for this purpose.

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Date of Submission: 12-11-17

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Section 1: Nature of Project and Problem Identification

In recent decades, there has been a surge in the belief that faith communities should make a conscious effort to reach out and improve their inclusive practices for individuals with disabilities (Amado, DeGrande, Boice & Hutcheson, 2012; Carter, 2016; Carter et al., 2015; World Health Organization (WHO), 2010). The World Health Organization (2010) identified religious institutions as potential places to promote advocacy for social change and the inclusion of disabled individuals (WHO, 2010).

Further establishing this inclusive philosophy, and understanding the barriers against participation is a broad topic that has multiple considerations for faith communities and their memberships (Amado et al., 2012; Carter et al., 2015; Hobbs, Bonham & Fogo, 2016; Kunz, 2011; Morris, 2010; White, 2014). Carter (2016) recently proposed that faith communities need to "shift beyond the why and move into the how" (p. 179). He appealed to faith communities to move beyond the philosophical agreement, and begin to take active steps in penetrating the practices of religious institutions across the country. As recently as May of 2017, Carter, Bumble, Griffin and Curcio conducted research using a method called community conversations to brainstorm and categorize over 1000 ideas that faith communities might consider implementing. Serendipitously, a faith community in a Kentucky metropolitan city was beginning to explore the topic of inclusion for people with disabilities at about the same time. The researcher (who was a member of this particular faith community) was invited to participate in the initial committee discussions.

In order to gain a deeper understanding of the interrelated concepts involved in this Capstone, the topic of inclusiveness in Christian faith communities was initially explored. This was followed by investigating the philosophical relationship that exists between occupational

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therapy and current Christian philosophy as it applies to the social participation of individuals with disabilities. The information gleaned from the literature review of both philosophies offered a solid foundation for this project.

Inclusiveness in Faith Communities

The promotion of inclusive environments for people with disabilities has been encouraged by both Christian scholars and scholars in the area of disability professionals (Hobbs et al., 2016; White, 2014). Kunz (2011) professed that "the deepest spiritual need of every person is acceptance as a member of the family of God" (p.15). The objective of inclusion is such an important part of society, that the law has mandated the concept for programs that receive federal funding and required many public facilities to be accessible according to defined standards (U.S. Department of Justice, 2016). Government agencies in the United States have established National Core Indicators intended to measure inclusiveness (Carter et al., 2015) and the World Health Organization (2010) promotes inclusion through its Guidelines regarding Community Based Rehabilitation (CBR).

Entities that are considered religious organizations are typically exempt from physical accessibility laws (U.S. Department of Justice, 2016), but the philosophical underpinnings of the Christian faith do honor the principles associated with physical and social inclusion. White (2014) reminded readers of the biblical teachings of the Christian community when he stated that "within churches, para-church organizations, and any other entity claiming to be 'Christian,' all people, from all backgrounds and all walks of life, should be invited and included into the essential functions of that specific entity" (p.12). Despite the shared belief that this objective is important, faith communities have struggled to make full social inclusion a reality (Ault, Collins & Carter, 2013; Carter, 2016; Carter et al., 2015; Carter, Boehm, Annandale & Taylor, 2016; Hobbs et al., 2016; White, 2014). Carter and colleagues (2015) found through an analysis of the data offered by the National Core Indicators, that almost half of the nation's adults with intellectual developmental disabilities attended a religious institution within the last month. But other authors indicated a lack of quality in that inclusion.

Many places of worship address the physical barriers of building accessibility (Amado et al., 2012; Ault et al., 2013), but White (2014) reported that 40.9 % of his survey respondents referenced attitudes within the Christian community as a significant barrier to full social inclusion. Hobbs and colleagues (2016) also found through interviewing congregation members with disabilities, that these churchgoers longed for a deeper emotional acceptance. The parents of children with disabilities were reported to seek out faith institutions that supported inclusion beyond physical accessibility (Ault et al., 2013). Adult interviewees (Hobbs, et al., 2016) acknowledged their various limitations, but also felt that they had something of value to offer the mission of their faith community. Most of the Christian scholars echoed similar implications and substantiated the need to improve inclusiveness within faith communities (Ault et al., 2013; Carter et al., 2015; Hobbs et al., 2016; White, 2016).

Carter and colleagues (2015) further suggested that professionals within the disability field could play an active role in supporting their faith community in the mission of full inclusion. Occupational therapy is one profession well situated to address this issue. Scholars in the field of occupational therapy have suggested that Occupational Therapist's are in a position to actively ally with individuals who have disabilities to promote their "connection to others and their inclusion into society" (Shulz, 2005). Not only is the link between spirituality and health common in scholarly writing (Amado et al., 2012; Carter et al., 2015), but spirituality is identified within the Occupational Therapy Practice Framework (OTPF- 3) (AOTA, 2014) as a domain that adds meaning to life occupations and routines. Howard and Howard (1997) offered deeper implications for the link between the Judo-Christian tradition and the influence this spiritual belief system can have on an individual's occupational values. Thus, occupational therapists have an opportunity to explore their formal and informal roles within religious organizations.

Similar Philosophies between Christian Literature and Occupational Therapy

While the Occupational Therapist is not limited to assisting only those who choose to pursue the Christian path of spirituality, this particular Capstone Project took place in a Christian faith based community, and therefore sought to offer a relationship between these two philosophies. A similar alignment may exist between Occupational Therapy and other spiritual belief systems, but this Capstone primarily focused on the Christian philosophy.

Scholarly readings within the Christian literature offer philosophical rationales regarding inclusion, which align with many of the philosophical principles of Occupational Therapy. Morris (2010) reminds us that we must approach people with disabilities as individuals and see what each individual can offer the church" (p.17). Carter and colleagues (2015) advocated for person-centered planning efforts as well. Other authors further promoted a need to address the decreased attendance rate of individuals with complex mobility problems, communication challenges, and severe intellectual disabilities (Carter, 2011). Ault and colleagues (2013) conducted a survey of parents who seek inclusion for their disabled child within faith communities and found that attendance often hinges on the individualized support(s) offered to

maximize participation. Finally, Hobbs and colleagues (2016) honored the philosophy of occupational therapy when they referenced Hammell (2004), who stated that it is "the subjective meanings of activities that contribute to an individual's perception of competence, worth, and the quality of life" (p.42). These writings support the occupational therapy philosophy that occupations need to be individualized, and supports for success are individualized as well.

Problem Statement

What barriers exist that may impede the inclusion of people with unique needs at Christ Church United Methodist, and what actions can the committee "*ALL God's People*" take in response to these identified barriers?

Purpose of the Capstone Project

This Capstone Project was designed to meet a portion of the graduation requirements required by Eastern Kentucky University's Doctor of Occupational Therapy (OTD) program. This project offered a committee of stakeholders a method towards reaching its identified mission of creating a worship environment that is ability inclusive.

The cyclical process of PAR was used as a guiding method for the committee. Steps in the PAR process included ongoing research to identify problem(s), group dialogue (which helped the group organize an action plan to include data collection), and ongoing group reflection as the action plan progressed. The researcher served as an active committee member and co-facilitator, charged with implementing leadership strategies to encourage equal power among stakeholders.

The committee used the overall church mission and goals as a guide to create a Logic Model (Blumenthal, 2012) for intervention plans (Figure 2). Blumenthal discussed the use of this model as a method for implementing and evaluating PAR. He defined the concept as "a visual depiction of a program's goals, inputs, strategies, outputs, outcomes, objectives, and the assumed casual relationship among them" (p.232).

The ultimate purpose of this project was to objectively measure the degree of progress made towards creating a more inclusive environment within a religious congregation, and to identify what interrelated components are a necessary means to that end. A secondary purpose was to promote understanding about disabilities within a faith-based community for participation and engagement. A tertiary purpose of the Project was to offer the field of occupational therapy, useful information regarding the process of PAR within change theory for creating opportunities in community-based practice.

Primary Objective: Measuring Progress Towards Inclusiveness

The main objective of the Capstone Project was to assist a faith-based community in the facilitation and implementation of four identified goals that fell within the existing church wide goals. As the members of "*ALL God's People* Committee" started to dialogue about a course of action to address identified barriers, we recognized a direct correlation between the committee's activities and the church-wide goals of the organization. The committee situated these church-wide goals into a Logic Model (Figure 2), which then offered committee participants a visual guide for the actions they identified for their intervention plan. How the Logic Model (Blumenthal, 2013) was used will be further discussed under the procedures and results sections of this document. In this section, the four church-wide goals will be introduced.

The stated mission of the church is: *Becoming living proof of God's love, one person at a time* (Christ Church United Methodist, 2016b). The four main goals of Worship, Prepare, Serve and Bridge are then highlighted as a means of achieving this overall mission. (Christ Church United Methodist, 2016b).

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Church Goal 1: Worship. "experiencing life-giving moments in God's presence. Through passionate prayer, inspiring music, and considering God's Word together, our hearts are refreshed and reoriented toward God each week" (Christ Church United Methodist, 2016b).

Church Goal 2: Prepare. "pursuing a deeper understanding of God's love. In groups of 2 or more, we explore God's Word, asking questions that challenge and change us, so we can live as God's people in God's world" (Christ Church United Methodist, 2016b).

Church Goal 3: Serve. "showing God's love in practical ways. We use the abilities God has given us to share His love, taking tangible action to serve and care for those around us" (Christ Church United Methodist, 2016b).

Church Goal 4: Bridge. "bringing God's love to others every day. We constantly look for opportunities to show God's love to others in the normal activities of life" (Christ Church United Methodist, 2016b).

By aligning the committee goals with these four church-wide goals, the "*ALL Gods People* Committee" sought to foster congregational change. Through implementation of the change process, attitudes would be reframed (Bolman & Deal, 2013) to meet the committee's mission of "creating an environment that is ability inclusive and empowers ALL individuals to be integrated and engaged at all levels of church participation - worship, prepare, serve and bridge" (Christ Church United Methodist, 2016a).

Theoretical Framework

Christian Philosophy. While Occupational Therapists inherently promote inclusion in all areas of community and belief systems, this Capstone Project occurred within the community context of a Christian church. Therefore, Christian philosophy was at the cornerstone of the

mission of the *ALL God's People* committee. As such, the basic principles of Christian philosophy were used as one of the theoretical frameworks for this Project. At the root of Christian philosophy are the beliefs that

- Humans are uniquely made in the image of God.
- The church and its people represent the body of Christ.
- Christian's have a responsibility to go out into the world and spread the message of Christ's love (Kunz, 2011; Morris, 2010; Pierson, 2010; White, 2014).

Bach (as cited in Kunz, 2011) eloquently reflected on the lack of distinction between individuals with and without disabilities in relation to the Christian belief that we are all uniquely made in God's image.

Both are respectively created by God; both live in the fallen creation; both (as damaged creation) are dependent on the salvific deed of Christ; both are reconciled to God through Christ; both are members of the body of Christ, both deficient and dependent upon others; both gifted with divine gifts, both expectant of salvation (p.29).

Young (2007) also bridged the commonality between those with unique needs and those without when she explained her "appreciation of the core elements of the Christian tradition" through her experience of parenting a son with a disability. "I stand alongside him as a vulnerable creature, disabled and mortal, knowing my creaturely limitations and my lack of knowledge, especially of God" (p. 59). Finally, Carlton (2000) emphasized the point that the image of God in every human person is identified through our own uniqueness. "No matter how dehumanizing modern life may be, it can never suppress the absolute uniqueness of the human person, for that uniqueness is the imprint of God upon us all" (p. 19).

As we embrace the idea of this imprint suggested by Carlton (2000) we begin to comprehend that the church (the *body* of Christ) must be made up of all individuals. Morris (2010) contends that the church community must be different than the community of a wider society and proposes that Christian maturity involves this *body* of social interdependence. It is through this interdependence that we create a unity more profound than our own individual needs. Young suggested that we all have something to contribute to this body and we all are transformed through this experience to grow into the likeness of God (2002 as cited in Morris, 2010).

In bridging the acceptance of all people into this body, we are all called to spread the word of Christ through our actions in the wider society. Pierson (2010) referenced the guiding principles of Christian belief by contending that all Christians are to go into world and spread the message of Christ's love. He ascertained that "There is no footnote that reads, '*Everyone* is limited to people with heights over 5'7"; 20/20 vision; ability to hear; IQ 100 or higher; or acceptable public behavior" (Pierson, 2010, p. 184).

Philosophy of Occupational Therapy. Similar to the arguments offered by Christian scholars, the profession of occupational therapy is built on the principle that all human beings have a right to participate in activities they find meaningful. The American Occupational Therapy Association (AOTA) offers a definition of the profession and the interrelated constructs that influence practice in a document titled *Occupational Therapy Practice Framework: Domain and Process, 3rd Edition* (OTPF-3). Within this document, the purpose of the profession is defined as "the therapeutic use of everyday life activities (occupations) with individuals or groups for the purpose of enhancing or enabling participation in roles, habits, and routines in home, school, workplace, community, and other settings" (AOTA, 2014, p.S1). The document

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further explains the therapists' role as one that enables engagement and participation in desired occupations through needed modifications. Modifications may be needed as a result of some interruption in desired occupation(s), but also as a means of prevention or preservation of occupational identity (AOTA, 2014). Modifications include but are not limited to adaptations, education, training and self-advocacy. The process of providing assessment and intervention can occur on an individual level, or at the community level; either directly or in a consultative fashion (AOTA, 2014).

The OTPF-3 also offers an explanation of the holistic components involved in assessment and intervention, one of which is a spiritual component, since this aspect greatly influences meaning making and its influence on the potential value placed on an occupation (AOTA, 2014). Howard and Howard (1997) strongly linked spiritual practice to the meaning an individual attaches to desired occupation(s) and therefore proposed a "direct link" (p.182) between occupational therapy and spirituality. Several studies have also found a link between spiritual or religious involvement and health among individuals who either present with or provide care for someone with disability (Amado et al., 2012; Carter et al., 2015; Hobbs et al., 2016; Stav, Hallenen, Lane & Arbesman, 2012; Treloar, 2002). As such, an occupational therapist has the appropriate training and the philosophical background needed to guide a committee of stakeholders who are interested in creating a more inclusive environment for all within a faith community.

Participatory Action Research. The theoretical framework of PAR is one that empowers a marginalized population to come together to create desired social change (Taylor, Suarez-Balcazar, Forsyth, & Kielhofner, 2006; Taylor, Braveman & Hammel, 2004). This type of research steps away from traditional, positivist research because there is rarely a manipulation of variables in order to gain knowledge (Cockburn & Trentham, 2002). Instead, this approach seeks to gain knowledge through its cyclical process (Letts, 2003) while also empowering the stakeholders by systematically gathering and sharing information, taking action, and reflecting on that action in order to promote social change (Cockburn & Trentham, 2002; Taylor et al., 2006). Cockburn and Trentham (2002) explained that the intention of PAR is to include the very people who feel the impact of various constraints that prevent them from fully participating in their communities. As such, this model of research is considered to be "consistent with occupational therapy's concern for the elimination of environmental and contextual barriers to occupational performance" (Cockburn & Trentham, 2002, p.22).

Therapists often report a gap between positivist research and practice. Some activists report that PAR serves a better purpose in the community context (Taylor et al., 2006). While PAR may use quantitative, qualitative or mixed methods to measure results (Cockburn & Terntham, 2002; Taylor et al., 2006), a specific outline of steps are advised in the PAR process. These steps include identifying the problem(s), engaging in dialogue to determine a course of action, implementing action, data collection on that action, and reflection regarding the action (Taylor et al., 2004). As the PAR process unfolds, these steps may begin to overlap in implementation (Taylor et al., 2006; Taylor et al., 2004).

Theory of Change: The Theory of Change was an important construct to consider in structuring and implementing the Captone Project. As advocates for inclusive practices in a faith-based community, the participants who are members of the "*ALL God's People* Committee", sought to achieve "impact and sustainability" (Stachowiak, 2013, p.20) while promoting social change in the church. A specific theory of change is closely linked to a person's worldview. It becomes relevant to a team of people working together, because it closely aligns with that team's

belief system and the set of assumptions they use regarding the linkage between strategies, goals and outcomes (Stachowiak, 2013). The set of assumptions that the team works from, can strongly impact the team's selection of what tactics to undertake (Stachowiak, 2013).

A "grassroots" theory of change applied well to this Capstone Project because the concept honors the idea that "groups of people can create power by taking mutual action to achieve social change" (Stachowiak, 2013, p.20). This theory of change also correlates well with the method of PAR because it includes some of the same underlying assumptions. Some of those assumptions include the belief that power bases can be shifted through actions and events. A grassroots effort aligns well with PAR because it shares the belief that a group's organizing efforts should reflect the wishes of the people directly affected by the problem, and that this requires building the capacity of those affected to address identified problems. Grassroots efforts focus on working with the many, not with the few. Also relevant, is that the advocacy group is not considered the leader, but rather, they facilitate the efforts of a collective to achieve social change (Stachowiak, 2013, p.20). As this project evolved, the concepts related to the grassroots theory of change were considered and the researcher worked in her role as co-facilitator to shape their implementation within the PAR process.

Significance of the Capstone Project

As healthcare becomes more evidenced based and preventative in nature, the field of occupational therapy will likely have a growing presence in community settings (Baum & Law, 1997; Hinojosa, 2012). Occupational therapists believe that purposeful activity promotes wellbeing (AOTA, 2014) and is influenced by one's spiritual practices (Howard & Howard, 1997; Schulz, 2005). It is relevant for our profession to assist in pursuing inclusion for the disabled within a religious context. This Capstone Project may offer useful information to other faith communities and the profession of occupational therapy regarding the interrelated systemic components that may need to be considered to make measurable progress in promoting this type of community inclusion.

PAR is a relatively new form of research used in the field of occupational therapy in the United States. This Capstone Project may also provide the profession with useful information on strategies to consider when conducting PAR within a community context.

Summary

Although the inclusion of disabled persons in all aspects of community life has become a common social initiative, recent data indicates that individuals with unique needs long for more social acceptance in their faith communities. A committee of stakeholders at Christ Church United Methodist in central Kentucky came together to answer this call by creating a group identified by the name "*ALL Gods People*".

As an interested stakeholder on this committee, the occupational therapist and the author of this document, requested permission to co-facilitate this committee and serve as an advisor for the implementation of PAR to address committee goals. The use of PAR offered the committee a guide for identifying current barriers, creating a plan of action, collecting data and reflecting on implemented actions in order measure the degree of impact and social change that occurred within this religious community.

The results of this impact, the inter-related components identified to promote social change, and the strategies used to encourage a medium to high level of involvement in the PAR process, are offered as information to occupational therapy practitioners who have an interest in promoting inclusion for the disabled in their communities.

Section Two: Detailed Review of the Literature

The main objective of this Capstone Project was to investigate barriers and promote solutions to improve the inclusion of people with unique needs at a large metropolitan United Methodist Church. As such, a literature review was conducted in order to ascertain what is currently known about inclusivity in Christian faith communities.

The Type of Literature Available

An initial search of the literature resulted in very few studies that measured the success of social inclusion within Christian faith communities. Multiple search attempts included various forms of the word "inclusion" and terms related to "Christian faith" or "churches". These initial inquiries resulted in several scholarly articles within Christian based journals. A few articles within the occupational therapy literature referenced spirituality and organized religion, but none had a primary focus on promoting social inclusiveness within a faith community. While the topic of inclusion appears to be relevant to Christian scholars, scholars in the field of disability, and occupational therapy scholars, most of the information initially obtained offered insights limited to a theoretical perspective.

The American Occupational Therapy Association (AOTA) offers a *Guidelines for Systematic Reviews*, which is based on the requirements outlined by the American Journal of Occupational Therapy (AJOT) (AOTA, 2015). In this document, levels of evidence are described. The initial articles located within the last fifteen years as a part of this literature review offered evidence primarily at Level V (AOTA, 2015). Level V evidence typically includes "case reports and expert opinion that include narrative literature reviews and consensus statements" (AOTA, 2015, p. 4). Three of the articles obtained focused on a philosophical rationale or a professional opinion regarding the concept of inclusiveness within a church

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context. Four articles reviewed other current literature to develop information on the relevance of spirituality for those who experience disability, gain an understanding of how churches are offering educational material to the disabled, and gather information on how faith communities are supporting their members with Alzheimer's. The remaining articles sought to gather information from disabled individuals themselves. One article used a case study, but all others used interviews, focus groups or survey methods to gain a better understanding of religious experiences from the perspective of the person with a disability.

As the Capstone Project ensued, additional search inquiries included "the challenge of spirituality for those with disabilities" and "physical accessibility in churches". These phrases resulted in articles that offered an analysis of intervention outcomes on the subject, and may have achieved evidence at Level IV by offering a more descriptive study (AOTA, 2015). One article offered a reflection on the process that two separate churches used to develop committees and improve inclusivity within their faith communities. While this article was of particular interest to this Capstone Project, it was not identified as a study that implemented any particular method or approach in guiding committee decisions.

An article by Amado and colleagues (2012) supported some of the findings of this particular Capstone Project. The article discussed the survey results of 400 churches whose participation was randomly selected after their congregation agreed to be involved in The National Organization on Disability's Accessible Congregations Campaign (ACC). This was a national campaign initiated in the United States to increase the congregational inclusion of people with intellectual/developmental disabilities. The article offered data on the correlation between physical accessibility and full social inclusion (including attitudinal barriers, communication barriers, programmatic barriers and liturgical barriers). The fact that most of the articles found in the literature were at a Level V, may be appropriate given the relatively new interest on the topic of inclusion within faith communities. This level of literature is relevant because it is important to the foundational theory involved in creating inclusiveness in these community settings. In addition, philosophical beliefs on the topic may offer Occupational Science scholars the information needed for descriptive and relational research (Pierce, 2014). However, the abundance of literature at Level V also signifies a need for research at other levels. Studies conducted at Levels I through IV would intentionally offer interested stakeholders information on what types of interventions are needed to successfully attain a goal of inclusiveness in the Christian culture. Carter (2016) recently called for research to go beyond the philosophical level and begin to investigate what intervention techniques promote full social inclusion.

Information From Recent Studies

Some of the consensus statements within the Level V articles were relevant to the members of the committee involved in this Capstone Project because they supported a need for this committee and offered stakeholders validation in some of the experiences they reported. The literature indicated that the concept of inclusive churches is not new, and has been acknowledged as a need since the 1950's and 1960's (Holt-Woehl, 2010). In an attempt to include individuals with disabilities, many congregations have offered segregated opportunities, especially in the area of Christian education (Webb-Mitchell, 2010). As the general culture has grown more accustomed to the integration of disabled individuals into other areas of life (work, school, public events) there has been a growing interest in addressing the issue of inclusiveness within religious institutions (Collins & Ault, 2010).

Person's with varying levels of disability typically report a relationship between their spiritual practice to their overall well being and ability to cope with the challenges of having a disability, but many also voice frustration in their ability to become an involved member of the Christian community (Boswell, Hamer, Knight, Glacoff & McChesney, 2007; Dalby, Sperlinger, & Boddington, 2011; Griffen, 2012; Mooney, 2004; Snyder, 2003; Stav et al., 2012; Treloar, 2002). Segregated attempts to address the needs of this population have resulted in continued marginalization and loneliness (Morri, 2010; Webb-Mitchell, 2010). Attitudinal barriers were often cited more than physical barriers as playing a role in this marginalization (Amado et al., 2012; Carter, 2016; White, 2014). As a result, it seems as though religious scholars have started to address this issue by offering a frame of reference rooted in Christian belief (Morri, 2010; Webb-Mitchell, 2010). This belief is based on the premise that the church is the body of Christ and all individuals are given unique gifts to contribute to that body (Morri, 2010; Webb-Mitchell, 2010). Several authors suggested that the church steer away from its focus on segregated education and instead investigate the unique gifts each person possesses as a means of becoming an active participant in the body of the church (Dalby, et al., 2011; Griffen, 2012; Holt-Woehl, 2010; Morri, 2010; Snyder, 2003; Webb-Mitchell, 2010). This concept resonates with the philosophical underpinnings of occupational science and occupational therapy, indicating that occupational therapists may be well equipped to support initiatives to improve inclusion in Christian faith communities (AOTA, 2014).

Qualitative studies in the form of interviews and surveys with open-ended responses have been important in offering this marginalized population a voice on the topic of inclusion in the Christian church culture. While physical accessibility is an important inclusive practice to consider, there is an overwhelming consensus that interventions continue past physical accommodation. Attitudinal barriers are frequently cited as an important topic to address (Amado et al., 2012; Boswell et al., 2007; Dalby et al., 2011; Snyder, 2003; Treloar, 2002; White, 2014). Amado and colleagues (2012) did find a link between physical and attitudinal barriers. Their study found a correlation between the promotion of accessible worship space and the church congregations' welcoming attitude, increased awareness and emotional ties to those with disabilities. Boswell and colleagues (2007) as well as Treloar (2002) suggested that spiritual education from the clergy is an important component of breaking down attitudinal barriers within the congregation. Several other authors also recommended that the church make an effort to educate the congregation through the use of speakers who are experts on the topic of disability (Carter, 2011; Treloar, 2002).

Collins and Ault (2010) offered an interesting distinction between the terms *inclusive practices* and an *inclusive community*. While both are important, and one may impact the other, the distinction in terms is important to note. An *inclusive practice* involves the procedures or structures of a program to encourage participation. Examples include the philosophical statements, procedural plans, and a focus on building accommodations to promote inclusion. An *inclusive community* involves the beliefs of the congregation and exemplifies a willingness on the part of churchgoers to exhibit a commitment "to include all people into the life of the congregation regardless of their labels or differences" (p. 128). Pierson (2010) warned church congregations about making the objective of social inclusion too complex by over focusing on procedures or programs. Instead, he promoted the idea of promoting a "positive attitude" and a true desire for inclusion to happen among churchgoers (p.185). A majority of articles identified in literature review promoted the idea of building an *inclusive community* by modeling acceptance and finding ways individuals can use their specific talents to be actively involved

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(Dalby et al., 2011; Griffen, 2012; Holt-Woehl, 2010; Morri, 2010; Snyder, 2003; Treloar, 2002; Webb-Mitchell, 2010; White, 2014).

Case studies, literature reviews and surveys also highlighted the need for disability professionals and clergy to collaborate on efforts for an *inclusive community* (Boswell et al., 2007; Carter, 2011; Collins & Ault, 2010). Articles published in one disability professional journal offered some specific strategies for intervention including recommendations for caregiver respite care (Treloar, 2002), the use of religious songs, readings and creative outlets to calm dementia patients who are agitated or anxious (Dalby et al., 2011; Mooney, 2004; Snyder, 2003). Volunteer opportunities were also cited as offering an increased sense of meaning for the person with a disability (Dalby et al., 2011; Griffin; 2012). Carter (2011) was very specific in offering strategies for the church to partner with existing organizations that provide care for these individuals. He suggested the following ways of improving the quality of life for people with significant disabilities: Congregations may work with programs to provide employment opportunities, congregations may work to support/fund residential opportunities. Congregations can offer respite and transportation for individuals with disabilities. Finally, congregations should work with community organizations regarding church needs as well as requesting that disability professionals support the congregation through education and consultation using their expertise.

The Multiple Roles of the Occupational Therapist

The information gleaned as a result of this literature review not only offered validation of personal experiences to stakeholders, but also several potential action items for the committee's consideration. A review of the literature also helped to substantiate the premise that individuals trained in the field of Occupational Therapy are appropriate professionals to assist in promoting inclusiveness in faith communities, based upon the profession's basic educational preparation and leadership training (ACOTE, 2017). Occupational therapists can provide leadership and direct education to the congregation to better equip volunteers to work with this population through respite programs or spiritual engagement. Occupational therapists are also very well equipped to assist the church in matching individuals with disabilities to a purposeful activity within a church community. An occupational therapist may be valuable in assisting the church in finding support systems through other existing professionals and organizations. Many occupational therapists may also be skilled in fulfilling a leadership role and serving as a facilitator for a team of stakeholders. Thus, occupational therapists are prepared to assume many roles in faith-based communities.

Participatory Action Research as a Method for Change

Similar to the article offered by Collins and Ault (2010), this Capstone Project sought to offer information on how a committee of interested stakeholders worked together to promote an inclusive church community. The distinction between the Collins and Ault (2010) article and this Capstone Project has been the use of Participatory Action Research to guide that process. PAR seeks to empower interested stakeholders by systematically gathering and sharing information to research a problem, taking action on that problem, and reflecting on the action steps order to promote social change (Cockburn & Trentham, 2002; Taylor et al., 2006). Typically, the intention of PAR is to include the very people who feel the impact of various constraints that prevent them from fully participating in their communities (Cockburn & Trentham, 2002).

Blumenthal and colleagues (2013) discussed the recent increase in community based participatory research in their book *Community-Based Participatory Health Research: Issues,*

Methods and Translation to Practice. According to this source, PAR first appeared in 1989 and has been gaining "currency as a research approach" (Blumenthal, et al., 2012, p.xv). Blumenthal and colleagues (2013) clearly showed a pronounced increase in this approach since 2001.

A review of the occupational therapy literature indicated that this particular profession has also seen an increase in the use of PAR as a means of empowering the marginalized individuals and groups and encouraging self-advocacy (Blakeney & Marshall, 2009; Niekerk, Lorenzo & Mdlokolo, 2006; Taylor et al., 2004). Letts (2003) proposed that occupational therapists have started to consider the use of PAR to be a worthwhile research tool for the profession. Blakeney and Marshall (2009) added to the knowledge of PAR through their research, which empowered community stakeholders to improve their water supply in eastern Kentucky. These early authors of PAR are the pioneers for other occupational therapists who follow, because they serve as a model for implementing a relatively new research process. This Capstone Project seeks to offer continued information about the PAR process within a community context. As such, it is important to review what is currently known about PAR.

Most sources state that PAR is a fluid process that may look different from one study to the next (Blakeney & Marshall, 2009; Mackay, 2016; Taylor, et al., 2004), but most authors agree that the researcher(s) may play multiple roles and change roles throughout the research process (Blakeney & Marshall, 2009; Mackay, 2016; Taylor, et al., 2004). Taylor and colleagues (2004) suggested that the PAR process does involve a sequence of steps. They proposed that these steps typically evolve into a cyclical process where the steps may then begin to occur simultaneously. First and foremost, the problematic issue must originate within the community where the research will take place and it must involve on some level the perspective of those most affected by it (Blakeney & Marshall, 2009). Once the problem has been identified, involved stakeholders dialogue to choose an action in response to the problem (Taylor et al., 2004). From here, the team selects a research design and a method for collecting data (Taylor et al., 2004). The next logical step includes engaging in that action while also taking data, and then coming together to reflect on how the intended plan is going (Taylor et al., 2004). The team may adapt the plan as needed in order to remedy the initial problem. Thus begins the cyclical process of reflexive dialogue and action steps. Mackay (2016) further describes her experience with this process as follows:

Participatory action research is not a series of iterative cycles that lead on from each other but rather a self-reflecting spiral that is continuous. Having an ongoing spiral enables the process of critical participatory action research to be determined by the participants, rather than the research process (p.1).

The "*ALL God's People* Committee" believed that PAR evolved as a natural course of action for the team to follow as it provided guidance regarding a process for the team's mission while promoting shared responsibility and power in that process.

Information gleaned from this literature review also served the committee by providing knowledge on the level of research that currently exists, and offering consensus on what scholars and individuals with disabilities are saying about promoting inclusive faith communities. As such, the committee used the gathered information in planning action steps, collecting data and reflecting on how well the mission progressed.

Section Three: Methods

Project Design

PAR was selected as the research method for this Capstone Project. This decision was rooted in the researcher's desire to assist the committee in a progression of steps to reach the

identified mission of "creating an environment that is ability inclusive and empowers ALL individuals to be integrated and engaged at all levels of church participation - worship, prepare and serve" (Christ Church United Methodist, 2016a). As the group worked to formulate a name (*ALL God's People*) and a mission, the researcher started to see a natural fit between her expertise as an occupational therapist and the committee's need for leadership in this change process. As a result, this Capstone Project naturally evolved.

As part of their initial dialogue, the committee decided to use the term *unique needs* in place of the term *disability* or *special needs*. This was an effort to choose language that is not offensive, but would apply to a wide variety of churchgoers; including the aging population, children with developmental delays, and individuals with physical impairments.

Setting

Christ Church United Methodist is a Christian church located in the east end of Louisville, Kentucky. At the time of the Capstone Project, the church included one senior pastor and two associate pastors as well as a pastoral counselor. One assistant pastor is in charge of *Care Ministries*. This assistant pastor organized the initial meeting of stakeholders, who eventually became known as *ALL God's People*. In addition to the pastoral team, the church also has a Faith Formation Team, and an individual who functions as a Director of Servant Ministries. The church has a large music staff, and as this Capstone Project unfolded, plans were underway for hiring a new children's minister (Christ Church United Methodist, 2016b; face to face interview with Melissa Head, November 9, 2016).

During the Capstone Project, the church provided weekly worship services on Sundays. The music ministry included a Chancel choir, an Ensemble choir, Hand bells and Instrumentals for both children and adults. Sunday school classes were organized mostly by age, but sometimes according to interest. There were also frequent gender specific groups or service groups. Finally, there is a preschool housed at the church, which provides preschool services to the Louisville community at large (Christ Church United Methodist, 2016b).

A phone interview with the pastor's administrative assistant (phone interview with Kim Keller, August 2, 2016) confirmed that 99 % of the church attendees are Caucasian. The average attendance for Worship is 1,100 and for Prepare groups (Sunday school) the average attendance is 500. While the church is open to anyone, it is located in the eastern end of the city, so most of the attendees live within the ten zip codes that surround the vicinity of the church. Many of the members are college educated and working professionals or retired professionals. Ms. Keller (2016) offered the following breakdown of age percentages as of August, 2016: Thirty percent of churchgoers were children under the age of eighteen. Nine percent were in their twenties, twenty percent accounted for the thirty through forty-nine year olds, eighteen percent of the congregation was between the ages of fifty and sixty-five, and twenty three percent of the congregation was over the age of sixty-five.

As a means of serving the community and sharing its mission of *Becoming living proof of God's love, one person at a time*, the church has a history of working with several community partners within the area (phone interview with Kim Keller, August 2, 2016). Some of these community partners included a feeding program called Backpack Buddies, several tutoring programs at Breckinridge-Franklin Elementary School, The Cabbage Patch Settlement House, Kentucky Refugee Ministries, Lighthouse Community Center, The Portland Promise Center, and The West End School for Boys. The church has created a mission called God's Designs to help furnish the homes of those in need. The Fuller Center / Helping Hands Ministry is another collaborative effort among other Christian communities to build housing for those who cannot

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afford it. The church has also had volunteers located at The Kentucky United Methodist Homes for Children and Youth, The Louisville Wesley Foundation, and Wesley Manor. Finally, there was an ongoing mission program called Love the Hungry, designed to feed the hungry in all parts of the world. Christ Church also sponsored mission programs that went overseas, which were coordinated in partnership with other organizations (Christ Church United Methodist, 2016c). Christ church is a consistent in its ongoing plan to seek ways to reach beyond the church walls to express its mission (Christ Church United Methodist, 2016c).

In regards to serving individuals with unique needs, Christ Church previously implemented a sensory room and has worked in the past to accommodate persons with unique needs on an as needed basis, but at the initiation of this Capstone Project, there were no partnerships with other like-minded organizations and no services at the church that reached out to this population outside of the church walls.

In an effort to expand services and create a more inclusive church environment, the assistant pastor in charge of Care Ministries initiated the "*ALL God's People* Committee". In addition to the assistant pastor, initial attendees included parents and caregivers of individuals with unique needs, members who were interested in the topic, and professionals who work with individuals who have disabilities. The final participants in the study also included one individual with a unique need, who was also a parent of a child with a disability.

As the committee evolved, it became apparent that facilitators were needed. The current researcher (and occupational therapist) participated in committee meetings from the beginning. After some time, the researcher realized the potential fit for PAR as a method of offering the committee a direction in meeting its mission. The author of this project served as a co-facilitator and active participant on the team. Other committee members also brought agenda items and plans for implementation to the committee and participated in the implementation of identified activities. This resulted in a medium to high level of stakeholder involvement and implementation (Taylor et al., 2006). This Capstone Project evolved from this realization.

As the committee evolved, some initial members resigned or changed churches. Other churchgoers also learned of the committee through various means and decided to join. At the initiation of the Capstone Project, the committee consisted of six women and two men. We gained two women one month into the Capstone, which resulted in a final count of eight women and two men. Five members were caregivers of a person with a unique need, one caregiver had a physical disability herself. Two committee members were professionals in the field of disability, two were lay person's interested in this topic, and one represented church leadership. There was an ongoing invitation on the church website regarding the "*ALL God's People* Committee", but educational events and word of mouth primarily served to promote the growth in volunteers **Inclusion and exclusion criteria, recruitment procedures**

Any interested adult churchgoer was a potential candidate to serve on the "*ALL God's People* Committee". Initially, the assistant pastor approached most of the original committee members because she felt they might have an interest in the topic. Due to the nature of PAR research, an exclusion criterion only included individuals who were not involved with the church or the committee in any way.

Aside from the committee members, all potential churchgoers and community members who participated in the services provided through "*ALL God's People*" were included as informal participants in this study. Data regarding their participation was mostly aggregate. Qualitative data did not include identifiers. The committee members of "*ALL Gods People*" recruited all participants through traditional means of advertisement (signs, announcements and church website).

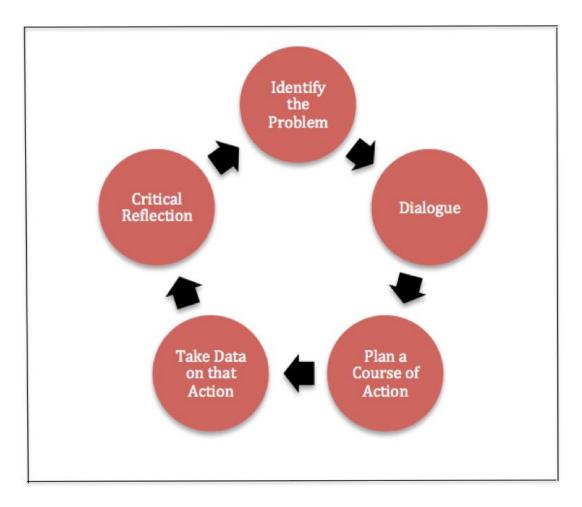
Project methods and procedures

Participatory action research (PAR). PAR was chosen as the identified method for this Capstone Project because of its intent to empower those who are impacted by the research topic, and guide them as a team of stakeholders in promoting social change. While authors on the subject of PAR offered different subcomponents to their protocols, all contend that the stakeholders are involved throughout the process and that the process involves research to identify the problem, dialogue among stakeholders to determine a course of action, action to address the problem, data collection, and reflection regarding the action(s) chosen. These steps often occur in a cyclical process as needed (Cockburn & Trentham, 2002; Henry, 1996; Jones, 2015; Taylor et al., 2006; Taylor et al., 2004). The researcher has offered a visual representation of the process proposed for this Capstone Project (adapted from Taylor et al, 2006) in Figure 1.

The researcher served as a co-facilitator on this committee throughout the Capstone Project, and obtained group approval to use PAR as a means of creating and measuring the impact of the identified mission. The other co-facilitator is a church member who previously sought to initiate the Sensational Kids room in the children's wing. Both co-facilitators met on a monthly basis to discuss the upcoming agenda and review the previous meeting notes as a means of offering continuity.

Research to identify the problem. At initial meetings, group members learned about each other, discussed their experiences with disability and their experiences as a churchgoer. Authors

who offer information regarding the process of PAR contend that the subjective experience of the stakeholder is a relevant step in identifying the problem to be addressed (Blakeney & *Figure 1.* A Cyclical Process of Participatory Action Research



Adapted from a process offered by Taylor et al., 2004.

Marshall, 2009; Blumental et al., 2013; Taylor et al., 2006). While many of the committee members were not individuals with a unique need, their experience as a caregiver for someone who is, was considered relevant to identifying problems. The researcher followed these initial sessions by conducting a literature review on the subject of inclusivity within a worship environment. One relevant article (Carter, et al., 2015) was presented to the committee, which served to validate committee members' subjective experiences and substantiate a need to identify what specific barriers existed at Christ Church that may impede the inclusion of people with unique needs.

"ALL God's People" then conducted a needs assessment using a church wide survey that was designed to answer questions regarding the church atmosphere in relation to inclusivity (Appendix A). To create the survey, a subcommittee was formed to brainstorm survey questions. Questions were designed based on the study's purpose of identifying barriers and strengths of the inclusionary opportunities already in place. The entire committee then participated in a debriefing interview to pilot the document before it was made available to the congregation. The final version included questions designed to gain demographic information, accessibility, perceived needs and perceived attitudes.

The survey was made available to all churchgoers using the online format offered through Survey Monkey, but the survey was also made available in paper format. Committee members distributed and collected the paper surveys across several consecutive Sundays to maximize participation. Data from the paper formats were then entered in the online portal by the researcher, who then compiled the data, and presented the results to the committee using a multimedia presentation. Northway (2010) suggested that researchers conducting PAR should take the time to explain specialized language to participants as a means of maintaining equal power among committee members. In honoring this strategy, an explanation of how the data was compiled was explained by the researcher during this presentation.

Dialogue regarding a course of action. The committee dedicated one meeting to review the results of the survey through the presentation and a discussion of the findings. Several subsequent meetings were held for committee members to dialogue and plan a course of action using the results. The co-facilitator worked with the committee members to organize the identified needs into categories of what could be addressed immediately, and what needs would be considered long-range goals. As the committee worked to prioritize, it became evident that each need was linked to a plan of action, which ultimately fit nicely within the already existing church wide goals of Worship, Prepare, Serve and Bridge.

Course of action and data collection. After the team correlated several identified action items in a way that corresponded with the broader church-wide goals, they discussed a natural means of data collection for each. The church-wide goals are offered below and then followed by the committee's action plan (or activities) and identified means for data collection.

Worship. The committee of "*ALL God's People*" wanted to offer an inviting place of worship to people of all needs by first ensuring an accessible building with adapted materials for worship time. The committee initially used a church wide survey to ascertain what types of environmental barriers might be addressed to help people feel welcome. Throughout the Capstone Project, the PAR process brought to light other methods of inquiry that influenced the committees' course of action under the goal of Worship. The first activity included a guest speaker at one of the "*ALL God's People*" committee meetings and the second activity included observational data intended to give the committee more information about handicapped parking spaces and churchgoers' ability to maneuver the environment.

The final data for the Worship goal consisted of aggregate data (which was a count of the number of tasks achieved), and the quantitative information gathered through the committees' observational inquiry.

Prepare. The church-wide Prepare goal was aligned with the committee's goal to address attitudinal barriers through education. The "*ALL God's People* Committee" and the *Dig Deeper* Committee hosted an educational speaker on January 8, 2016 as one activity to address this goal (Appendix D).

The following Sunday, The "*ALL God's People* Committee" conducted a follow up focus group questionnaire (Appendix E) to ascertain what impact the presentation may have had on perceived attitudinal barriers within our church community (Appendix F). The responses were then organized by theme for the purpose of data collection.

Serve. Members of the "*ALL God's People* Committee" identified two subcommittees responsible for planning and coordinating services to the congregation and the community. One group was a Caregiver-to-Caregiver Group, which was designed to meet once monthly to support, educate, and offer resources to those who are providing care to someone with a unique need (Appendix G).

The second subcommittee worked towards implementing a respite service titled the *Buddy Break Program*. This prearranged program is offered in other faith communities and it is designed to offer respite services to families of young children. While the goal of the *Buddy Break Program* is to serve the greater community, the committee also saw it as an opportunity to offer church volunteers potential growth in the area of exposure and empathy. Data plans for both programs included an aggregate count of how many participants attended each month. The committee felt that this aggregate data would offer evidence of need and use.

Bridge. "ALL God's People" formed a subcommittee to create a process that will assist the associate pastor in matching churchgoers with unique needs to activities that match their interest. The long-range outcome for this goal is for churchgoers with unique needs to have the natural supports they need to be successful in church activities of their choosing. The committee also postulated that natural friendships may emerge and then transfer into other church activities. Data on this initiative was qualitative in nature with plans to include the impressions of one pilot family who tried to encourage more church involvement for their son. (Appendix H).

Reflection. Due to the cyclical process of PAR, reflection is ongoing and inevitably circles back to problem identification and dialogue. The co-facilitators for this project used meeting minutes to create upcoming agendas and keep the group on a consistent trajectory towards reaching the goals in our Logic Model (Figure 2). Specific activities were a flexible component of the PAR process. During group dialogue, members would reflect on new information, which would often lead them back to the process of more inquiry. Examples of this occurrence included the decision to conduct observational data after we initially obtained more handicapped parking spaces. Our guest speaker with Parkinson's was another end result of group dialogue and reflection.

In order to gain qualitative data about participants' perceptions of the PAR process, information was gathered from committee members through the use of a questionnaire (Appendix K). The questionnaire was completed at three different intervals, and collected from participants in a manner that encouraged anonymity. The researcher then analyzed the data through coding the responses under prominent themes that emerged. A stakeholder check then occurred for purpose of accurately reflecting the participant's experiences (Appendix L) (Lysack, Luorsky and Dillaway, 2006).

Ethical Considerations

The process of PAR presents several unique ethical considerations (Northway, 2010; Taylor et al., 2004). Since the intent is to empower the consumer(s) and the community, the shared responsibility of the co-researcher and team can complicate the process of decisionmaking, allocation of power and commitment needed to see the project through.

Interpersonal skills and encouraging participation. An important aspect of creating a participatory process is building a trusting relationship (Northway, 2010). Northway suggested a need for researchers to develop or improve skills in facilitation and negotiation in order to empower an effective team. She further recommended that reflexivity (self critique and self awareness) is an important component to creating the interpersonal skills needed to facilitate this type of effort. As a means of addressing these skills, the occupational therapist acting as the researcher, simultaneously worked to enhance such skills through the university required Applied Leadership Experience (ALE). Readings, journaling and self-reflection were a required as part of the ALE plan. As a result, the researcher worked to maintain awareness and improve skills in interpersonal relating in order to also empower the participants involved in this Capstone Project.

In addition to the ALE, the researcher incorporated several recommendations gleaned from articles on the subject of PAR. Taylor and colleagues (2004) discussed the importance of choosing a context for PAR that embraces the need for social change, is stable, and has a respect for the PAR process. Since the researcher was invited to participate in this committee by the assistant pastor in charge of *Care Ministries*, consent for this Capstone Project was secured through this pastor. This identified assistant pastor also served as a committee member and consistently communicated with the lead pastor and other organizational entities at the church. At one point during the Capstone Project, a conflict occurred which resulted in a formalized approach to ensure follow through and communication between the committee and church leadership. As a result, the PAR process was improved and action items were less likely to lose momentum.

Northway (2010) suggested that researchers attend to their use of specialized language and knowledge during the PAR process. In order to encourage shared power, she suggested that the researcher educate participants on the concepts of research. The stakeholders involved with "*ALL God's People*" are all college educated and familiar with the general concepts of research. Frequently, committee members proposed ideas for gathering information, taking data or promoting an activity designed to address a need. The researcher worked cautiously as the cofacilitator to steer the committee in a direction that may show productivity, but not limit individual power or the inspiration of new ideas. In doing so, the researcher used several minutes of committee time to educate the committee members on the process of PAR and the process of identifying "themes" in qualitative data (Lysack et al., 2006).

This Capstone Project was approved through the Institutional Review Board (IRB) process at Eastern Kentucky University. As part of that process, all ethical considerations were analyzed and met approval of the IRB (Appendix M). Formal consent forms (Appendix I) were also signed (Northway, 2010) as a part of the IRB process. As committee members grew, they were given the option to participate and the researcher offered answers to any questions participants had.

Finally, the researcher also encouraged meeting times and places that were conducive to the most members as a means of maximizing participation (Northway, 2010). Initially, the committee met at night at the church. The committee mutually decided to move monthly

meetings to a weekday morning at a public coffee shop because this offered more opportunity for all members to attend regularly.

Timeline of Project

The timeline for the project is presented to assist readers in understanding the deliberate nature of PAR. The original committee members of "*ALL God's People*" were recruited by the assistant pastor in charge of Care Ministries at Christ Church United Methodist. The initial meeting took place in February of 2016. As the group worked to decide on a name and identify its mission, the researcher saw a fit between the needs of the group and the expertise she might offer through her required education in the Eastern Kentucky University OTD program. As a result, the researcher served as a co-facilitator for the group, conducted an independent study to improve her leadership skills, and educated the group on the process of Participatory Action Research (PAR) as her Capstone Project requirement. The timeline for the entire Capstone Project is outlined below:

February 2016 – initiation of a committee of stakeholders by the assistant pastor. *March 2016 through May 2016* – Monthly meetings occurred with an identified lay facilitator.
The initial meetings focused on the experiences of stakeholders, a suitable name for the committee, a mission statement, and brainstorming ideas to improving inclusivity. *June 2016* – This monthly committee meeting resulted in the realization that the committee would benefit from a church wide needs assessment. A subcommittee was created to discuss this process and the OTD student served on this subcommittee.

June 2016 and July 2016 - The OTD student assisted the committee in creating a church wide survey. The survey was conducted on line and in person during the month of July.

August 2016 through November 2016 – The OTD student agreed to serve as a co-facilitator on the committee. The initial lay facilitator had to resign, so the OTD student agreed to share the responsibility with another stakeholder. The OTD presented the survey results to the committee and collaborated with the group to prioritize the results. The list of priorities naturally progressed to a discussion of action ideas. As this process continued, it became evident that the priorities and action ideas aligned well with the church wide goals of Worship, Prepare, Serve and Bridge. *November 2016* – The OTD student requested permission from the assistant pastor and committee members to conduct the Capstone Project using Participatory Action Research. All stakeholders approved of the Capstone.

January 2017 – The committee promoted the speaker Taryn Skees and conducted a follow up focus group to gather data on the speaker's impact.

March 2017 – The OTD student secured approval from the Institutional Review Board at Eastern Kentucky University. The OTD secured informed consents from all participants.

August 2016 through present – The committee meets monthly and to discuss identified action items, assign members to follow up on tasks, design a plan for data collection, and reflect on the progress of each action item. A review of all action items and the data collection through August 2017 is discussed in the results section of this paper.

June 2017 through August of 2017 – The OTD student participated in an Applied Leadership Experience (ALE) which was an independent study designed to improve her skills in leadership strategies. Mentorship occurred with the assistant pastor and strategies were implemented during monthly meetings. During this time, data was also assimilated and compiled into a written document used as a Stakeholder Check (Appendix L).

September 2017 – Committee members reviewed the Stakeholder Check document for approval.

September 2017 through November 2017 – Capstone Proposal updated/Results Section Written. November 2017 – OTD Capstone Project presented.

Section Four: Results and Discussions

Introduction

Using the cyclical process of PAR, the stakeholders were able to use the research and inquiry they conducted to identify barriers that may impede the inclusion of people with unique needs at Christ Church United Methodist. With that information, the committee engaged in dialogue to create a plan of action to address those barriers. With each plan of action, the team aligned a plan for multiple forms of data collection so that at the end of the Capstone Project, our degree of progress towards creating an *inclusive community* (Ault et al., 2013) could be measured. Table 1, Multiple Methods of Data Collection used to Measure Progress Towards Inclusivity, highlights the various forms of data collected, along with the church-wide goal that is targeted. The image is mentioned here to alert the reader of the concise table that summarizes the multiple methods of data collection. The results of the data are also briefly reviewed in the text that follows, using each step in the PAR process as a heading.

This information is then followed by the results of the PAR feedback forms, which were completed by the 10 participants. A deeper analysis of the interrelated components that became evident for this committee of stakeholders is proposed, followed by a discussion of what the committee learned about participation and engagement for individuals with unique needs in a faith based community.

Results

Step one in the PAR process: Problem identification. The "*ALL Gods People* Committee" used several methods to seek clarification regarding barriers to inclusion. These included initial stakeholder experiences, church-wide survey results, observational data, and a guest speaker at one of our committee meetings.

Subjective experiences. The team of stakeholders initially offered their subjective experiences as churchgoers who had close relations with someone with a unique need. This has been identified as an important step in the PAR process (Blakeney & Marshall, 2009; Blumental et al., 2013; Taylor et al., 2006). Taylor and colleagues (2006) suggested that the individuals who experience the problem make sense of the situation in ways that outsiders cannot possibly comprehend from their own frame of reference. This is an important step in thoroughly understanding the problem and identifying specific components that may need to be addressed. The stakeholders who are caregivers of an individual with a unique need often talked about the hesitancy they felt from other members of the congregation in approaching or interacting with their loved ones. As a result, they too felt somewhat isolated within the faith based community. The subjective experiences of the stakeholders were then further supported by a review of the literature. The survey results and personal interviews from several studies aligned with the experiences expressed by the stakeholders (Carter et al., 2015; Hobbs et al., 2016; White, 2014). This not only offered the stakeholders a sense of validity and further substantiated a need for this committee and its mission, but it seemed to establish a bond among committee members.

Church-wide survey. Once the committee felt firm in its identified mission, we felt that a needs assessment was appropriate to identify current barriers to inclusion. This was obtained through a church-wide survey (Appendix A), which helped the committee distinguish between two distinct groups at the church who needed support: the aging population (54.31% of those with unique needs identified in the survey were over the age of 65), and individuals who are

diagnosed with a disability of some kind (45.70% of individuals identified through the survey were under the age of 65).

The survey included 294 respondents, who offered information on the adaptations they or their loved one currently used, as well as information on the barriers that existed. 90% of the respondents were members of the church. Examples of adaptations being used at the time of the survey included: the use of existing handicapped parking spaces, a quiet room in the back of the sanctuary, gluten free communion, assisted listening devices, a fragrance free balcony, large print hymnals, a buddy to assist with tasks, a sensory room called Sensational Kids, and wheelchairs for those in need.

Also identified through the survey, where specific suggestions to promote more inclusivity. Some of these suggestions included addressing the sound quality in the sanctuary, improving the attitudes of the congregation through education, offering support groups, getting family bathrooms, offering those in need assistance in physically maneuvering around the church, signing services during worship, and a standing alter for communion.

Observational data. After the committee worked for several months to address some of the identified environmental barriers for the Worship goal, a group decision was made to follow up on the topic of parking and accessibility by conducting an informal observational assessment across three consecutive Sundays (Appendix B).

This inquiry served the purpose of gathering information through observation rather than congregational report. In the spring of 2017, several stakeholders took observational data on the use of the new handicapped parking spaces and how well churchgoers were maneuvering to access the building physically. The committee identified forty-five total handicapped parking spots, eight of which were van accessible. Our observations across three consecutive Sundays confirmed that we had enough handicapped parking spaces to accommodate our churchgoers with unique needs. Those in the congregation who did not need handicapped parking, politely parked further away, which resolved one of the committee questions regarding a need to campaign for this type of behavior. From this inquiry, the committee ultimately suggested that the seven available wheelchairs be placed near the entry doors with the greeters so that churchgoers who need them can access them easily. The committee also decided to offer informal education to the church greeters by networking with them and educating them on the action items taken to decrease the church's environmental barriers. Through this networking, the committee hopes to ensure sustainability in promoting our Worship goal. This observational data collection was also responsible for identifying a need for automatic door openers, which was promoted to the Trustees in a letter that referenced our data (Appendix C).

One committee member reflected on the strategies they learned through participating in the inquiry component of PAR by stating,

I have learned that effective change requires analysis of the problem, sometimes through data collection. I tend to see issues from one perspective – mine – and this process has shown me methods to get a clearer picture of issues and directions for proceeding.

Guest Speaker. Finally, the committee identified additional barriers through hosting a guest speaker at one of our meetings. A churchgoer presented on her experiences with Parkinson's in order to educate the stakeholders on potential needs of those with mobility challenges. The speaker was well informed on the subject. She offered the committee more potential barriers to consider as we created our course of action to promote physical accessibility during worship. Examples included the decision to create weighted binders for the bulletin, requesting that people stand for communion or sit in the front rows to be served. The committee

members also unanimously felt that this speaker could offer more presentations as a means of improving compassion and addressing our Prepare goal.

Step two in the PAR process: Dialogue about a course of action. By using the cyclical steps suggested by Taylor and colleagues (2004), the committee used initial and ongoing research to intentionally identify problem(s) to then dialogue about a course of action to address the identified needs.

The leadership strategies learned through the ALE process were an important component in encouraging the participation of stakeholders. Northway (2010) suggested monitoring the use of specialized language, critically analyzing ones interpersonal skills to encourage the equality of power, and meeting the stakeholders at a time and place that is easiest for their participation. These strategies were all implemented and adjusted throughout the Capstone Process in hopes of promoting optimal participation. The researcher conducted reading and reflection on the topic of Emotional Intelligence (Walton, 2012) and leadership strategies (Bolman & Deal, 2013; Johnson, 2015) as part of the OTD program's ALE requirement. This intentional behavior on the part of the researcher seemed to carry over in the interpersonal dynamic between stakeholders.

One stakeholder reflected on the strategies he learned by participating in "*ALL God's People*" by stating, "Listen first and speak second! Actions speak louder than words: take the risk to volunteer and participate beyond the meetings".

Step three in the PAR process: Organize a course of action and engage in data collection. The committee used wall charts to list the barriers we identified through our initial survey. These items were then separated into the two topics of what barriers could be addressed immediately and quickly and what may be more involved.

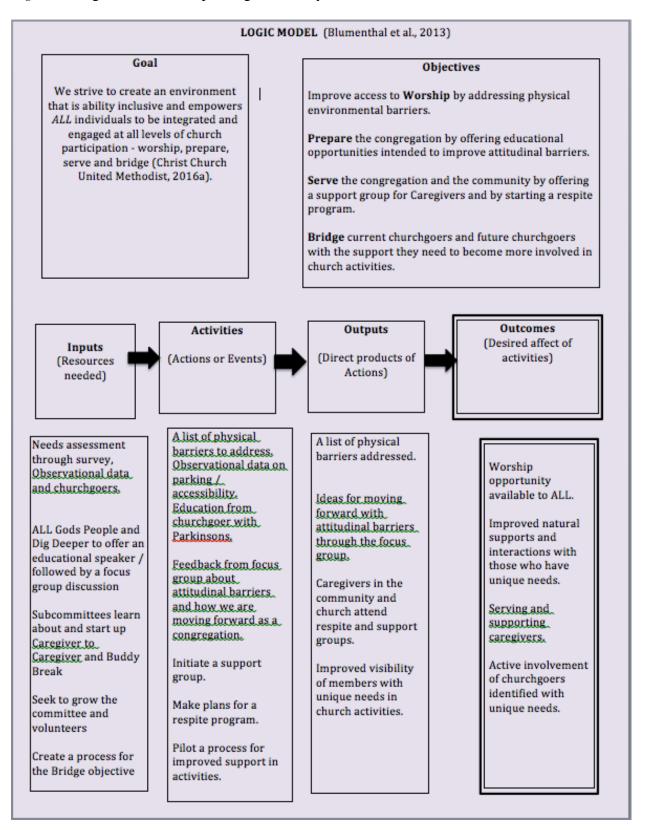


Figure 2. Logic Model for Improving Inclusivity at Christ Church United Methodist

Organize a course of action: Logic Model. As stakeholder dialogue ensued, the researcher promoted the use of a Logic Model (Blumenthal et al., 2013) to the committee as a means of offering an overall intervention plan with goals, action steps and a method for assessment. The Logic Model created by the committee is offered in Figure 2. Engaging in this process ultimately resulted in an alignment between the church-wide goals and committee goals.

The visual result ultimately served as an aid in keeping the committee focused as they engaged in the PAR process. While the Logic Model (Figure 2) offered an overarching map for the committees' ultimate destination, it was not strictly imposed. Since dialogue among stakeholders is an integral part of the PAR process, it was understood that the committee's Logic Model (Figure 2) served as a guide, but not a fixed document impermeable to adaptation (Blumenthal, et al., 2013). As a result, the church wide goals and committee goals remained constant, but activities and tasks were adjusted as needed. These activities were consistently reviewed and prioritized during ongoing committee meetings.

Data collection. The activities implemented ultimately resulted in several methods of data collection by the researcher. Lysack and colleagues (2006) discussed the use of triangulation as a method of increasing the validity of a particular finding. This is commonly done using different types of data methods, which was the approach used in this Capstone Project. By using a variety of data collection methods, the results are more likely " 'true' due to the complementary strengths of the respective methods" (p.353). Table 1 offers results on the variety of data collection methods in relation to each church-wide/committee goal.

To further improve the validity of these findings, a stakeholder check of this data was conducted at the close of the Capstone Project (Appendix K). This was to further ensure the accuracy of the information gathered from the perspective of other committee members. Lysack

Table 1. Multiple Methods of Data Collection Used to Measure Progress Towards Inclusivity

Church Wide Goal	Committee Activities	Data Collected
Worship	Address Environmental Barriers (improve access to worship)	 7 items More handicapped parking spaces Address sanctuary acoustics Construction of 2 family bathrooms Lead pastor announces standing as acceptable behavior for communion Request for automatic door openers Wheelchairs moved near greeters Creation of a weighted binder for Bulletin
Prepare	Educate Ourselves / Congregation (improve empathy)	 Speaker with Focus Group Follow up (Appendix D and E) Taryn Skees (speaker – discussed how to react to families who have a child with a unique need) 14 Participants offered the following data: 100% of respondents reported that our church is improving in its mission to enhance inclusiveness for ALL people. 33% of respondents stated that the presentation improved their compassion for families who experience a child with a unique need. 33% said that the presentation informed or enlightened them. 14% were inspired 93% of respondents felt that listeners left with an improved comfort level for reaching out to people and their families who experience a unique need.
Serve	Caregiver to Caregiver Support Group Respite Program (Buddy Break)	 Aggregate data: 28 people have attended at some point. Monthly meetings average in attendance between 9 and 15. Other data: Group has been up and running since November 2016. Church members and community members attend. The group has secured an outside facilitator through Jewish Community Center. Funding is secured through a grant. The group appears to be sustainable as the facilitator plans to continue into this year. Two committee stakeholders went to visit Buddy Break at another church. They gathered information on how Buddy Break can work. The stakeholders presented to the committee, but other priorities moved to the forefront. The committee continues to have this as a goal.
Bridge	Connecting Individuals with Activities	 A subcommittee create an informational / interview form which will be used to pilot the process (see Appendix I). <i>ALL God's People</i> approved of the form and the name "Getting Connected". The committee agreed on conducting a pilot with one individual. The mother of this individual completed a brief interview with the researcher. She reported that she tried to initiate opportunities for her son without the support of a process. Her impression was that the church staff seemed generally uncomfortable and reluctant (Appendix H).

and colleagues (2006) stated that this is a vitally important step in confirming the investigators conclusions' with those who experienced the event(s). The committee stakeholders reviewed the data together, posed a few questions and ultimately approved the information in Appendix K.

Step four in the PAR process: Reflection. Reflection is the final component of the cyclical PAR process (Taylor and colleagues, 2004). Stakeholders often failed to naturally engage in the reflection component of dialogue so the researcher promoted the reflection component, through the use of Stakeholder Checks, a celebration of our accomplishments at one year, and through the use of the PAR feedback form outlined in the methods section of this Capstone Project (Appendix J).

PAR feedback form. The PAR feedback form was completed anonymously by all stakeholders at two-month intervals. Data was first collected in April of 2017. The second data collection date occurred at the June 2017 meeting, and the final probe was during the early September 2017 meeting. (The committee elected not to meet in August 2017, due to vacation plans and the impact on attendance).

Quantitative information regarding stakeholder participation: The opportunity to participate was typically given a 5 (1 represented little opportunity for input and involvement, and 5 represented open opportunity for input and involvement). On four occasions this scale was given a 3 or a 4, but the reason was consistently due to lack of attendance by the stakeholder.

Qualitative information regarding stakeholder participation: Stakeholder written feedback forms were reviewed by the researcher and the concepts of phenomenological analysis were applied to summarize the essence of the participant's experience (Creswell & Poth, 2018). Significant statements were categorized into frequent themes and then a written summary was offered to participants through a stakeholder check (Lysack, et al., 2006). Stakeholders generally described the group as having open lines of communication, an ability to prioritize tasks, and an ability to be as involved as desired with implementing those tasks.

Stakeholders often used the word "determined" to describe the work of the group. Respondents typically commented on the number of tasks the committee achieved. Members were particularly proud of the committees influence to address seven tasks under the Worship goal (environmental barriers). Members especially took pride in our ability to obtain two new family bathrooms and an approval to get bids on automatic door openers by the trustees committee.

The stakeholders also took great pride in the initiation of the Caregiver-to-Caregiver group, which has obtained a consistent trained counselor who is funded through a grant written by the Jewish Community Center. The aggregate count for monthly attendance at this support group is between 9 and 15 attendees, who consist of church members and people from the community at large.

Several stakeholder respondents observed that progress on the goals related to attitudinal barriers (Church Serve and Bridge goals), were taking much more time than the tasks intended to address environmental barriers (Church Worship goal). The stakeholders also commented on the realization that the committee goals of Serve and Bridge require the team to outline a process that includes many steps. In their responses, they recognized the need for approval and support by the church leadership and how this also takes time and education.

On the third and final Stakeholder input form, participants responded to a question As a result of participating in this PAR process, do you feel you have learned any strategies that you would take with you in order to work effectively with a team of people? Two respondents were

quoted previously in the Results section under Problem Identification and Dialogue. A third stakeholder responded by saying,

Strategies I would use in the future working with a team of people would be - emphasize member participation and putting each member into action to meet goals. – Good dialogue with all members heard and respected to look at ways to solve problems and reach goals.

Discussion of Findings

The ultimate purpose of this project was to objectively measure the degree of progress made towards creating a more inclusive environment within a religious congregation, and to identify what interrelated components are a necessary means to that end. A secondary purpose was to promote understanding about disabilities within a faith-based community for participation and engagement. A tertiary purpose of the Project was to offer the field of occupational therapy, useful information regarding the process of PAR within change theory for community-based practice.

Degree of progress made towards creating a more *inclusive community*. Ault and colleagues (2013) distinguished between *inclusive practices* and *inclusive communities* by offering an explanation of each. *Inclusive practices* are the procedures or structures of a program to encourage participation, while an *inclusive community* involved the beliefs of the congregation and exemplifies a willingness on the part of churchgoers to exhibit a commitment to include all members of the congregation. The stated mission of "*ALL God's People* Committee" includes "creating an environment that is ability inclusive and empowers ALL individuals to be integrated at all levels of church participation – worship, prepare, serve and bridge" (Christ Church United

Methodist, 2016a). While an *inclusive community* does depend on *inclusive practices*, it is the former that was the long-term goal of this Capstone Project.

Various methods of data collection revealed some level of progress within each of the Worship, Prepare and Serve objectives. The committee used the aggregate count of seven activities within the Worship goal to reflect progress. These seven items addressed environmental barriers that may impede attendance for individuals with unique needs. After the environmental objectives were accomplished, the committee felt a level of pride in their accomplishments. The task of addressing attitudinal barriers related to the Serve and Bridge goals quickly became daunting. After some reflection, the committee recognized the potential impact of improved accessibility in helping them reach the goal of an *inclusive community* (Ault et al., 2013). Amado and colleagues (2012) found that "changes in physical accessibility brings attention to the issue of social inclusion". The authors further explained that addressing physical accessibility within churches "increases the presence of people with disabilities" which then correlates to their "being welcomed and accepted" (p.415).

Within the Prepare goal, qualitative data collected from the focus group indicated that our guest speaker helped 94% of the focus group respondents feel more comfortable in knowing how to approach a family with a member who has a unique need. The "*ALL Gods People* Committee" believes that continued information on various topics regarding the disabled will promote a positive attitude among members. One hundred of the 294 respondents on our initial survey felt that education of the congregation was key to creating a more *inclusive community* (Ault et al., 2013). Scoir (2011) conducted a systematic review of the literature to ascertain the level of adequate knowledge the general public has in regards to intellectual disability and how that knowledge impacts attitude towards inclusive practices. She found that level of education was

one indicator of a positive attitude. Pierson (2010) also highlighted the concept of congregational attitude as a simplistic method for encouraging *community inclusion* (Ault et al., 2013).

Another aggregate count indicated that the Caregiver-to-Caregiver support group has a monthly attendance of 9 to 15 people. Carter and colleagues (2017) recently verified through community discussion the prominent need for churches to reach out into the wider community and offer support to families through respite and support groups. The "*ALL God's People* Committee" perceived this aggregate count of consistent attendees to mean that caregivers were getting their needs met at this support group, and they were extending an invitation to others outside of church membership. This finding reinforces what the literature says about identifying issues and promoting inclusion (Boswell et al., 2007; Carter et al., 2017; Collins and Ault, 2010).

An interview completed with the caregiver of our pilot participant confirmed for our committee that leadership education and a process for the Bridge goal is warranted. This parent voiced some frustration with trying to engage church staff in getting her son more involved at the church (Appendix H). As a result of this information, a subcommittee of four addressed the initial step related to the Bridge goal by designing an initial interview form called Getting Connected (Appendix I). The committee has also worked with church leadership in developing a process to gather volunteers. This continues as an area for ongoing work.

While the multiple methods of data collection did show some progress in reaching the identified long-term goal of establishing an *inclusive community* (Ault et al., 2013), these efforts in data collection failed to acknowledge the interim progress made using several other interrelated components deemed necessary for success. These components included ongoing inquiry, networking with other entities of the organization, community networking, and subcommittee work towards creating a process for the Bridge goal.

Interrelate components: Concept (or systems) mapping to visualize progress. Since the process of PAR moves away from traditional positivist science, an analysis of its impact does not easily fall within a definitive parameter of success or failure. Several authors discussed the use of concept (or systems) mapping as a visual aid in effectively measuring advocacy or ongoing social change (Coffman and Reed, 2017; ORSImpact, 2010; ORSImpact 2013; van Bon-Martens, van de Goor & van Oers, 2017). Meadows (2013) stated that "some shy away from what can feel squishy on the path to impact" (p.8), but concept mapping can offer a look at these "interim outcomes" (p.3) as a "representation of discrete areas of progress" (p.3), to support change. This method of advocacy evaluation has grown in use over the last decade (Coffman & Reed, 2017; ORSImpact, 2013, van Bon-Martens et.al, 2017). In an effort to summarize this complex Capstone Project and offer a succinct way of depicting interrelated components and interim progress, a visual representation developed by the researcher, is offered in Figure 2.

The viewer can easily assess the committee's efforts to identify problems, network with other committees, and take action steps. The interdependency of all steps were ultimately relevant in considering the community system and making progress towards the ultimate goal of promoting an inclusive community (Ault et al., 2013). The concept (or systems) map also visually highlights these interim steps so that viewers can appreciate the multiple tasks that were accomplished over the eighteen-month Capstone Project.

Within the Worship section, an observer of this concept/systems map can see that the committee spent their energy on networking as much as researching to accomplish the action items. The Prepare section also includes networking and inquiry, which resulted in action steps and data towards progress. The Serve and Bridge sections however, required much more

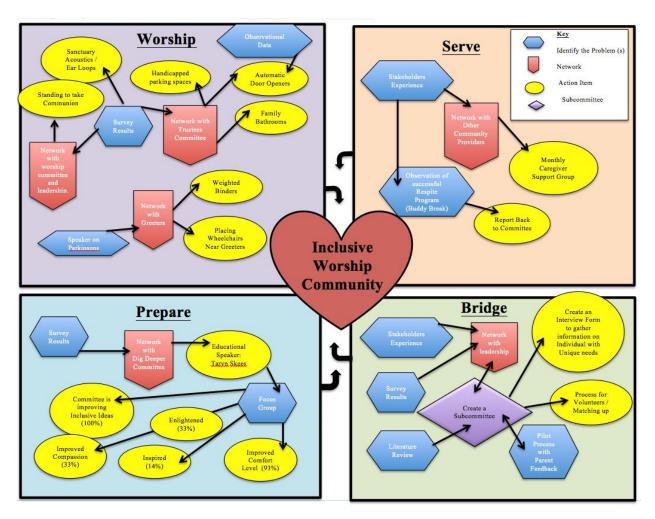


Figure 3. Concept (or Systems) Map To Measure Interim Change

Figure 3. Adapted from concepts offered by: Coffman & Reed, 2017; ORSImpact, 2013; van Bon-Martens et al., 2017.

research and inquiry to inform the committee of what steps they might need to take. Both of the goals related to these sections, also required networking with other community entities and consideration regarding how a new process might be implemented to achieve the identified action items. In several instances, one of the four goals (Worship, Prepare, Serve, Bridge) inevitably required overlap with another. For example, the Worship goal (environmental barriers) required networking with other committees and educating greeters on the location and function of the adaptive materials. As such, one goal (Worship, Prepare, Serve, Bridge) rarely stands alone. Instead, each goal has the potential to intersect with the other(s). This overlap became evident as the Logic Model (Figure 2) began to unfold. As a means of measuring progress however, if one measured only the action items outlined in the original Logic Model (Figure 2) as a sign of progress, much of the information and effort towards progress could easily be overlooked.

After the "*ALL God's People* Committee" accomplished several of the tasks related to environmental accessibility (Worship goal), it became clear that working towards the Serve and Bridge goals would be a process that demanded time, determination, and the consideration of all of the interrelated components. The goals in Serve and Bridge also require reframing of attitudes, and the process of viewing things from multiple perspectives (Bolman & Deal, 2013). This is an ongoing process that will take more time to implement and evaluate.

Participation and engagement for people with disabilities in a faith based community. The stakeholders had initial opinions regarding effective methods to encourage more participation and engagement for individuals with unique needs. The ideas of individualized supports and well orchestrated positive interactions were verified using recent studies on the subject. The literature offers evidence that family and individual support strategies offered in faith-based communities should be individualized (Carter et al., 2017; Carter et al., 2016; Ault et al., 2013). Since positive interactions breed positive attitude, careful planning should also take place to promote a successful, pleasurable experience for all churchgoers (Scior, 2011).

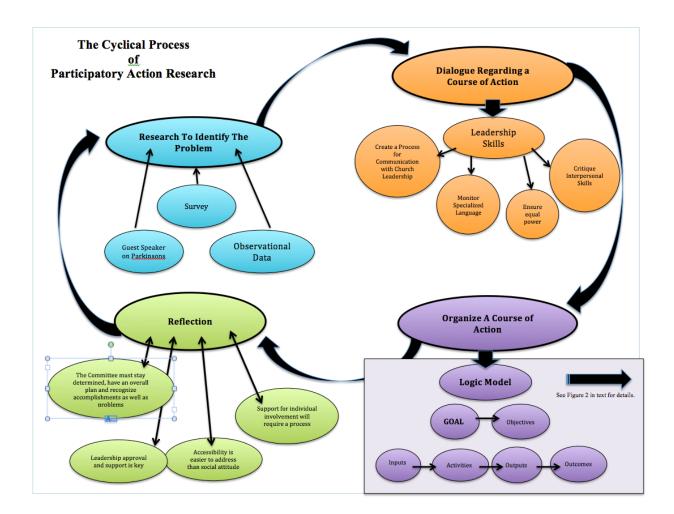
Individualized supports. Two studies conducted on the topic of inclusion within Christian worship environments, offered similar information regarding the need for individualized supports within the Serve and Bridge objectives of this Capstone Project (Carter et al., 2016; Ault et al., 2013). Both studies sought to identify the supports families desired in order to involve their disabled child at church. In both studies, parents appreciated their worship communities desire to address physical barriers, but this type of support fell to the bottom of their priority list. Parents ranked support for social-related barriers as their highest priority (Carter et.al, 2016; Ault et.al, 2013). Ault and colleagues (2013) reported that their survey data highlighted the parents desire for individualized supports to promote successful participation in church activities over other forms of support. Carter and colleagues (2016) found that parents valued very different action items because the supports they listed related specifically to the needs of thier loved one. The fact that the data in this study rarely identified the same supports from two different parents emphasizes the need for congregations to avoid a "one-size-fits-all approach" in their planning process (p. 385).

The stakeholders on the *ALL Gods People* committee communicated a similar desire for individualized supports and a well-planned process in meeting individualized needs. At the conclusion of this Capstone Project, a subcommittee had created an initial interview form (Appendix I) intended to initiate the process for providing this individualized method of support. *Pleasurable experiences with the disabled: Impact on attitude*. Scior (2011) conducted a systemic review of seventy-five descriptive studies that investigated the topic of attitude towards people with disabilities. The study found that "age, educational attainment, and prior contact with someone with a disability predict attitude" (p.2178). Several studies cited by Scoir (2011) suggested that a laypersons' hesitancy to engage, is due in part to discomfort and anxiety around the potential interaction. From the results of this review, Scoir (2011) suggested the importance of controlling the quality of interaction. Several studies found that "positive contact can reduce social distance, while negative contact experiences can have the opposite effect" (p. 2179). The committee members of "*ALL Gods People*" are advocates for these individuals and understand the relevance that positive interactions have on the ultimate goal of *community inclusion* (Ault et al, 2013). Since committee members have an understanding that reaching our ultimate goal will take patience and time, we are committed to taking the time required to promote successful interactions.

PAR in the context of a faith based community. The researcher chose to implement a cyclical process of PAR adapted from one suggested by Taylor and colleagues (2004). A simple visual representation of this process was offered in the Project Methods and Procedures section (*Figure 1*), but was adapted again at the conclusion of the Capstone Project (*Figure 4*).

Figure 4 offers a clear representation of the cyclical process of PAR in this community context. In this particular project, the use of surveys, observational data and a guest speaker were some of the initial research tools used to identify problems. Leadership skills proved to be a vital element in the group dialogue, and the use of a Logic Model was a helpful tool in

Figure 4. Using the Cyclical Process of Participatory Action Research to Promote an *Inclusive Community* (Ault et al., 2013) within a Worship Environment.



Adapted for a second time from concepts offered by Taylor et al., 2004.

establishing the committees' course of action. Ultimately, the reflection component grew in importance as time elapsed because it promoted a deeper level of problem solving followed by more inquiry within the group. As the group addressed the physical barriers for the Worship goal, the more complex goals of Bridge and Serve came to the forefront and the group began to acknowledge the research and networking that needed to occur to address these objectives. The sustainability of the committee also began to rely much more on the reflection portion of PAR at this time. The committee could see that to accomplish an *inclusive community* (Ault et al., 2013) we must carefully consider the *inclusive practices* (Ault et al., 2013) we want church leadership to embrace. This process must also include the interim steps identified within the concept/systems map in order to be fully achieved. Finally, committee members learned through reflection that they must remain determined but patient in order to see their concept of an *inclusive community* (Ault et al., 2013) come to fruition.

Strengths and Limitations

The strengths within this Capstone Project were often simultaneously the source of weakness within the study. The committee participants included ten church members, most of which were caregivers of someone with a unique need. The researcher and co-facilitator was also a member of this faith-based community.

The fact that the researcher was a church member, created an element of trust among other stakeholders and church leadership. Researchers' who come from outside of the community entity, often experience difficulty in developing community partnerships (Blumenthal et al., 2013; Doll, 2010). A significant component of building a strong partnership is related to the researchers' cultural competence (Blumenthal et al., 2013). Since the researcher in this project had the same underlying spiritual values as the stakeholders on the committee, this served as an influence in the way meetings were facilitated and was a unifying element in building trust. By the same token, there was also a potential for bias to occur because the researcher is personally invested in the outcome of the research.

Most of the participants in the "*ALL God's People* Committee" were caregivers of someone who experiences a unique need. One individual also experiences a physical disability. While caregivers can offer insightful information about the barriers that exist towards creating an inclusive faith based community, the nature of PAR is intended for those who experience the marginalization. Ferguson and Nusbaum (2012) discussed the questions surrounding the active participation of disabled individuals in progressive community research and advocacy. While the role of disabled participants may vary, the inclusion of more disabled churchgoers would have strengthened the rigor of the Project. Since those participants did not volunteer, other methods of rigor were introduced. The project implemented the use of several strategies to improve rigor. These included the use of multiple data collection methods, stakeholder checks, intentional leadership skills to conduct the PAR process, and deep analysis of findings, which were further supported by the literature from other recent studies.

A final weakness worthy of mention is the researchers novice experience with the PAR process. Many authors agree that this method of research presents with multiple challenges (Blumenthal et al., 2013; Doll, 2010; Taylor et al., 2006). Leadership style is relevant in maintaining equal power among stakeholders, PAR typically takes much longer than traditional research methods to complete, and the theoretical application of the PAR process prevents the researcher from having a definitive process outlined from the outset of the study. The level of flexibility required is something that has to be learned and embraced. As a result, PAR is typically conducted by more experienced researchers over a longer period of time. The learning

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for this researcher occurred during the evolution and implementation of this Capstone Project, which may be considered a potential weakness.

Implications for Practice and Future Research

A recent study conducted by Carter and colleagues (2017) used community conversations to identify potential action items for congregations to consider in promoting an *inclusive community* (Ault et al., 2013) within a worship environment. As a result of the study, the authors promoted the idea that future studies might focus on "how congregations make decisions about which ideas to adopt and how they enact them within the life of their faith community" (Carter et al., 2017, p.592). This Capstone Project offers insight on how one committee within a faith community used a cyclical process of PAR to engage in reflection and decisions to promote this type of social change. Similar faith-based committees may benefit from and expand upon the knowledge gained in this Capstone Project.

Doll (2010) proposed that the profession of occupational therapy should learn to expand its interventions to natural community settings. Miller and Nelson (as cited in Doll, 2011) proposed that not doing so, may deprive society of the benefits of an occupational science approach. This Capstone Project offers the field of occupational therapy one example of an appropriate fit for community practice. Specifically, it offers an example of how an occupational therapist might promote advocacy skills in clients at the community level (AOTA, 2014). The Capstone Project further expands upon the potential role of leadership in occupational therapy by offering an example of one researchers' role as a co-facilitator and change agent using the method of PAR.

The use of PAR as a construct for research in occupational therapy has been proposed as a good fit for the profession because of two foundational concepts valued by OT: client centered practice and advocacy for meaningful occupation (AOTA, 2014; Blakeney & Marshall, 2009; Law, 2013). Law (2013) proposed that PAR is a viable research methodology because it offers the field a level of knowledge not typically obtainable through traditional positivist methods. In participatory research, the action-reflection process promotes change while also generating knowledge (Law, 2013). Furthermore, this knowledge emerges in the hands of those who are marginalized by the original problem, thereby empowering them to take ownership in selfadvocacy (AOTA, 2014; Blakeney & Marshall, 2009; Law, 2013).

At its inception, the guidelines for the implementation of this Project were vague at best. Law (2013) acknowledged "within occupational therapy, there has been little application of any one tradition of participatory research to develop new knowledge in our field" (p.80). True to her description, engaging in the PAR process has generated some new knowledge. As a result, implications for further research in the field of occupational therapy using the PAR process may prove beneficial.

Leadership skills are of paramount importance when the occupational therapist functions as a facilitator or researcher in PAR. An ability to apply concepts related to Emotional Intelligence (Walten, 2012) and Reframing (Bolman & Deal, 2013) as well as critically analyzing ones own interpersonal skills are helpful in equalizing power among a group of stakeholders. Additionally, the occupational therapist should consciously consider the theoretical constructs employed when moving a team of people toward an identified goal. Theory of Change Models (Stachowiak, 2013), Logic Models (Blumenthal et al, 2013) and Concept Mapping (Coffman & Reed, 2017; Meadows, 2017; ORSImpact, 2010; ORSImpact, 2013) were strategies used in this Capstone Project to offer the team a direction in their course of action. While these models offered an over arching conceptual direction, they also allowed for fluctuations in the action plan, which is a necessary component of the PAR process. The visual strategies involved in Concept Mapping assisted the team in measuring interim progress towards their daunting task of creating a more *inclusive community* (Ault et al., 2013). As occupational therapists continue to implement PAR as a method for research, we can share and expand upon our experiences with different conceptual models to promote a construct that is an appropriate fit for our profession.

Summary

The initial action plans and multiple methods of data collection outlined in this Capstone Project were helpful in measuring the degree of social change towards achieving an *inclusive community* (Ault et al., 2013), but they were not complete. A Concept / Systems Model (Coffman & Reed, 2017; Meadows, 2017; ORSImpact, 2010; ORSImpact, 2013) proved helpful in identifying and acknowledging the interim steps and interrelated components that were also needed to initiate this social change. By considering the four original goals (Worship, Prepare, Serve and Bridge) as an interrelated system, the committee began to learn through the PAR process that time and careful planning are necessary to offer individualized supports and the pleasurable experiences necessary to promote an *inclusive community* (Ault et al., 2013). The method of PAR served this committee well. Our knowledge grew as a result of the cyclical process that pushed the members to engage in reflexive dialogue. As a committee we continue to advocate for this mission of social change in our faith community. We hope others can learn from our experiences and use the information to develop more *inclusive communities* (Ault et al., 2013) in their faith organization(s).

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Appendix A: ALL God's People Survey

The Christ Church team ALL God's People is seeking information from churchgoers in order to effectively support persons of all abilities levels in our church community.

Our committee has chosen the language of "unique needs" in replacement of the term "special needs" as an attempt to be sensitive to those we hope to support. Many of us have a unique need, so this term is intended to include all devices or adaptations that may be needed to help individuals participate. Examples include (but are not limited to) large text, hearing amplification, help with mobility, a buddy to assist, or any other type of accommodation.

Your participation in completing this survey is completely voluntary, meaning you can decline participation if you choose. If you elect to participate, the information you offer will be anonymous and will be combined with answers from other participants to provide the *ALL God's People* committee with information they are seeking to make decisions.

1. Please tell us about your connection to Christ Church.

- O I am a member at Christ Church.
- O I attend Christ Church regularly.
- O I am currently looking for a church

2. Please select your age range.

- O 12 or younger
- O 13 to 17 years of age
- O 18 30 years of age
- O 31 49 years of age
- O 50 64 years
- \bigcirc 65 or older

3. Please select all that apply:

- O I am a caregiver or family member of a person who has a unique need.
- O I am an individual with a unique need.
- O As someone who attends this church, I know other attendees personally who have a unique need.
- O As someone who attends this church, I am aware of others who have unique needs, but I do not know them.
- O As someone who attends this church, I am not aware of anyone who has a unique need.

4. Please check the resources you or your loved one currently use at Christ Church. You may check more than one.

- O Large Print Hymnal
- O Large Print Bulletin
- O Church provided Listening Devices
- O Special Olympics Team that practices here at church
- O Braille Hymnals
- O Wheelchairs Provided at the Entrance
- O The Quiet Room in the Back of the Sanctuary
- O Sensational Kids Room

- O Children's Workers that Buddy with a Child
- O Buddies who assist others with Greeting, Ushering, and Music Involvement
- O Gluten Free Communion
- O Fragrance Free Balcony
- O Handicapped Parking
- O None of these
- O Other, _____

5. How comfortable are you in your understanding of others who have unique needs and your ability to interact with them effectively? Select the option that fits you best.

- O I am comfortable with acknowledging someone with a greeting.
- O I am pretty uncomfortable interacting with someone who has unique needs.
- O I find that I am uncomfortable when a person has many needs because I don't know how to interact.
- O I am comfortable with conversing or sitting with the person and / or their caregiver (or parent).
- O I would be willing to help a person or caregiver in getting a need met while at church.
- O I would be interested in learning how I could be more involved. Please share your name and contact info.

6. What factors would improve your comfort level and encourage interaction with this population? Check all that apply.

- O Education about what to expect
- O Meeting the caregiver and gaining information
- O An increased awareness of the need for me to reach out
- O I'm comfortable with my current interaction level

7. How important do you think it is for Christ Church to build an inclusive Christian community for persons with varying ability levels?

- O I had not considered this as a potential issue until I was asked to complete this survey. I do not see this as a need in our church community.
- O The church has many needs. This is important, but other items take precedence.
- O I would like to see our church move towards making everyone feel welcome and doing what needs to be done to make that happen.
- O This topic is so important, I would volunteer my time to learn more about what I can do to help. Please provide your name and contact information.

8. Is there a unique need keeping you or your loved one from becoming more involved at church? If yes, what is it?

9. Please list anything you would suggest in order to make our church better at involving people with unique needs.

10. Please select the unique needs of your loved one or yourself.

- O Memory problems
- O Physical or sensory impairment
- O Walking Safely
- O Vision
- O Hearing
- O Stamina needed to move about the church
- O Difficulty sitting still or often seeks sensory input that may seem unusual
- O Struggles with social interactions
- O Cannot communicate verbally
- O Difficult to understand
- O Intellectual capacity hindered, and needs support in this area.
- Medical needs, where precautions must be considered and / or followed.
- O Other (please specify)

LEADERSHIP ROLES: CREATING INCLUSIVENESS

11. Please identify the age of the person with unique needs:

- O Infant or Toddler
- O Child between ages 4 and 10
- O Age 11 to 18
- O Age 19 to 30
- O Age 31 to 60
- O Age 61 to 79
- O Over 80

Thank you for completing this survey. Please return to the reception desk by July 27, 2016.

Appendix B: Observational Data Regarding Building Accessibility

ALL Gods People – Accessibility Inquiry (April 2nd, 9th and 16th – Easter) Parking Spaces:

We have 45 total handicapped parking spaces – 8 of these are van accessible There may be more added to back area at youth center entrance.

Regarding **special parking** spots on some future date (for a courtesy shuttle idea) Melissa and Dan spoke about this – perhaps these people may park at portico side close to Hwy 42.

Data from 4-2-17 (spring break), 4-16-17 (Palm Sunday),4-16-17 (Easter) (Participants 1,2,3 and 4)

4-2-17 – Participants 1 and 2

Areas	8:30-9:00		9:30 - 9:45		10:00 – 10:15		10:45-11:00		11:00 – 11:15	
	Н	NH	Н	NH	Н	NH	Н	NH	Н	NH
Portico side			9	1	0	0			0 3	
Front of Church			12	20	0	0			0 3	
Children's side			4 55		1	1			2	1
Back side					N/A a few				N/A	5
New Lot Area					N/A	~10			N/A	~10

4-16-17

1 10 17										
Areas	8:30-9:00		9:30 - 9:45		10:00 – 10:15		10:45-11:00		11:00 – 11:15	
	Н	NH	H NH		H NH		Н	NH	Н	NH
Portico side			1111							
Front of										
Church										
Children's										
side										
Back side										
New Lot Area						I				

Areas	8:30-9:	00	9:30 – 9	:45	10:50 – 11:05			11:05 – 11:15	
	Н	NH	Н	NH	Н	NH	H NH	Н	NH
Portico side	9	10	8	9	17 12			7	1
Front of Church	8	7	1	0	10	9		2	4
Children's side	4	15	3	0	6	4			
Back side	n/a	15	n/a	1	n/a lots			n/a a few	
New Lot Area	n/a several		n/a several		n/a several			n/a a few	

Easter -	
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Other observations:

Participants 2 and 3: Front of church – door opener / thresholdParticipant 1:Benches?

Wheelchairs

(information offered via email from participant 4) we have 7
2 are kept by portico entrance
5 are kept in fellowship hall
More are in the preschool wing
3 have a wheelbase of 25.5"
4 have a wheelbase of 17"

Family Bathroom

Toilet sits 16 -17 inches high (this is without seat attached) Grab bars are installed (not sure where) There will also be a handicapped accessible bathroom in the children's wing – can be used during church hours.

Appendix C – Letter to Trustees: Automatic Door Openers

Dear Trustees:

As a co-facilitator of ALL God's People, I have been asked to write this letter on behalf of our committee.

Our group has been meeting monthly for a year and a half to work on meeting the mission of "creating an environment that is ability inclusive and empowers ALL individuals to be integrated and engaged at all levels of church participation - *worship, prepare and serve*" (Christ Church United Methodist, 2017).

As part of that mission, we often look closely at our church environment to try to ensure physical accessibility. The construction of family bathrooms were a recent example of decreasing environmental barriers for individuals with unique needs. The ALL God's People committee wants to take this opportunity to thank the trustees for accomplishing this objective.

Over the last several months, our committee has had several conversations and informal assessments regarding the potential need for automatic door openers in areas of the church where none currently exist.

This letter comes to you with the intent to communicate some of the committee's observations of several entrances that may be considered for handicapped accessible door openers. Thank you for giving us the opportunity to share our thoughts and observations with you.

Children's Wing:

With the exciting renovations going on in the children's wing, we feel it is important to communicate a rationale for accessibility sooner than later, since construction is well underway.

It appears that the main entrance on the children's side is on level ground, which is of course an important factor for wheelchair users and persons with mobility problems. Our committee would like to promote the idea of a handicapped door opener with a button for consideration as well.

A part of this rationale is not only to meet the needs of current churchgoers, but to communicate an openness to the community and potential churchgoers. The new entry way for the children's wing will welcome many families who may not attend our church during worship times, but our committee would like to represent the church as a community that is open to all.

Entrance at Memorial Hall:

This area may be a logical place for a handicapped accessible door opener due to the handicapped parking spaces nearby, the walkway without stairs, and it's appearance as a main entrance to the church. Since accessible doors will likely need to be prioritized, our committee is of the opinion that this door is one of higher traffic for those who may have mobility needs.

Those with mobility needs include not only wheelchair users, or those with walkers, but individuals with low endurance and decreased strength. Fifty-four percent of the respondents to our survey (conducted in the summer of 2016) were age 65 and over. When asked what types of unique needs were experienced, the problem of walking safely was selected by 36% of the 294 respondents.

The two main issues concerning the adaptation of the Memorial Hall entrance include:

- 1 The threshold where concrete meets the path has a rather large difference in height and may be difficult for some wheelchair users to get over.
- 2 The pathway itself is beautiful and relatively even, but may be cumbersome for those with walkers.

These issues are not necessarily a reason not to place a button at this entrance, but should be considered as a forethought to the decision.

Entrance directly off of the new sanctuary:

This door has been proposed as an entrance by one of our churchgoers who has mobility problems and fatigues quickly. The short distance from handicapped parking to the sanctuary is a valid point and a door opener may be beneficial, but making this entrance wheelchair accessible would be complex due to current steps and drainage needs. If this door were chosen for an automatic opener, a handrail may be beneficial.

The members of ALL God's People understand that financial budgets are difficult, but we feel that our committee's mission and the message our church wants to convey is important to consider. Families and individuals who have unique needs or physical disabilities are sensitive to the openness they perceive from institutions. Our committee feels that increasing our building's accessibility expresses our love and desire for these individuals to feel welcome in our building at all times. Thank you for considering our ideas as we all work to make Christ Church the best it can be.

Sincerely,

Susan Morreau on behalf of the committee of ALL God's People

Christ Church United Methodist (2017). Ministries: Unique and Special Needs [church website].

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Appendix D: Educational Speaker – Taryn Skees

SPECIAL EVENT



UNDERSTANDING DIFFERENCES AND GOD'S CALL TO KINDNESS FEATURING TARYN SKEES

Taryn is a wife, proud mom of 4 boys, friend, writer and public speaker. She currently helps communities/ churches/schools learn how to demonstrate genuine kindness, empathy, compassion and inclusion to persons and families who have differences. Co-sponsored by Adult Ministries and All God's People, join us to hear her real story, helpful instruction, and thoughtful inspiration.

WHEN AND WHERE

Sunday, January 8 10:05 - 11 am Fellowship Hall

www.ccum.net/care



Christ Church United Methodist • 4614 Brownsboro Road • Louisville, KY 40207 502.897.6421 • www.ccum.net

Appendix E: Focus Group Questionnaire

Focus Group Questions Follow Up to Taryn Skees Presentation

ALL God's People will be holding a follow up discussion from Taryn Skees presentation last Sunday (1-8-17). Please join us if you are interested! If you do not want to attend our follow up session but you do want to provide our committee with feedback, please complete the questions below and return to the reception desk. Thank you!

1. ALL God's People has a mission to enhance inclusiveness for ALL people at our church. How do you feel we are doing with this as a congregation?

2. How did the presentation make you feel?

3. Do you think that our guest speaker helped listeners have an improved comfort level with reaching out to people (and their families) with unique needs?

4. What did Taryn Skees share that was most influential to you?

Other comments that may be helpful to our committee:

Appendix F: Focus Group Results

Focus Group Questions / Results: 14 Respondents

Question one: ALL God's People has a mission to enhance inclusiveness for ALL people at our church. How do you feel we are doing with this as a congregation?

100% of respondents did report some level of improvement. Of those, some respondents had additional comments:

21% said we are off to a good start (perhaps suggesting that we have further to go) 14% stated we have made improvements – particularly by having this event 7% reported that our church was not doing bad before our efforts began.

Question two: How did the presentation make you feel?

Some respondents had more than one emotion that they highlighted, so the numbers below do not total 14.

5 respondents – Improved Compassion

5 respondents – Informed / Educated / Enlightened

2 respondents – inspired

1 respondent – fortunate (not to have similar problems)

1 respondent – sad (the respondent has a similar situation that did not result in positive outcomes)

Question three: Do you think that our guest speaker helped listeners have an improved comfort level with reaching out to people (and their families) with unique needs?

13 respondents - Yes
1 respondent - No
1 respondent had an additional comment: "Somewhat. Her talk helped to dispel fears."

Question four: What did Taryn Skees share that was most influential to you?

7 respondents – She offered us advice on how to handle a similar situation (meeting someone with a unique need and having questions or feeling awkward).

1 respondent – She inspired me because she took a difficult situation and made it positive with her mission.

2 respondents – Saddened that she (Taryn) still struggles.

 $1\ \text{respondent}$ – She made me think about the importance of advocating / asking questions regarding medical advice.

2 respondents – Her story as a whole was influential / how she dealt with her situation.

1 respondent – N/A

Appendix G: Caregiver-To-Caregiver Support Group Flyer



When my responsibilities shifted from my family role to that of a caregiver, I needed to receive encouragement through sharing my experiences and listening to the care giving experiences of others. - Karen, Christ Church Member

ABOUT THE CAREGIVER-TO-CAREGIVER GROUP AT CHRIST CHURCH

The CareGiver-to-CareGiver group is a lay-led group for anyone who cares for a loved one with unique needs... parent, spouse, adult child, sibling, extended family member or friend.

Opportunities to learn about the aging process, stress management, problem solving, self-care, setting boundaries, safety, long-term care, and more.

This program is facilitated by Jewish Family & Career Services with funding from KIPDA through the Older Americans Act and the Cabinet for Health Services.

WHEN AND WHERE

First Monday of each month

3 - 4:30 pm

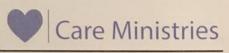
Room 253

CONTACT

Rev. Melissa Head, Associate Pastor 893-2201 x263 melissa@ccum.net Susan Basinger (703)946-0276 susanbase29@gmail.com

REGISTRATION

No registration required. If you cannot attend, but would like to receive information about this group, contact Rev. Melissa Head.



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Appendix H: Interview Questions for Caregiver – Pilot for the Bridge Goal Interview questions for participant 2.

- 1. What was your son's level involvement in church before the ALL God's People Committee was organized?
- 2. What steps have you taken to increase your son's involvement in the church?
- 3. Did you feel supported by anyone at the church as you pursued opportunities for your son?
- 4. Have you noticed any shift in support or openness in making efforts to get your son involved? Please share any applicable examples.
- 5. Is your son more involved now than he was in question #1? Do you think he would like to be more involved than he currently is?
- 6. As the committee moves forward to achieve the Bridge goal, are there any words of advice you would like to offer?

Appendix I: "Getting Connected" Informational / Interview Form Getting Connected

Getting To Know - ___

Christ Church United Methodist is committed to supporting individuals with unique needs as they become more involved in our church community. This form will help us get to know you, and help us provide the support to make that happen. This information will help us provide the best experience possible, and will be communicated, as needed, only with those involved.

- Parent/guardian/caregiver name (please circle) –
- ♦ Cell number –
- ♦ Email –
- Diagnosis, medical condition and/or learning difference -
- Allergies and/or food sensitivities -
- Allergies (life threatening) -
- ♦ What type of communication style works best -
- Behavioral plan What would you like to have happen when behaviors occur? (At what point do you want to be notified, what is best to do to keep behaviors from escalating, are there any behaviors that require medical attention, etc.) -
- Describe any physical restrictions/adaptations -
- Currently receives therapies and instruction for -
- Can do these things independently (eat, toilet, ask for help, talk, write, walk, etc.) -
- Needs assistance with -
- Uncomfortable with/aversion to (loud noises, being around several people, etc.)-
- Doing/seeing/experiencing this one thing is important -
- * Most relaxed when -
- ♦ What are some known areas of interest within the church (worship, prepare group, one-on-one activity, etc.) -
- Please add any other details/instructions/training that should be known -

Appendix J: Stakeholders Consent Form



Consent to Participate in a Research Study

LEADERSHIP ROLES: CREATING INCLUSIVENESS WITHIN A WORSHIP ENVIRONMENT

Why am I being asked to participate in this research?

You are being invited to take part in a research study about Participatory Action Research. You are being invited to participate in this study because you are currently a member of the committee *ALL God's People*. If you take part in this study, you will be one of about eight people to do so.

Who is doing the study?

The person in charge of this study is Susan Morreau, MS, OTR/L (Principal Investigator) an OTD student at Eastern Kentucky University. Susan is being guided in this research by Shirley O'Brien, Ph.D., OTR/L. Kelly Leigers, MS, OTR/L may also play a role on the research team at different times during the study.

What is the purpose of the study?

The purpose of the study is to learn more about Participatory Action Research (PAR). PAR is a type of research that seeks to empower stakeholders by systematically gathering and sharing information, taking action and reflecting on that action in order to promote social change (Cockburn & Trentham, 2002; Kielhofner, 2006). By doing this study, we hope to learn more about the effectiveness of this approach in order to share it with others who may be interested in using PAR as a research method to create change.

Where is the study going to take place and how long will it last?

The research procedures will be conducted at Christ Church United Methodist Church in Louisville, Kentucky. Regular meetings and activities will occur as part of this study and will be determined as the group works to achieve its mission. You will need to be an active member of the committee and attend as many meetings and activities as possible. Most of the meetings will last one and a half to two hours. The total amount of time you will be asked to volunteer for this study is two to five hours a month over the next six months.

What will I be asked to do?

The committee of *ALL God's People* has identified it's mission as: "creating an environment that is ability inclusive and empowers ALL individuals to be integrated and engaged at all levels of church participation - worship, prepare and serve" (Christ Church United Methodist, 2016a). The decision making process, plans for action, and considering the results of the data collected will be the components of this PAR. This cyclical process will be ongoing as the research continues

through August of 2017. As member of *ALL God's People*, you will be considered a participant in this capstone project. The following plans fall under the broad goals of the church and have been outlined as action steps and methods for data collection. The researcher will analyze the raw data and report back to the committee:

1) Worship—experiencing life-giving moments in God's presence. Through passionate prayer, inspiring music, and considering God's Word together, our hearts are refreshed and reoriented toward God each week (Christ Church United Methodist, 2016b).

The committee of *ALL God's People* (and the church community) wants to offer an inviting place of worship to people of all needs. The committee will work to improve accessibility, promote a family bathroom, improve parking, and address other identified short term goals obtained through a church wide needs assessment. As each item is achieved, the responsible committee member will report on the status of the goal and the committee will keep an ongoing list of accomplished tasks. This number will be used to quantify what the committee has done to improve worship opportunities to individuals with unique needs.

2) Prepare—pursuing a deeper understanding of God's love. In groups of 2 or more, we explore God's Word, asking questions that challenge and change us, so we can live as God's people in God's world (Christ Church United Methodist, 2016b).

The *ALL God's People* committee and the *Dig Deeper* committee will host an educational speaker on January 8, 2016. The committee contends that educating the congregation is an important aspect in building an inclusive church mentality. The speaker, Taryn Skees, is a local mother who speaks to groups about her family's journey with her son who has a diagnosis of Apert syndrome. Much of what she discusses revolves around how to interact with and respond to families who have a member with a unique need. The committee plans to ask for interested volunteers to join *ALL Gods People*. Follow up focus questions will be offered to random Sunday school classes that attended the event, to ascertain the impact on attitudinal barriers in our church community.

Serve—showing God's love in practical ways. We use the abilities God has given us to share His love, taking tangible action to serve and care for those around us (Christ Church United Methodist, 2016b).

ALL God's People will identify two subcommittees responsible for planning and coordinating services to the congregation and the community. One group will be the Caregiver-to-Caregiver Group, which will meet once monthly to support, educate, and offer resources to those who provide care to someone with a unique need. The second subcommittee will work towards a respite service titled the *Buddy Break Program*. This is a predesigned program designed to offer respite services to families one Saturday a month. This program will be adapted to meet the needs of this particular faith community and will require many church volunteers. The respite program will be a service to the congregation and the community, but will also offer volunteers growth in the area of empathy and comfort in interacting with persons who have a unique need.

Data for both programs will include a count of how many participants attend each month and optional comment cards offered to participants.

<u>Bridge</u>—bringing God's love to others every day. We constantly look for opportunities to show God's love to others in the normal activities of life (Christ Church United Methodist, 2016b).

ALL God's People will work alongside the associate pastor who is responsible for Care Ministries to create a method for matching churchgoers with unique needs to activities and mission projects that match their interest. Many of these individuals will also require some support to be successful. There are current members who work with a buddy to assist with the offering, serving as a greeter, and assisting with other duties during a Sunday service. ALL God's People has a hope of increasing volunteers to assist in creating additional opportunities for these individuals and others with similar needs. Our desire is for natural friendships to emerge and then transfer into other church activities. Data on this initiative will occur through documenting the story and status of each case and reporting back to the committee for feedback. No names or personal identifiers will be reported in this capstone project.

Are there reasons I should not take part or are there any risks?

There are no discomforts or risks anticipated since responsibilities will be no different than that of your typical voluntary efforts as a committee member.

Will I benefit from taking part in this study?

There is no guarantee that you will get any benefit from taking part in this study. However, you may learn more about effective group planning and implementation as part of participation.

Do I have to take part in this study?

You have a right to decline participation or withdraw from this capstone project at any time without explanation. If you decline or withdraw, your participation as a committee member are not contingent on participating in the capstone project in any way.

What will it cost me to participate?

There are no costs associated with taking part in this study.

Is there a payment?

You will not receive any payment or monetary reward for taking part in this study.

Who will see the information I give?

Your contributions as a participant will be combined with information from other participants in the study. When we write up the study to share it with other researchers, we will write about this combined information. You will not be identified in these written materials.

We will make every effort to prevent anyone who is not on the PAR team from knowing your personal contribution to the research. For example, your name will be kept separate from the information you contribute, and these two things will be stored in different places.

However, there are some circumstances in which we may have to show your information to other people. For example, the law may require us to show your information to a court (IF APPLICABLE: or to tell authorities if we believe you have abused a child or are a danger to yourself or someone else). Also, we may be required to show information that identifies you to people who need to be sure we have done the research correctly; these would be people from such organizations as Eastern Kentucky University.

What if I have questions?

Before you decide whether to accept this invitation to take part in the study, please ask any questions that might come to mind now. Later, if you have questions about the study, you can contact the investigator, Susan Morreau, MS, OTR/L at 502-235-4809. If you have any questions about your rights as a research volunteer, contact the staff in the Division of Sponsored Programs at Eastern Kentucky University at 859-622-3636. We will give you a copy of this consent form to take with you.

I have thoroughly read this document, understand its contents, have been given an opportunity to have my questions answered, and agree to participate in this research study.

Date

C ¹ C	•	1	• .1 . 1
Signature of	person agreein	o to take nar	t in the study
Dignature or	person agreem	5 to take par	i m mo study

Printed name of person taking part in the study

Name of person providing information to subject

Appendix K: PAR Questionnaire Participatory Evaluation Questions For Stakeholders

Instructions: Please respond to the three questions below by discussing how you perceive the committee's progress in reaching the mission and goals of *ALL God's People*. Please comment openly about your personal involvement in this process.

Mission: Creating an environment that is ability inclusive and empowers ALL individuals to integrated and engaged at all levels of church participation.

Goals:

Worship:	Decrease environmental barriers to make our facility physically accessible.
Prepare:	Decrease attitudinal barriers and improve compassion by educating the congregation.
Serve:	Reaching out to churchgoers and the community through caregiver support and respite.
Bridge:	Creating a method of support to involve individuals in church functions and missions
	based on their interests and needs.

- 1. Please comment on how you feel the committee is working to solve any identified problems and come to consensus on how to address those problems.
- 2. Please comment on how well you think the committee is doing in achieving its goals.

3. With 1 being little opportunity for input and involvement and 5 being open opportunity for input and involvement, please rate your personal involvement with the committee over the last two months. _____

(Optional) As a result of participating in this PAR process, do you feel you have learned any strategies that you would take with you in order to work effectively with a team of people?

Appendix L: Stakeholder Check PARTICIPATORY ACTION RESEARCH PROCESS AND RESULTS

Step I. Research to Identify the Problem

Conversations early on about personal or family member experiences within community (church) environments. Article presented by Susan that affirmed that real inclusion within churches is a nationwide issue.

Survey Results (June of 2016):

Who Needs Us? Two distinct groups: The aging population (physical and mental aging) and those who are not elderly, but have a diagnosis or delay of some kind.

Adaptations used at the time of the survey: handicapped parking spaces, quiet room, gluten free communion, assisted listening devices, a buddy to assist them in participating, wheelchairs, fragrance free balcony, Sensational Kids, large print hymnals

What is needed: improved sound quality in the sanctuary, improved acceptance / attitude (education, meeting the caregiver, learning about what to expect), sign language interpreter,

Specific Suggestions: education, matching individuals with opportunities, acoustics, support groups, parking, family bathrooms, service other than a Sunday, signing services, standing alter, assistance in getting around the church,

Observational Data on Parking Spaces and Accessibility (Conducted in Spring):

We have 45 total handicapped parking spots. 8 of those are van accessible.

Many people drop their loved one off at the portico.

We have 7 wheelchairs for use. We suggested they be placed near the doors for ease of use.

During our Sunday observations, there was not a lack of handicapped parking spaces.

People seemed respectful of their use / parked away if they had no sticker.

Linda and Susan analyzed the entrances/ thresholds / etc for automatic doors. This information was used in a letter to promote automatic door openers.

Step 2. Dialogue Regarding A Course of Action

Monthly Committee meetings, Wall Charts, Prioritizing, use of agenda and meeting minutes to stay focused on identified goals. *Aligning goals with Church wide goals*

Step 3. Organize A Course of Action and Engage in Data Collection

Worship / Address environmental barriers so that people can access the church

Data: 7 items

Increase and improve parking spaces promote the need for acoustics in the sanctuary to be addressed promote the need for a family bathroom request that Dr. Strunk encourage standing at communion for those who need it promote the need for automatic door openers request that wheelchairs be posted at the doors for greeters to offer weighted binder

Prepare / Educate our Congregation to improve empathy

1 - Taryn Skees and follow up Focus Group Questions:

14 Respondents:

100% of respondents did reported that our church improving in it's mission to enhance inclusiveness for ALL people.

33% of respondents stated that the presentation improved their compassion for families who experience a child with a unique need.

33% said that the presentation informed or enlightened them

14% were inspired

93% of respondents felt that listeners left with an improved comfort level for reaching out to people and their families with a unique need .

2 - Church member with Parkinsons presented to ALL Gods People which further influenced our list of tasks to achieve.

Serve / Caregiver to Caregiver and Respite (Buddy Break)

Caregiver to Caregiver group.

Aggregate data: 28 people have attended at some point.

Monthly meetings average attendance is between 9 and 15.

Group has been up and running since November 2016. The group has secured an outside facilitator through JCC. The group appears to be sustainable as the facilitator plans to continue into this year.

Respite.

Participant 1 and participant 6 went to visit Buddy Break and gathered information on how Buddy Break can work. We presented to our committee but other priorities moved to the forefront. Participant 6 continues to get emails and stay in touch with the program.

Bridge / Connecting individuals with activities in the church

Subcommittee worked to create an interview / informational form. Participant 6 presented this to the committee for approval.

The name "Getting Connected" was decided upon.

Step 4. Reflection

Our committee has made some great strides over the last 18 months. We are particularly proud of our ability to address several accessibility items and we feel that the Caregiver to Caregiver group is something to take pride in.

We are learning that goals intended to address environmental barriers are easier to achieve than goals that address attitudinal barriers. We have also seen that creating programs (such as Respite and Getting Connected) can be complex processes that take time.

We have learned that despite our eagerness, our goals require a process. Some tension around this encouraged communication about creating a process so momentum is not lost between approval from leadership and committee members. A process was created to encourage clear communication between monthly meetings.

We are a unique group that shares a common passion. We have become friends and often look forward to our meetings.

Current Data from PAR Forms from Stakeholders:

- Stakeholders often used the word "determined" to describe our group.
- Most of the respondents comment on goals the committee has achieved. Many have also observed that making progress on attitudinal barriers takes more time than addressing physical barriers. The stakeholders have also realized that some of our goals require creating a process that includes many steps. Each step has to be approved and embraced by the church leadership.
- Stakeholders describe the group as having open lines of communication, an ability to prioritize tasks, and an ability to be as involved as desired with implementing those tasks.
- The opportunity to participate is typically scored a 5. On four occasions it was given a 3 or a 4, but the reason was consistently due to lack of attendance by the stakeholder.

On our third and final Stakeholder input form, I would like for you to consider this question:

As a result of participating in this PAR process, do you feel you have learned any strategies that you would take with you in order to work effectively with a team of people?

Appendix M: Institutional Review Board: Exemption Status Document



Graduate Education and Research Division of Sponsored Programs Institutional Review Board

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EASTERN KENTUCKY UNIVERSITY Serving Kentuckians Since 1906

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NOTICE OF IRB EXEMPTION STATUS

Protocol Number: 000622

Institutional Review Board IRB00002836, DHHS FWA00003332

Principal Investigator:	Susan Morreau	Faculty Advisor: Dr. Shirley O'Brien
Project Title:	Leadership Roles: Crea	ting Inclusiveness within a Worship Environment
Exemption Date:	3/3/17	
Approved by:	Dr. Jonathan Gore, IRB	Member

This document confirms that the Institutional Review Board (IRB) has granted exempt status for the above referenced research project as outlined in the application submitted for IRB review with an immediate effective date. Exempt status means that your research is exempt from further review for a period of three years from the original notification date if no changes are made to the original protocol. If you plan to continue the project beyond three years, you are required to reapply for exemption.

Principal Investigator Responsibilities: It is the responsibility of the principal investigator to ensure that all investigators and staff associated with this study meet the training requirements for conducting research involving human subjects and follow the approved protocol.

Adverse Events: Any adverse or unexpected events that occur in conjunction with this study must be reported to the IRB within ten calendar days of the occurrence.

Changes to Approved Research Protocol: If changes to the approved research protocol become necessary, a description of those changes must be submitted for IRB review and approval prior to implementation. If the changes result in a change in your project's exempt status, you will be required to submit an application for expedited or full IRB review. Changes include, but are not limited to, those involving study personnel, subjects, and procedures.

Other Provisions of Approval, if applicable: None

Please contact Sponsored Programs at 859-622-3636 or send email to <u>tiffany.hamblin@eku.edu</u> or <u>lisa.royalty@eku.edu</u> with questions.

Kentucky

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