SCHOOL-BASED EXTRACURRICULAR ACTIVITY PARTICIPATION
OF HIGH SCHOOL YOUTH WITH DISABILITIES

BY

COLLEEN M GIBBONS

DISSERTATION

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Doctoral Committee:

Professor Brent McBride, Chair & Director of Research
Associate Professor Aaron Ebata
Associate Professor Jennifer Hardesty
Associate Professor Karrie Shogren
Abstract

The current study explored the participation of high school students with disabilities in school-based extracurricular programs. Survey data were collected from 71 high school youth from 10 different schools in East Central Illinois. Interviews were conducted with a subset of nine high participating students and nine low or non-participating students, followed by interviews with parents. Data were also collected from 150 coaches and youth leaders via an online survey. With respect to participation, student survey participants demonstrated no significant differences in activity participation by disability type, race, age, grade, or gender. Students participated in a range of activities, including prosocial, performance, team sports, school involvement, and academic clubs. Of the 71 students who completed the survey, 45.1% (n = 32) do not currently participate, 39.4% (n = 28) participate in one activity, and 15.5% (n = 11) participate in multiple extracurricular activities. Most students chose to participate based on interest in the particular activities, but most also experienced some form of barrier to their participation. In their interviews, student participants discussed societal participation barriers enacted by their school peers. Parents who were interviewed explained both societal and structural barriers, although more emphasis was placed on societal barriers, enacted not just by peers, but also coaches and activity leaders. Coach and leader data indicated that leaders recognize students encounter barriers to their participation, but often do not understand the ways in which their perceptions of disability shape some of the barriers students with disabilities encounter. In some instances, student participation was affected by family boundaries, and both impairments and societal barriers were cited by parents as they established family boundaries. Students’ reported roles in both extracurricular activities and within their families were relatively straightforward. Almost all students explained their roles without perceiving disability to be a major influence. This was not the case for parents, however, and many parents, specifically parents of children with more involved or visible disabilities, defined their roles in their children’s participation as being affected either by their children’s impairments or societal barriers, or both. While interview participants were selected based upon their level and range of participation, findings suggest that there are not substantive differences in the barriers experienced by students who are high participators, or students who are low participators. In general, students participate based upon their interests, and are facilitated in or discouraged from participating by parents based on established boundaries and roles. While there were differences
among students with disabilities in their experiences of barriers, establishment of family boundaries, and acting of roles related to participation, distinctive patterns among students who were high participators and students who were low participators did not emerge. In this sense, participation was a situational experience for students with disabilities, with each student negotiating his or her disability identity as participation occurred. Implications for further research as well as implications for families and school settings are discussed.
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Chapter One: Introduction

American youth participate in extracurricular activities and programs at high rates (Balsano, Phelps, Theokas, Lerner, & Lerner, 2009). Such activities cover a broad spectrum of youths’ interests, including sports, arts, religious activities, service programs, and academics (Eccles & Barber, 1999). Because of the diversity in available types of program activities, most typically developing adolescents are able to find at least one activity to enjoy and participate in with their peers during their leisure time (Balsano et al., 2009). Research indicates that such high levels of participation may not be as common in youth with disabilities, however. Recent research has shown that youth program participation of student with disabilities with their non-disabled peers is fairly limited (Carter, Sweeden, Moss, & Pesko, 2010b; Simeonsson, Carlson, Huntington, McMillen, & Brent, 2001). Such a lack of interaction with peers is not uncommon, as Wehmeyer (1996) posited, indicating that youth with cognitive disabilities often have little opportunity to demonstrate avenues of self-determination, which could include participation with peers in after-school programs of interest.

In light of the potential lack of involvement of youth with disabilities in programs cited above, the following questions can be raised: What does participation look like for high school students with disabilities? What is the relationship of disability and family on adolescents’ participation in youth programming? Recent statistics indicate that the prevalence of developmental disabilities in US children is as high as 15 percent (Boyle et al., 2011). What options are available for these youth? Are students with disabilities being included outside of the classroom? Do they choose to participate in their schools’ extracurricular activities?

To answer these questions, this study will use an integrated model incorporating the social-relational approach to disability with family systems theory. This model allows us to approach youth participation not only from a school and social perspective, but through the perspective of parents and family. Exploring the participation of high school youth with disabilities will provide greater insight into their lives and contribute to the sparse literature on extracurricular participation for youth in this population.

Results from this study will inform researchers, administrators, youth leaders, coaches, and policy makers on the participation and experiences of high school youth with disabilities. It will provide insight into their relationships and support, potentially providing for new avenues of
participation or ways to reach this potentially overlooked student population. In addition, it will be the first known application of this integrated theoretical model.

Definition of Key Terms

When referring to youth programs in the context of this paper, the hypothesis and subsequent research is limited to structured programs within a school setting (Feldman & Matjasko, 2005). All programs and sports chosen are run with adult supervisors or coaches who are likely to be teachers within the same school district. Examples of these programs include clubs and organizations, such as yearbook, band or orchestra, a school play, or student government. School sports and interscholastic sports led by coaches are also included within this study. While discussions of youth programs in general incorporate many other types of activities, including community based organizations, this study is limited to school specific programs and sports, with the assumption that the leaders and coaches have received professional training, have experience working with adolescents, and have had potential contact with students outside of the extracurricular activity.

When discussing youth participation, defining what participation looks like is essential. In this study participation is defined as the act of selecting, joining, and continuing to be involved in a specific sport or extracurricular activity. Such participation would necessarily look different depending on the type of program chosen (for example, being a member of stage crew in the school play or being on the soccer team). Additionally, as participation is likely to be more than just membership, level of participation should be considered in the participation equation (Weiss, Little, & Bouffard, 2005).

Definitions of disability will be discussed extensively in the following sections. However, for practical purposes, when discussing students with disabilities throughout this paper, reference is being made to students who have a disability as defined by schools. School definitions of disability are established in either an Individualized Education Plan (IEP) or a 504 plan, which is designed to prevent discrimination as a result of a disability.
Chapter Two: Review of the Literature and Theoretical Frameworks

Youth Activities and Sport

Research has consistently shown that extracurricular activities can be an avenue for positive youth development (Durlak et al., 2007; Fredricks & Eccles, 2006b; Larson, 2000). Extracurricular activity contexts for typically developing youth can provide opportunities for identity exploration, the cultivation of friendships with peers, and the establishment of mentoring relationships (Dworkin, Larson, & Hansen, 2003; Youniss et al., 2002). Different activity contexts may serve different functional purposes for youth participants, with the categorized participation types possibly leading to alternate outcomes by type (Barber, Eccles, & Stone, 2001; Broh, 2002). Another benefit of participation for youth is the association with positive peer groups, academic adjustment, and the development of psychological competencies (Fredricks & Eccles, 2006b).

With many different participation options, youth must make choices as to which activities they will join. Eccles and Barber (1999) identified five different categories of participation: prosocial activities, performance activities, team sports, school involvement, and academic clubs. Historically in youth program literature, sport participation formed the basis of research related to positive outcomes (Broh, 2002; Holland & Andre, 1987). As research in program participation widened to include other youth programming contexts, findings relating to youth participation in competitive sports activities were found to differ slightly in outcomes and relevance. Sports participation is the most popular of activity options for youth, which includes intermural and competitive interscholastic sporting activities (Mahoney, Cairns, & Farmer, 2003), with boys more likely than girls to participate in athletics (Antshel & Anderman, 2000).

However, having a diverse participation experience has been shown to be associated with the most beneficial outcomes for adolescents (Bartko & Eccles, 2003; Mahoney, Lord, & Carryl, 2005; Morris & Kalil, 2006), and youth who participate exclusively in sporting activities have fewer positive outcomes than those who participate in sports combined with additional activities (Linver, Roth, & Brooks-Gunn, 2009). Such findings may be indicative of the fact that different types of extracurricular activities provide different authentic learning experiences (Hansen, Larson, & Dworkin, 2003). Additionally, participation in a broad range of contexts may serve as a protective factor should youths encounter negative experiences in a particular activity, and participation may offset the lack of fit with youth in other contexts (Feldman & Matjasko, 2005).
Fredricks and Eccles (2006a) found that students who participated in a greater number of extracurricular activity contexts demonstrated higher levels of academic adjustment, psychological adjustment, and civic engagement, and lower rates of involvement in risk behaviors (including drug and alcohol usage) during adolescence.

Amount of time spent in activities may also affect outcomes related to involvement. In a 1995 study of adolescent time usage, students who spent 1 to 4 hours a week in extracurricular activities were less likely to drop out of school, and students who spent between 5-19 hours a week in activities demonstrated fewer risky behaviors (Zill, Nord, & Loomis, 1995). To be considered a participant, youth must not simply profess membership in a club, organization or sports team, but actively participate in the activities being performed (Weiss, Little, & Bouffard, 2005).

While positive outcomes relating to participation are heartening, this study does not focus on outcomes of participation, although similar positive outcomes may be possible for youth with disabilities. Rather, the study will attempt to determine what extracurricular participation of youth with disabilities looks like, including range of activity participation, intensity of participation, and choices of participation. But to explain what participation looks like for students with disabilities, it is first critical to define disability and the context in which it will be used in this research study.

Theorizing Disability

Historically, the overarching societal concept of disability has been static. Merriam-Webster (2011) defines the word disabled as “incapacitated by illness or injury”. For most, being labeled with a disability indicates a set state of being, in that one either has a disability, or one does not, with the disability limiting daily life and activities. This conceptual model of disability is referred to as the medical model, or occasionally the deficit model, in which a disability is seen as a diagnosis or label, with deficits needing to be overcome or fixed (Robinson & Stalker, 1998). Identification terms, such as “autistic,” “learning disabled,” and “retarded,” place the emphasis on the person as the disability, and medical model research often reflects such a basic conceptualization of disability.

The medical model of disability. This medical model of disability is the one most commonly adopted in the special education programs in school systems in the United States. Such conceptualization is used to frame services students receive, individual education plan
goals, and accommodations students are given in their schoolwork and testing. Framing disability in such a way fits the standardized education model that is in effect in the United States, in which students are expected to pass specific exams and conform to state-wide standards prior to graduation from high school, regardless of individual skill or ability.

In Illinois, specific disability categories have been established for labeling purposes in public school systems. Each student with an IEP has a specific categorical label. These labels include: autism, cognitive disability (which has recently been reclassified from the previous label of mental retardation), deaf-blindness, deafness, emotional disability, hearing impairments, multiple disabilities, orthopedic impairment, other health impairment (which can include ADD/ADHD), specific learning disabilities, speech or language impairment, traumatic brain injury, and visual impairment (Illinois State Board of Education, 2011). Throughout this paper, I will use cognitive disability and intellectual disability interchangeably. Each of these categories is framed by specific explanations used to define the disability and classify students who may have these impairments. Such methods of disability categorization are standard in the medical model.

The social model of disability. In recent years, following the civil rights and feminist movements, a group of disability theorists have rejected the medical model of disability, labeling it “disablist,” and have reframed disability as a social construction (Goodley & Lawthom, 2006; Shakespeare & Watson, 1998). To proponents of this social model of disability, referring to someone as a disability status is a form of discrimination, with disability being a creation of society, rather than an inherent medical, emotional, or physical condition. Those who promote the social model of disability refer to people with disabilities as a minority group, similar to racial or sexual minority groups, and believe that society disables an individual by creating a sense of “other” due to the presence of differing abilities.

The social-relational model of disability. The research conducted in this study uses a model that extends beyond both common models, with a more recent approach to the concept of disability, referred to as the social-relational model of disability (Goodley & Lawthom, 2006). As this is a developing model, there are several differing terms in current literature that refer to the same basic theoretical concepts (the bio-psychosocial model of disability (World Health Organization, 2001), the psychosocial model (Woolfson, 2004) and the capability model (Reindal, 2008)), but for consistency and clarity within this paper social-relational model of
disability is the term that will be used. The social-relational model of disability (Goodley & Lawthom, 2006) incorporates elements from both the medical model of disability (Chilman, Nunnally, & Cox, 1988), and the social model of disability (Barnes, Mercer, & Shakespeare, 1999).

The social-relational model acknowledges that people with disabilities have impairments in some areas of their life due to the nature of their disability (Goodley & Lawthom, 2006). In this way, the social-relational model is similar to the medical model because there are specific activities that are likely to be limited by the impairment itself. In conducting research on youth program participation by students with disabilities in public schools, for these youth, having a disability is a fact, and is documented in an IEP or 504 Plan. But, the ways in which awareness is given to disability infuses the social-relational model and separates the actual impairment from others’ perception of the disability label. By recognizing the social elements in the concept of disability, the social-relational model also incorporates aspects of the social model of disability. To more fully explain the social-relational model, it is important to explain the two key pieces of its definition: impairment and barriers.

**Impairments.** Impairments are restrictions that result directly from the disability itself. Such impairments can be either physical or intellectual, and would include an inability to do certain things related to the disability (Murphy, Carbone, & the Council on Children with Disabilities, 2008). In the case of a physical impairment, a youth in a wheelchair would not be expected to be a gymnast. A youth with cognitive or intellectual disabilities would likely not participate in math league as a result of his or her intellectual impairment. The social-relational model recognizes that such limitations are indeed a result of impairments due to the nature of the youth’s disability; however, it does not concede that such impairments equal the entire definition of disability. Some youth with autism may be considered to have social skill impairments, as this is a direct result of their disability status (Schall & McDonough, 2010). In looking at the social-relational model of disability, it is important to recognize that the impairments that are present in persons with disabilities are only part of the complete definition of disability. Limitations experienced by people with disabilities that are not a result of personal impairments are termed barriers.

**Barriers.** The social-relational model recognizes the presence of additional limitations routinely faced by people with disabilities that do not stem from their impairment; these
limitations are known as barriers (Goodley & Lawthom, 2006). According to the social-relational model of disability, barriers are obstacles that are in place as a result of restrictions within society, and can generally be seen as structural (including physical obstacles) and social (such as avoidant interpersonal encounters) (Goodley & Lawthom, 2006; Tremain, 2005). Sometimes these two types of barriers are referred to as “barriers to doing” and “barriers to being” (Connors & Stalker, 2007).

**Structural barriers.** As their name suggests, structural barriers are physical limitations that youth with disability experience as a result of their environment. Youth program literatures reference potential barriers to participation that all youth could face (Feldman & Matjasko, 2005), but in this case, these structural barriers are a specific result based upon the presence of the disability. Youth with disabilities may experience structural barriers as they attempt to participate in youth organizations due to lack of transportation (Carter et al., 2010a; Connors & Stalker, 2007), segregated schools (Connor & Ferri, 2007), supplemental costs of participation (Murphy et al., 2008) and inaccessible areas (Goode, 2007; Murphy et al., 2008). Such structural barriers are often straightforward and relatively easy to identify. However,remedying structural barriers may be a difficult fix, possibly requiring expensive changes in architecture, such as those at universities in Goode’s (2007) study of youth with disabilities in their first year of university study. Similarly, transportation issues may not be considered for many non-disabled youth as they begin to learn to drive, some youth with disabilities are not able to obtain a driver’s license, and are therefore limited in their ability to access programs joined by their peers (Connors & Stalker, 2007). The presence of structural barriers creates substantial issues in the potential participation of youth with disabilities. In a survey examining leisure participation of youth with mild intellectual disabilities, Buttmer and Tierney (2005) found that both youth and their parents cited structural barriers (“not having a place nearby,” “not having a means to get there”) as obstacles in their pursuit of leisure activities.

While structural barriers and societal barriers are examined separately in the social-relational model, some authors make the argument that they may work interchangeably to create each other. For instance, in Goode’s (2007) study of 20 British college students with disabilities, she raises the idea that experiencing structural barriers creates environmental exclusion for some students, which then causes an “invisibility” which leaves students hidden from view, eventually to be forgotten by their peers. Such experiences may give students
without disabilities the perception that youth with disabilities do not want to or are unwilling to participate, thus creating a societal barrier.

**Societal barriers.** Societal barriers are more conceptual than structural barriers. Sometimes referred to as stigmas, attitudinal barriers, or interpersonal barriers, societal barriers may result in youth with disabilities being socially segregated or victims of hurtful treatment due to attitudes demonstrated by peers or adults that are a result of generalized disability stereotypes (Moses, 2010; Murphy et al., 2008). Societal barriers are not always verbalized, and may be reinforced without realization through actions including looks and stares (Hall, 2004). Labels such as autistic, mentally retarded, and learning disabled often carry attached stigma, with socialized meanings that have implied behaviors or disabilities attached. Because expectations for the abilities and behaviors of the person with the disability are attached to the label, as opposed to knowing and valuing the actual abilities of that individual, youth with disabilities may become accustomed to being treated differently than their peers without disabilities. Over time, as disability stereotypes are internalized by persons without disabilities, societal barriers are reinforced (Castañeto & Willemsen, 2006; Coates & Vickerman, 2008; Schall & McDonough, 2010). In their study of 200 college students in an introductory psychology class, Castañeto and Willemsen (2006) hypothesized that social stereotypes of disabled people as helpless may lead students to negatively rate their peers’ perceptions of youth with disabilities. The perception of the person as inseparable from the disability creates a social barrier for participation by making individual differences and abilities unimportant and irrelevant.

Youth with disabilities may experience societal barriers from peers or adults, including youth activity leaders or coaches (Schall & McDonough, 2010). In a study examining the ways in which afterschool care is available to youth with disabilities, Jinnah and Stoneman (2008) found that fear and lack of training in program leaders often led to the exclusion of children with special needs. Such an unavailability of program options could be considered a structural barrier; however, it is the attitudinal and system-wide exclusion of youth with disability that indicates the presence of a social barrier. Without appropriate training and education to deal with youth with disabilities as individuals, discrimination based upon stigmatizing labels causes barriers for all youth with a specific disability status. Activity leaders’ lack of awareness of the functional skills and strengths demonstrated by individual youths with disabilities can lead to exclusion from programs that may otherwise be accessible (Schall & McDonough, 2010).
Societal barriers can also come from within, as a form of “internalized discrimination,” in which youths with disabilities experience frequent negative feedback from teachers, parents, and others. This consistent negative feedback can cause self-doubt and a sense of internalized inferiority, creating a barrier to future participation (Sanders, 2006). In Hall’s (2004) examination of the experiences of inclusion and exclusion of 21 Scottish adults with learning disabilities, he indicated a process of self-exclusion or withdrawal in which people with disabilities no longer frequented places where they expected to experience social rejection or “othering” as a result of their disability status. In Watson’s (2002) analysis of identity and disability, adults with disabilities who blamed their impairments for all their day-to-day problems were likely to internalize personal barriers and limit their activities beyond the restrictions imposed by the impairment. Such internalized barriers are considered socially created.

The ability to differentiate impairment from the larger “disability” allows for a greater recognition of the roles outside influences play in shaping the lives of youth with disabilities. By using the social-relational model of disability in framing this research, differences can be explained and barriers can be identified to determine what may hinder youth with disabilities’ integration into program activities with their non-disabled peers. However, it is important to remember that these youth are not independent, but operate within a family unit. Influences of family, specifically, the operation of the entire family system, are likely to play a key role in the ability of youth with disability to participate in youth programs. Although the social-relational model addresses impairment and societal barriers, it does not look at what may be the most critical support system available to youth: the family. For this reason, family systems theory is also an important theory to consider in the creation of an explanation of what participation looks like for youth with disabilities.

**Theorizing Family**

To be able to fully address the question of participation by adolescents with disabilities in youth programs, inclusion of a theory addressing family is essential. Many youth with disabilities retain family bonds longer and rely on their families more frequently than do their typically developing peers (Powers, Singer, & Sowers, 1996; Trainor, 2008). Because of this strong connection within the family, it is important to identify ways in which parents encourage, discourage, support, or ignore participation by youth with disabilities. The most appropriate
theory to address this parental involvement is family systems theory. Incorporating family systems theory will allow me to explain the influence that parents have on the participation and involvement of their children with disabilities in afterschool programs (Sanders, 2006; Thomas, 1998).

*Family systems theory* developed out of general systems theory. In defining family systems, each member is a separate entity with individual characteristics, and it is these individuals and their relationships and interactions with each other that combine to create the larger family system as a whole (Broderick, 1993). The family is viewed as a system, as the functions of one family member directly impact the functions of the other members. Actions taken by a family member directly affect other members, and cause compensatory reactions from other members. The conceptualization of family as a system indicates that the family becomes the unit of attention, as opposed to the individual, as every action influences another. Within the family system are subsystems, including marital, parental, sibling, and extended family (Turnbull & Turnbull, 1996). Subsystems are a substructure of the greater family system, as these relationships and interactions in essence form smaller systems. For purposes of this analysis, when discussing the family system, I am referring to the parental subsystem, which consists of the parents and their child with a disability (Altiere & von Kluge, 2009; Broderick, 1993; Seligman & Darling, 2007).

Each family system is defined by boundaries that are developed within that system, and through the interaction of the family and outside systems. Boundaries are the family’s way to include and exclude elements from the system. The more open a family’s boundaries, the greater the influence from outside systems, while more closed boundaries indicate a more tight-knit and self-contained family system. The concept of boundaries is used to interpret spatial boundaries, and more importantly, a symbolic family domain, which would include family meanings and world views (Broderick, 1993; Seligman & Darling, 2007).

Family systems theory is a complex theory, and due to scope and size constraints, several aspects related to family systems will not be addressed specifically within the proposed research. For purposes of explaining the ways in which disability and family affect participation of adolescents with disabilities in youth programs, two specific concepts will be applied: boundaries and roles.
**Boundaries.** In considering youth participation, it is important to address family boundaries, which guide the interactions and relationships between individual family members and outside systems (in this case, the programs, schools, and society). Family boundaries can be open or closed, or anywhere along the continuum. Optimal boundaries differ for each family, with the goal generally to maintain affiliations of family members, while appropriately allowing growth and transition as members mature and develop (Broderick, 1993).

The permeability of family boundaries varies from one family to another. Some families have very open boundaries, in which family members freely interact with others outside the family without much restriction, while other families have tight limits on what activities family members are involved in, and who interacts within the family system. In more closed families, the rules strictly regulate where members go, while in contrast, in families with permeable boundaries, family members may come and go as they please (Broderick, 1993).

Frequently, closed family boundaries are the result of a desire to “protect” and care for family members with disabilities (Hall, 2004). Sanders (2006) explains that overprotection by parents is often intended to shield their children with disabilities from difficult challenges, discrimination, or hurtful attitudes in society. Sanders presents these closed boundaries as being more harmful than good, in that such overprotection in fact causes passive, dependent behavior in youth who are capable of learning responsibility and acceptable behavior. However, Lippold and Burns (2009) argued that in families of youth with more severe intellectual disabilities, more closed family boundaries were in fact protective and created a stronger, albeit smaller, network of caring supporters.

When looking at families of youth with disabilities, boundaries may also be impacted by cultural norms and beliefs. In some families, lack of knowledge about disabilities, or cultural beliefs that the presence of disability is shameful, may cause boundaries to be impermeable, as was the case with groups of Chinese immigrants in the United Kingdom (Sham, 1996). Such rigid boundaries may be detrimental to youth with disabilities, as they are unable to experience activities or events with age appropriate peers, causing social isolation.

Boundaries are not unchangeable; in fact they tend to be modified as a result of familial experiences and interactions with those outside the family system. Sivberg (2002) hypothesized that in families of children with autism, high amounts of stress and a lack of social support tend to create highly enmeshed families, as family boundaries tighten and interactions outside the
family diminish. Similarly, parents in Murray, Kelley-Soderholm, and Murray’s (2007) study were found to be affected by challenges and a lack of resources, but several parents were able to form connections with other families with similar experiences. In this way, familial boundaries were found to be more permeable as a result of the youths’ disabilities.

**Roles.** Roles are expected patterns of behavior demonstrated by individuals within the system and are formed through interactions of family members on a daily basis (Turnbull & Turnbull, 1990). Roles within each family system are defined by both the individuals playing them and other family members, in that roles are shaped both by expectations of others and the actual demonstration by individuals. Individuals may play multiple roles within the family system, with acted roles differing depending on situation. Specifically, I have chosen to focus on these aspects because they can all be affected by elements from outside the family system (such as program leaders, peers, and aspects of society as a whole), yet these elements are critical building blocks within the family system.

Roles within the family have been established over time, but are changeable given different circumstances (Turnbull & Turnbull, 1990). One example of the changing nature of roles within the family was highlighted in a specific case study of a family of a child with a disability. O’Connor (1995) described the actions of this family to place disability in a context where all family members have different needs, rather than continuously prioritizing the child with the disability. In this way, the family was able to maintain “traditional” roles of parents and child, with occasional modifications necessary when the child’s impairment affected family interactions.

Not all family roles are fluid and based upon actual abilities of family members. Woolfson (2004) describes familial roles based upon a parental view that their child’s disability is a tragedy. She explains that parents may play a placating role, attempting to make up for the disappointments in their child’s life that may result from having a disability. Such an indulgent role by parents would likely lead to non-age appropriate roles acted out by youths with disabilities, as parents tolerate problematic behaviors in their children.

Youth with disabilities may expect parents to play a role of protector or caretaker (Lippold & Burns, 2009). In families of children without disabilities, such a role would likely diminish as a child ages and begins to demonstrate independence through experiences such as participation in programs outside the family system. However, in families of youth with
disabilities, parents may continue to act out a protective role even as children enter high school and beyond. Such a protective role may be appropriate, as the child’s impairment may lead to the child’s delayed development of independence. However, the opposite may be the case, in that the child desires to play a more independent role, and may be capable of playing a more self-sufficient role, but may be limited by the actions of his or her parents (Knapp, Perkins, Beecham, Dhanasiri, & Rustin, 2008).

Parents and youth programs. Youth program literature has begun to examine the impacts parents have on the participation patterns of their typically developing children (see Morrissey & Werner-Wilson, 2005). Parents, while not directly involved in activities within youth programs, have impacted their children’s participation in various ways, and it is common for youth program literatures to include aspects of family support in determining why youth choose to participate (Huebner & Mancini, 2003). Parental support and encouragement of program activities can positively influence participation, affecting youth engagement within the program (Larson, Pearce, Sullivan, & Jarrett, 2007). Conversely, parents who hinder participation in programs, or negatively portray programs after youth have chosen to participate, often lead to negative participation effects, including program drop out (Dworkin & Larson, 2006; Persson, Kerr, & Stattin, 2007). These patterns of parental behavior may look different as we examine the ways in which parent participation and disability merge to determine youth program participation for adolescents with disabilities.

The social-relational model in family systems literature. It is true that there is ample literature that addresses disability and family in various settings. Family systems and disability are a logical research link. So why does the proposed research specifically focus on the social-relational model of disability? In family studies literatures, there is often a theoretical discussion when relating to family (quite often using family systems theory), but disability status is rarely, if ever, theorized. As an example, Bayat (2007) discusses factors of resilience in families with autism. He presents autism as a label, and his discussion references the ongoing changes within families as they come to term with a diagnosis of autism for their children. Such perceptions of disability are common in family studies articles, in which the authors fail to differentiate ways in which the impairment that the child has is separate from the barriers that the child and his/her family will face. The social-relational model of disability would argue that such barriers may be the result of societal generalizations pertaining to the meaning and impact of autism within a
family. Had Bayat chosen to look at patterns of resilience through an analysis of impairment effects and barrier experiences, he likely would have been better able to differentiate how patterns of resilience were tied to factors impacting children and families with autism (Goodley & Lawthom, 2006; Reindal, 2010).

Similarly, Jinnah and Stoneman (2007) examine disabilities and their effect on the family system, explicitly outlining barriers parents face as they search for after school care for their children with disabilities, but they never reference a concept of disability beyond the disability label. Had the authors applied the social-relational model of disability, including both impairment effects and structural/societal barriers, there would have been a greater ability to understand how the system of afterschool care could more effectively service children with disabilities. In what way does the actual impairment limit availability, as opposed to barriers resulting from misinformation, poor training, or stigma (Moses, 2010)? In creating a study integrating the social-relational model of disability and family systems theory, an examination of how relevant terms overlap and can be examined is necessary. To do this, each of three important terms (barriers, boundaries, and roles) is outlined according to how it is demonstrated both within the activity or sport and the family setting, and how these terms relate to the overall participation of youth with disabilities.

Integrated Concepts

Barriers. Use of the term barriers is common in literature on youth programs. In their paper offering participation strategies for youth with disabilities, Carter et al. (2010b) discuss specific barrier categories that may be experienced by youth, and contrast these barriers with opportunities. While the term barrier is specific within the social-relational model, in analyzing the discussion of participation of youth with disabilities, it becomes evident that barriers, both structural and societal, exist at many levels.

Barriers present within the youth program. Two specific forms of barriers are outlined within the social-relational model. Structural barriers within youth programs are often present for youth with more physical disabilities, but may not be as common for youth whose impairments are intellectual or cognitive. Although structural barriers may be less prevalent among adolescents with intellectual disabilities, they are still present. One example of a structural barrier would be if a potential participant needed an augmentative communication
device as a result of his/her impairment, and the device was unavailable at the program site, thus restricting participation (Barnes, Mercer, & Shakespeare, 1999).

Societal barriers to participation are likely higher for youth with intellectual disabilities than youth with physical impairments. Cavet (1998) explains that a lack of social acceptance for people with learning disabilities is common in their experiences of leisure. Moses (2010) indicates that the presence of a disability label generates less friendly and less tolerant behavior from same-age peers. Given these findings, we could expect that societal barriers would include negative responses from same-age peers who may adopt generalized expectations based upon disability labels. Such barriers are likely to be influenced by peer interactions in other common settings, including classrooms and school common areas.

It is also possible that differences in environmental settings could lead to a different set of barriers experienced by youth with disabilities. While normally developing youth may be accustomed to seeing youth with disabilities as peers in classroom interactions, youth programs are often thought of as an option for friends, not classmates. Barriers to participating may be greater in youth programs, because although interactions between those with and without disabilities are expected in a classroom environment (Carter et al., 2010b), cross-group relationships are currently not the norm in afterschool program settings (Watkins, Larson, & Sullivan, 2007).

It is also the case that program leaders may be enforcing societal barriers. Lack of appropriate training or inexperience in dealing with youth with intellectual disabilities may cause program leaders to adopt misconceptions about participation of youth with disabilities (Lippold & Burns, 2009). Such misconceptions and a lack of awareness can cause youth with disabilities to feel unwelcome or out of place (Castañeto & Willemsen, 2006). Societal barriers enacted by program leaders have been addressed preemptively in some successful afterschool settings, such as in one high school in which a principal held an in-service training demonstrating effective inclusion of youth with disabilities using staff from a local inclusive community recreation program (Carter et al., 2010b).

**Barriers and the family system.** It is possible that structural barriers may exist within the family system. An example of this could be lack of transportation by the family to a youth program related event, limiting participation for the child with the disability. However, most structural barriers do not appear to be specific to families.
While looking at educational and occupational aspirations of youth with disabilities, Burchardt (2004) indicates societal barriers that youth face if their parents are less educated, or uninformed as to the operating mechanisms of the school and program setting. Parents may unintentionally promote societal barriers by failing to support appropriate development of their children with disabilities, particularly if they limit their children by failing to set achievable expectations based upon the actual, rather than the perceived, abilities of their child (Sanders, 2006). If parents accept social stigmas related to disability labels, rather than view their child as a unique person with abilities impacted by impairment, they may create new barriers or enforce existing barriers to participation for their children with disabilities.

The influences of social perceptions related to disability status can also affect the way parents allow their children with disabilities to participate. Barriers to participation may include parental expectations of negative reactions from non-disabled peer program participants, or an ungrounded perception that their child would be unable to adequately perform in the program due to rejection by peers (Ryan, 2005). Such barriers are considered societal because they are often the result of stigmas and attitudes related to disability stereotypes (Moses, 2010). Barriers enacted by parents could be expected to lead to closed or tightened family boundaries.

**Boundaries.** In discussing family systems, the concept of family boundaries is presented as an explanation of the way in which a family functions to allow or reject participation outside of the family system arrangement. To demonstrate an integration of family systems theory with the social-relational model, I will outline ways in which boundaries exist in youth activities and the family, and present an explanation of why such boundaries are critical in looking at the ways in which youth with disabilities are able to participate fully in youth programs is presented. For continuity purposes, boundaries within the program setting are presented first, followed by boundaries as experienced within the family.

**Youth program boundaries.** Boundaries are created in a youth program setting in a variety of ways. Because the type of structured youth club and sport activities considered in the proposed research take place in a school setting, the natural boundaries established for all participants, regardless of disability status, would include a requirement that the youth be a student within the school, and be a participant in the particular program activity. Boundaries established in such a way would be considered rigid.
Beyond the program specific boundaries of participation, boundaries are established by activity participants and the activity leader or coach. As Carter et al. (2010b) define ways in which youth programs are able to be made accessible for potential participants with disabilities, they highlight the importance of the actions of the youth program leader in helping to create an environment in which boundaries are open enough to allow for participation of youth with disabilities, and yet closed enough to create a cohesive and meaningful experience for youth participants.

Jinnah and Stoneman’s (2008) study of organized afterschool care available for younger students with disabilities outlines program boundaries that are so rigid that programs do not allow for any participation of youth with intellectual disabilities. In fact, according to one parent, there was “nothing offered” (p. 973). Such closed boundaries indicate that those who create and run youth programs buy into societal stigmas tied to disability, leading to social exclusion for youth with intellectual impairments.

**Family system boundaries.** As explained in the section on family systems, there are many reasons that families create a range of open to closed boundaries. When looking at family system boundaries as they relate to program participation, however, it is important to identify the ways impairments shape the development of such boundaries, and whether system boundaries are impacted by barriers in place within society.

Family systems boundaries may expand, contract, and change as a result of participation outside the family system by children with disabilities (Canary, 2008). Murray et al. (2007) explains that by encouraging youth with disabilities to participate in extracurricular settings, parents of children with disabilities were able to forge connections with other families who had similar situations, thus expanding family boundaries. A gradual opening of family boundaries may also be likely to occur as children with disabilities experience acceptance within an afterschool program, especially if parents are looking to encourage outside peer relationships (Schall & McDonough, 2010).

This fluid nature of boundaries is especially noticeable in support situations. Certain impairments experienced by youth with disabilities create a need for social training or support. Research by Turnbull and Turnbull (1996) indicated the loosening of boundaries as families became more comfortable with the presence of outside support, including supports available within a school setting. Conversely, Smith et al. (2010) found that family boundaries would
close as parents felt the need to take care of and support youth with disabilities. Such fluidity of boundaries is logical. If youth are encountering barriers to participation within an afterschool program, it may be the case that family boundaries would contract as a protective measure to prevent harm to the child with a disability. Similarly, if youth are comfortable and supported in an afterschool program, it is likely that family boundaries would become more flexible, encouraging youth to experience positive participation opportunities.

Roles. Roles as experienced and enacted by youth were introduced and defined above in a family system context. Again, roles occur within many systems, including the youth activity and sport setting. In this section, I explain how the concepts of acted and expected roles may play a part in youth program participation for adolescents with disabilities.

Roles within the youth program. Roles within youth activities are affected by both participants and program leaders (Feldman & Matjasko, 2005). Additionally, roles are often program specific, with more structured programs (e.g. FFA, student government) having more clearly defined and regimented roles. Because programs are very diverse, it is impossible to define all the various individual roles youth could play. Instead, this literature review focuses on the general role of peer and co-worker within the youth setting (within clubs, activities, and sporting environments). It is also important to note that roles within the program may be affected by additional relationships that carry over from the day-to-day school environment.

In youth programs, roles are likely to be socially influenced, possibly being impacted by social stigmas and misconceptions related to disability labels. If participants have not had previous opportunities to interact on a personal level with peers with disability, it is quite possible that expected (negative) societal roles could be enacted within the youth program setting. Reeve (2006) refers to this as a form of “psychosocial disablism” in which the person with the disability is regarded by others as someone to be feared and avoided. Such a role would not be desirable, but could be possible, and is not an uncommon topic in disability narratives (Baines, 2011; Gere, 2009; Shaw, 1998; Thomas, 1998).

Roles within a youth program setting are also heavily influenced by program leaders. Ideally, roles played by youth would be shaped by well-trained leaders, who fill the role of facilitator and program guide. One mother who had positive experiences with her daughter with disabilities participating in the same settings as her non-disabled son said, “If the people involved are aware of her, they are always delighted to help. A positive attitude is paramount”
(Cavet, 1998, p. 101). Carter et al. (2010a, 2010b) also propose that educators and leaders need to play a role in developing the supports necessary for inclusion of youth with disability. As youth with disabilities become more fully integrated into program activities, it is possible that the role of the leader would change to one of supervisor, rather than providing special support. Murphy et al. (2008) propose a scaffolding effect, in which leaders are trained in modification to accommodate impairment, while also being trained to understand and be aware of the barriers faced by youth with disability.

**Roles and the family system.** Expected family roles are those roles that the youth play within the family system (Moses, 2010). While active roles within a youth program are established and maintained over the course of an afternoon or semester, family system roles are defined over periods of years, and have ingrained patterns of actions that play into the ways in which youth would be able to participate in external programs (Thomas, 1998; Turnbull & Turnbull, 1996).

**The Current Study**

**An integrated model.** When examining the experiences of adolescents with disabilities in youth programs, it is important to recognize the multiple roles of youth as individuals, family members, program participants, and members of society as a whole. In formulating key questions to define and guide this research, application of the framework integrating the social-relational model of disability and family systems theory is critical.

**Research questions.** I identified two research questions that, when defined, were expected to lead to a more nuanced explanation of the participation of youth with disabilities in extracurricular school-based activities. This study seeks to answer the following questions:

*Research Question 1: What does participation look like for high school students with disabilities?* This first question is framed by two sub-questions, and was addressed using student survey data.

*Research question 1a: What factors predict participation for students with disabilities?* According to Simeonsson and colleagues’ (2001) analysis of the participation of students with disabilities, differences in gender, race/ethnicity, and age were not found to be significant predictors of participation; however, students with disabilities in very small schools and very large schools were found to have low rates of participation. Wagner et al.’s (2004) findings that boys were more likely than girls to participate in sporting activities is consistent with findings
from general youth program literature (Antshel & Anderman, 2000). These findings were considered in examining this question, but, due to its exploratory nature, no specific hypotheses were formulated for this subquestion.

Research question 1b: To what extent does impairment type (disability label) impact participation? Certain types of impairments have been researched more than others. According to a broad national study by Wagner and colleagues (2004), differences in disability type were predictors of differences in levels of participation, with students with learning disabilities participating most frequently, and students with autism participating least. Simeonsson et al. (2001) reported similar findings in their survey of teachers who work with children with disabilities. Expected outcomes in this study were hypothesized to be similar to these studies, with impairment and level of impairment affecting youth’s participation differently.

Research Question 2: In what way do barriers, boundaries, and roles impact participation for students with disabilities? Similar to research question 1, this question was addressed by specific subquestions, which encompassed the ideas of barriers, boundaries, and roles as experienced by youth with disabilities. While the first research question builds upon established research in its hypotheses, the second question is based upon limited prior research, and in general was structured to explain relevant findings.

Research question 2a: What are the structural and societal barriers that youth with disabilities experience, and in what way do these shape participation of students with disabilities? Current literatures related to extracurricular program participation of youth with disabilities often inferentially reference barriers that youth experience. Hypotheses related to barriers experienced by youth with disabilities are based upon such literatures, with the current study designed to address barriers explicitly. I hypothesized that structural barriers related to transportation may be an issue for youth with disabilities, potentially limiting their participation. Expected societal barriers to participating included peer misconceptions about participation of youth with disabilities (Lippold & Burns, 2009), which may lead youth with disabilities to feel unwelcome or out of place (Castañeto & Willemsen, 2006), potentially leading to decreased participation, or cause youth to choose a different activity.

The influence of program leaders in creating or eliminating societal barriers is also be explored in the current study. I hypothesized that program leaders and coaches have the potential to influence barriers positively or negatively, with this possibly being impacted by the
experiences and training leaders have had in working with youths with disabilities (Carter et al., 2010b).

Research question 2b: In what way do family and program boundaries affect participation of students with disabilities? I hypothesized that the effect of family boundaries would vary for youth with disabilities, depending on the context and the family’s level of support. Research by Turnbull and Turnbull (1996) indicated the opening of boundaries as families became more comfortable with the presence of outside support, including supports available within a school setting. Conversely, Smith et al. (2010) found that family boundaries would close as parents felt the need to take care of and support youth with disabilities. Such fluidity of boundaries is logical. If youth are encountering barriers to participation within an afterschool program, it may be the case that family boundaries would contract as a protective measure to prevent harm to the child with a disability. Similarly, if youth are comfortable and supported in an afterschool program, it is likely that family boundaries would become more flexible, encouraging youth to experience positive participation opportunities. These concepts are explored in this question.

Research question 2c: In what way do acted and expected roles play a part in youth program participation for students with disabilities? Because little is known about the types of roles performed by youths with disabilities as they participate in extracurricular activities, the current study will examine roles as performed by youth within the family and within the activity setting. Due to the limited previous research related to youth roles in this context, a specific hypothesis is not warranted for this subquestion.

In answering these research questions, I have focused on three important considerations. First, it is essential to determine what students’ participation looks like on a broad scale. The model needs to utilize the social-relational model of disability, by differentiating youths’ impairments from barriers they experience due to being adolescents with disabilities. While these youth do have impairments (this is a given), they also have personal desires, interests, and abilities that need to be addressed when explaining why they would choose to participate in programs.

Second, in this age group, youth who participate are still living at home and are highly likely to be part of a functioning family system, which impacts the choices these youth make and the level of independence they have to make individual choices. For this reason, in the
integrated model used in this study, the influence and/or involvement of family is purposefully addressed, specifically when identifying boundary structures and role definitions.

Finally, there must be an understanding of the ways in which the school and society (in this case, peers of students with disabilities and their coaches/leaders) impact participation, either through the absence or presence of structural and societal barriers. Although these three steps do not explicitly define the youth's presence in the greater society as a whole, the societal barriers that youth, parents, and program peers and staff experience are, by definition, presumed to be shaped by larger societal structures.

Diagram A was proposed as a conceptual image to illustrate this integrated model. In this proposed conceptualization, overlapping elements combine to create participation possibilities for students with disabilities. To effectively answer these posed questions, and therefore explain the ways in which boundaries, barriers, and roles are created, acted, and enforced, analysis will include data from surveys and interviews. Students with disabilities, their parents, and club/activity leaders and coaches share their knowledge through surveys and interviews. The use of multiple data sources in this study allows me to explain both proposed questions by providing a deeper understanding of data collected.

Diagram A.
Chapter Three: Methods

This mixed methods study was based on surveys and interviews that involved youth, parents, and activity leaders/coaches who interact with high school students with disabilities. The surveys and interviews were completed across 11 different high schools over a period of nine months, during the 2011-2012 school year. I was granted preliminary access to 15 targeted schools, with surveys and/or interviews eventually being conducted in 11 schools. Data collection techniques included surveys of youth with disabilities, surveys of activity leaders and coaches, and interviews with youth and their parents.

Recruitment

Making contact with schools. To determine participating schools, I identified all high schools in the eastern central Illinois area within an hour and a half drive from Champaign, and used census data to obtain school population data. From this larger list of schools, 20 school districts were identified as possible recruitment sites. My goal was to recruit participants from 15 total schools, with schools ranging in size from small to large, across a variety of urban/rural settings. The schools I targeted ranged from larger, urban high schools with their own special education programs and varied after school activities, to smaller, rural schools with fewer activities offered, and special education services offered through cooperative agreements with other local districts.

Initial recruitment involved contacting each school district or individual school, generally through the high school principal or coordinator of special education. I made arrangements to meet individually with a contact person at each school, usually the principal, but occasionally meetings were held with a special educator, assistant principal, social worker, or the director of athletics. Each contact person was given an informational handout as well as a letter of introduction, which outlined my research background and the proposed topic and general organization of the research to be collected. Of the 18 schools in which I made contact with a person, 17 of the contact people agreed to meet. Two contacts declined to recruit at their schools after we met in person; one felt their school was too small and the logistics were too difficult, and one declined because I was not able to provide large enough compensation to the school. Fifteen schools expressed interest in participating in the spring of 2011. IRB approval was granted in July, 2011, and the Office of School University Research Relations confirmed the study in September, 2011. IRB documentation is provided in Appendix A. Although I
established initial contact with 15 schools in the spring of 2011, when data collection began in the fall, some schools were no longer accessible for data collection, due either to a change in leadership, failure to get final approval from the school board, or a lack of interest once data collection began. The total number of schools at which I received final consent to recruit participants was eleven. Table 1 lists schools that initially agreed to participate in the spring of 2011, along with final recruitment numbers of students and coaches/youth leaders.

### Table 1. School Survey Participation

<table>
<thead>
<tr>
<th>School</th>
<th>Student Participants</th>
<th>Coach/Leader Participants</th>
<th>Enrollment 9-12</th>
<th>Census Classification</th>
</tr>
</thead>
<tbody>
<tr>
<td>School 1</td>
<td>2</td>
<td>6</td>
<td>205</td>
<td>Town: Distant</td>
</tr>
<tr>
<td>School 2</td>
<td>N/A</td>
<td>N/A</td>
<td>1534</td>
<td>City: Small</td>
</tr>
<tr>
<td>School 3</td>
<td>8</td>
<td>16</td>
<td>1549</td>
<td>City: Small</td>
</tr>
<tr>
<td>School 4</td>
<td>14</td>
<td>20</td>
<td>1269</td>
<td>City: Small</td>
</tr>
<tr>
<td>School 5</td>
<td>12</td>
<td>14</td>
<td>1611</td>
<td>City: Small</td>
</tr>
<tr>
<td>School 6</td>
<td>2</td>
<td>8</td>
<td>219</td>
<td>Rural: Distant</td>
</tr>
<tr>
<td>School 7</td>
<td>9</td>
<td>20</td>
<td>869</td>
<td>Town: Fringe</td>
</tr>
<tr>
<td>School 8</td>
<td>10</td>
<td>17</td>
<td>1060</td>
<td>Town: Distant</td>
</tr>
<tr>
<td>School 9</td>
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<td>N/A</td>
<td>541</td>
<td>Town: Distant</td>
</tr>
<tr>
<td>School 10</td>
<td>3</td>
<td>14</td>
<td>605</td>
<td>Town: Distant</td>
</tr>
<tr>
<td>School 11</td>
<td>8</td>
<td>13</td>
<td>788</td>
<td>Town: Fringe</td>
</tr>
<tr>
<td>School 12</td>
<td>3</td>
<td>12</td>
<td>476</td>
<td>Rural: Fringe</td>
</tr>
<tr>
<td>School 13</td>
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<td>10</td>
<td>450</td>
<td>Town: Fringe</td>
</tr>
<tr>
<td>School 14</td>
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<td>N/A</td>
<td>325</td>
<td>Town: Distant</td>
</tr>
<tr>
<td>School 15</td>
<td>N/A</td>
<td>N/A</td>
<td>466</td>
<td>Town: Distant</td>
</tr>
</tbody>
</table>

^1This school neglected to mail consent forms to parents. They were found on a countertop three months after they had been labeled and stamped for delivery.

**Recruiting student and parent participants.** Student participant recruitment was ongoing throughout the fall semester 2011, with each school handling the recruitment procedure in a slightly different way. To recruit student participants, some districts required approval from their school boards, some required principal approval, and some required approval from the special education coordinator. Final survey recruitment was completed in January, 2012. Student and parent participants were recruited via direct postal mailing to the parent of each youth who met the inclusion criteria.

The inclusion criteria for recruited student participants included high school youth with disabilities between the ages of 14 and 21. Although the general age for high school students ranges from 14 to 18, special education regulations allow for a free and appropriate public
education through the end of age of 21 for students who are eligible; therefore the maximum recruitment age of student participants in this study was set as high as 21 years of age. Youth were considered eligible for the project if they were in grades 9-12, had either an Individualized Education Plan (IEP) or a 504 action plan, and were mainstreamed or included in at least one class with their general education peers. Eligible students who met these criteria were identified by special education coordinators, principals, or teachers at each site, with the consent form sent home to parents. Final student eligibility was confirmed by returned parent informational sheets, with confirmation by the schools to verify disability status and classroom inclusion.

Recruitment of student and parent participants involved the distribution of an informational flier to potential student participants in their classrooms, followed by mailed parental consent letters from the school to the parents of eligible students via the US Postal Service. A total of 1141 consent letters were mailed with an introductory cover letter from the school principal or lead special education teacher. Consent letters were then signed by parents and returned using enclosed addressed and stamped envelopes. The signed parental consent form granted consent in four areas. The consent form allowed student participation both at phase one (the survey data) and phase two (the interview), as well as consent for parent interviews, and for the audio recording of both student and parent interviews. Student assent was collected at the outset of the survey, either in hard copy or electronically, according to the survey format. The sample of student participants for the survey was eligible youth who were identified by completed parental consent forms and fit the additional inclusion criteria.

Demographic and initial disability information was collected from parents via a form attached to the parental consent. Attached to the consent form, there was an information sheet to be completed and returned, which provided demographic data including household size, income, educational level, race and ethnicity. I intended for the parents to also indicate their child’s disability status, but this apparently was not clear to several parents. In instances where parents did not volunteer disability status on the information sheet, I called parents using the telephone number provided on their consent forms. These collected data were then matched to student data using a unique ID code for each student. A sample information sheet is included in the recruitment materials in Appendix B. The informational questionnaire was returned by parents along with the signed parental consent form in an enclosed pre-stamped envelope. See Table 2 for data from the family questionnaire.
Exact response rates are impossible to calculate, because each school handled recruitment a little bit differently. Some schools told me a general number of envelopes to prepare, and then labeled the envelopes themselves. Other schools allowed me to label the envelopes on site, without providing exact numbers. Overall, I prepared 1176 envelopes to be mailed home. A total of 1141 are presumed to have been mailed out, and 83 signed consent forms were returned.
The final student sample comes from ten high schools in the Central/Eastern Illinois region, because one of the eleven schools forgot to mail the stamped and addressed student recruitment letters. Of the 83 returned consent forms, there were 71 total student survey participants. Six students had moved or dropped out when the survey was conducted, four students did not fit the inclusion criteria of being included in classes with students without disabilities, one student declined to participate, and one student was suspended indefinitely from school during the survey collection process.

**Recruiting activity leaders/coaches.** Activity leaders and coaches were recruited from 11 schools, with survey data collected from 150 leader/coach participants. See Table 1 for coach and leader participation by school. Potential activity leaders and coaches were identified by school administrators. Schools either provided me a list of email addresses for activity leaders and coaches, or distributed the survey link via email to their own internal list. Each leader/coach was contacted via email and sent a link to complete the survey. Every current leader or coach and every leader or coach who had control of a youth sport or activity within the previous year was eligible to complete the survey. Consent for youth leaders was obtained electronically at the outset of the leader survey. General demographic data were collected in the leader survey, with most of the coaches and leaders being teachers or administrators either in the high school where students were recruited, or other schools within the same district.

**Procedures**

Data in this study were collected via student surveys, student interviews, parent interviews, and coach and leader surveys.

**Student surveys.** Student participants completed a one-time online or paper survey, as determined by each school. Research has shown that there are no differences between collecting data through web-based surveys and paper-and-pencil surveys (Ritter, Lorig, Laurent, & Matthews, 2004), so it was left to the preference of each school to determine which survey format they felt best fit their students. Students were supported by classroom teachers or aides when taking the survey, unless schools requested that I administer the survey individually to students. The web-based survey portion of the study was hosted by SurveyGizmo.com and all electronic responses were collected through their website. Confidentiality of participants was taken very seriously. SurveyGizmo.com has a secure website, and no names were attached to
any data collected either online, or via paper survey. A sample student survey is attached as Appendix C.

The survey was designed to give a broad picture of the participation experiences of the youth in this study. The survey itself did not include the word disability, nor was it designed in such a way that students knew they were selected as a result of their disability status. Students first provided very basic demographic information (gender and grade in school), and then completed information about their current participation, past participation, and expected future participation in extracurricular activities, including clubs and sports. Surveys were school-specific, so youth participants were only able to select from participation options that were actually available at their school. There were also blank spaces available to fill in activities that may not have been listed, but were currently available at their school. These spaces were occasionally used for new clubs or activities. There were also questions that asked about the amount of time and frequency of student participation in activities.

Three additional survey questions addressed students’ perceptions of participation; the first asked why students chose to participate in activities (how they felt, and why they joined); the second asked about why students stopped participating, and the third asked about why students didn’t join in activities or sports in which they had expressed interest. Similar, more detailed questions were asked as follow-up in student interviews. These questions were designed to quantify participation barriers that youth with disabilities experienced.

**Student interviews.** Data obtained from student surveys were merged with demographic data provided by parents in the information sheet returned with consents. These combined youth and parent survey and demographic data were used to identify student interview participants using extreme case and intensity sampling techniques (Patton, 1990). Targeted interview participants were selected from youth who had high levels of participation across multiple categories (prosocial activities, performance activities, team sports, school involvement, and academic clubs; Eccles & Barber, 1999), as well as youth who had low levels of participation, or indicated no participation at all.

Following completion and analysis of the student survey data, I identified youth and parents to participate in semi-structured interviews. Potential interview participants were identified by students’ participation levels, which was measured by a varied activity participation total. Participants ranged from youth who participate in multiple activities, to those who did not
participate in any school-related extracurricular activities. Separate parent interviews were conducted following the completion of student interviews.

The interview sample of student participants and parents was gleaned from survey participants, following analysis of the survey data. The goal of the interviews was to explain and describe the participation patterns of youth who do not participate at all (or participate extremely minimally), along with the participation patterns of youth who were involved in very high levels of activities and sports. For this reason, the initial youth survey data was analyzed, and interview subjects were chosen based upon their levels of participation. Participants for student and parent interviews were selected based upon levels of student participation in a range of extracurricular activities. Student activities were identified as falling into one of five types of activity categories, as identified by Eccles & Barber (1999). These categories included prosocial activities (e.g., Key Club), performance activities (e.g., drama), team sports (e.g., basketball), school involvement (e.g., Student Council), and academic clubs (e.g., Spanish Club). Student participation was quantified by summing participation across each of these categories, and then ranked according to the number of categories participated in, creating a varied activity participation total. Using the varied activity participation total, interview participants were selected from students who had the highest activity participation total, and the lowest.

Interview participants were selected using a combination of extreme case and intensity sampling, both forms of purposeful sampling. According to Patton (1990), in extreme case sampling:

The researchers and intended users involved in the study think through what cases they could learn the most from and those are the cases that are selected for study…The evaluator may focus on studying and understanding selected cases of special interest, for example, unexpected dropouts or outstanding successes. In many instances more can be learned from intensively studying extreme or unusual cases than can be learned from statistical depictions of what the average case is like (p. 171).

Using extreme case sampling, I identified the top nine participators according to the varied activity participation total. Students who scored the highest were identified and contacted for participation. These students were the extreme participators, although the range of current participation reflected in these identified students was between five and two activities. To select lower participators, I used the intensity sampling method, because I was interested not only in
those who did not participate at all, but also those who reported low participation. Students who were identified using intensity sampling were students who had low scores (or no score) on the intensity participation variable. Patton (1990) describes intensity sampling:

Intensity sampling involves the same logic as extreme case sampling but with less emphasis on the extremes. An intensity sample consists of information-rich cases that manifest the phenomenon of interest intensely (but not extremely)…Using the logic of intensity sampling, one seeks excellent or rich examples of the phenomenon of interest, but not unusual cases (p.171).

Nine students were selected using intensity sampling, including 6 who according to the varied activity participation total, indicated no participation at all.

I conducted 18 total student interviews, and 15 parent interviews. Of the three parents who did not complete interviews, one hung up the phone every time I asked for her by name, and she had not provided an email address; one mother made an appointment for an interview, canceled it, and when I called again her telephone number and email address were no longer in service; and one mother set up an interview, canceled it, and never returned calls or emails again, despite repeated attempts.

Interviews occurred at locations convenient to the students and parents. Student interviews were conducted individually at the school, in a location arranged by the school contact person (teacher, principal, or special educator), at a time convenient to the student. During two student interviews, teacher aides were present; and one student was interviewed in the same room as the special education teacher due to unavailable space elsewhere. Parent interviews were conducted individually in the home or at another mutually accessible community setting (ie., a public library, coffee house, Dairy Queen). Of the 15 parent interviews, all but one were conducted with only mothers. One parent interview included both mother and father. During one parent interview, the student I had interviewed was also present in the room.

Interviews took place in spring and summer, 2012. Students were interviewed first, in May and June, 2012. Parent participants were identified based on the youth sample, and were interviewed in June and July, 2012. I intended that each youth interviewed would also have a parent interviewed, but my final numbers were 18 youth interviews, and 15 parent interviews (16 total parents). Parents interviewed were 14 individual mothers and one mother/father pair.
Surveys of activity leaders/coaches. Survey data were collected from school club and activity leaders and coaches during the 2011-2012 school year. The goal of the activity leader survey was to expand upon the youth and parent data for Research Question 2a, which focuses on structural and societal barriers youths with disabilities face in participation in activities. Although interviewing activity leaders and coaches would have been ideal, such an undertaking was beyond the scope of this study. Instead, program leaders and coaches were administered an open-ended survey, which gave me a basic understanding of their perceptions of the participation of youth with disabilities (Tierney & Dilley, 2002). In addition to collecting basic demographic information, survey questions were designed to assess the leaders’ openness to participants who have disabilities, and to determine if program leaders enforce or diminish barriers to participation. Leaders were also asked about their perception of the roles students with disabilities play in their sport or activity, and their perceptions of their school’s priority of having youth with disabilities participate. A sample leader survey is attached as Appendix D.

Data

Student surveys. For student participants, survey data were transferred to an excel file, double-checked for entry issues, and merged with completed online surveys. Demographic information obtained in the parent consent attachment was matched and added to these data, along with data collected from parents pertaining to the disability label of their children. These merged data were then imported into SPSS 17.0, at which point all data were cleaned and checked for outliers.

Preliminary analyses involved computing descriptive statistics (e.g. means and ranges) for all variables. Special focus was placed on the five identified participation categories from Eccles and Barber (1999): prosocial activities, performance activities, team sports, school involvement, and academic clubs. I summed participation within each of these categories separately, and then created a composite participation total (varied activity participation) which summed across all five participation categories.

The survey also measured student participation according to frequency and duration of participation. I anticipated that student responses to open-ended survey questions related to frequency and duration of participation would provide information as to the commitment level of each student to their activities. Frequency was assessed as number of times a week a student participates, and duration was assessed by the hours spent in activities and sports per week.
These data as self-reported by students were unclear and student responses varied so greatly it was impossible to create a variable that provided meaning to student responses. Part of the difficulty in assessing frequency and duration could have been from multiple types of participation; however, even students in similar types of activities reported widely varying responses. Therefore, these two variables (duration of participation, and frequency of participation) were not used to create an aggregate overall participation variable, which was part of the initial analysis plan. Instead, varied activity participation became the key method used to quantify student participation, and to subsequently identify interview participants.

Research question 1, “What does participation look like for high school students with disabilities?” was initially proposed to be explored using regression analysis. Correlations were conducted among demographic variables including gender, family income, parental education, parents’ marital status, number of children in the home, students’ years in the district, race, and mainstream/inclusion status. None of the correlations were found to be significant, possibly because of low sample sizes. To explain what participation looked like for students who completed the survey, I instead present descriptive data, found in Chapter 4.

In the proposal process, I had anticipated that the number of student participants would be significantly higher. The final response rate for parent consent appeared to be just over 7%, which resulted in survey participation numbers that made statistical analysis difficult. As this was an exploratory analysis, and since literature about the potential predictors was inconclusive, no specific predictions about participation were made at the preliminary stage. Survey data were used to guide the subsequent sampling process and to focus information for the interview questions. The quantitative data also adds depth to the interview explanations relating to student participation, specifically looking at questions relating to types of activities and reasons for student participation.

Data from the analyses of the student survey were used to inform the development of final interview protocols prior to conducting parent and student interviews, specifically in modifying each interview protocol to reflect on the reported participation activity of the student being interviewed. For example, if a student reported they were involved in student council, I would ask about that student’s participation in student council. Initial interview participants were selected based upon survey participation levels through the varied activity participation total. Using extreme purposive sampling, students who were highest participators were selected
to be interviewed. Students who participated in only one activity, as well as students who did not participate (including students who had never participated) were selected using intensity sampling, as determined by students’ varied activity participation total.

**Interviews.** Qualitative interviews were conducted with students and their parents, to expand upon and augment the data obtained in the surveys. Rubin and Rubin’s (2005) model of interviewing was followed, which highlights the relativism of culture (complementing the concepts of impairment and disability) and the importance of interviewee voice. In order to explain the ways in which students with disabilities participate, the words and ideas of these youth, and their parents, were explored, as they are the ones who experienced the reality in question (Tierney & Dilley, 2002). The study utilized individual in-depth interviews, which focused on the participatory interests of students with disabilities, the role of parents/family, the perception of impairment, and availability of support. Semi-structured, in-depth interviews, by design, involve “more active listening than aggressive questioning” (Rubin & Rubin, 2005, p. 10). For example, I asked the students to describe their typical day, to tell me about their activity participation, and how they felt about their experiences as they related to their disability status. This type of questioning allowed the interviewees to reveal what was important to them, and allowed them to establish their own definitions of participation and its importance.

The interview protocols were flexible and provided room for me to probe on issues of relevance to the study without being too personal. There were times when it became apparent that the student or parent being interviewed was having difficulties understanding a question. In such instances, I was often able to rephrase the question to allow for better understanding by the student or parent. In-depth interviews allowed me to directly engage with students and parents, and created an environment of trust, allowing students and parents to be at ease while discussing sometimes sensitive topics.

Student interview length ranged from 9 minutes to 51 minutes, with a mean length of 33 minutes. In one interview, the student became visibly upset, and we did not complete the final few remaining questions on the protocol. Student interviews were completed using one of two interview protocols, depending on levels of student participation. Parent interview length ranged from 25 minutes to 3.5 hours, with a mean length of 65 minutes. Parent interviews also varied depending on the level of student participation; one protocol was developed for students who were high participators, and one for students who were low or non-participators. Interview
protocols for each interview category are provided in Appendix E. Each interview, regardless of protocol, consisted of six sections; however, the sections were different for youth and parents.

**Student interviews.** The youth protocols began with a general overview, with questions to lay a foundation about school and leisure enjoyment. This section was designed to establish rapport with the participant as well as get a general background about the youth. Participants were then asked about specific organization participation, with detailed questions about current activities (or lack of activity). These participation questions established the student’s current program participation experiences, and addressed social and structural barriers the youth encountered, as well as the student’s perception of his or her role in each activity. The third section asked about student interests, what and who influenced their choices, and how they picked activities. The third section continued to address barriers the youth may have faced, boundaries, and roles, but in a more general sense, without specifically relating to specific organizations as in the second section.

Section four targeted family systems processes, by focusing on families and the ways in which the youth interact with and within their families. Specific questions were asked to address decision making and familial roles, as well as the youth's perceptions of family boundaries. The fifth section addressed the participants’ disabilities, specifically each student’s impairment. When conducting interviews, instead of initially asking about a student’s disability, I asked if the student had an IEP, to which all participants replied in the affirmative. This allowed me to modify subsequent wording according to each student’s response. This was the first section in which individual impairments and disability status were addressed.

The final section of the interview asked about youths’ feelings of being supported, and finished with two questions related to youths’ sources of support, which were hypothesized to be potentially influenced by boundaries or barriers. The interviews concluded by asking the participants if there was any additional information that should be shared. In several interviews students volunteered additional information after being asked. One student, who had talked throughout the interview about her great group of friends, when probed for additional things I should know about her, volunteered that she was constantly harassed and bullied by a small clique in her school. Another student discussed his upcoming heart transplant, and yet another student used the opportunity to talk about his parents’ recent divorce.
Parent interviews. Parent protocols were designed to overlap with student protocols in some of the six sections. The first section served as a general introduction and again assisted in developing rapport. I asked general overview questions, including the number of children the interviewee had, birth order of the student participant, and the student participant’s relationship with school and its importance. The second section explored the parent participant’s own school participation, their parental role in their child’s participation, sibling interactions, and family activities, in an attempt to develop information about established family boundaries. The third section addressed the student’s friendships and peers, including introducing the idea of impairment and the disability label, and how it may have impacted student friendships. Section four covered additional impacts of disability, and asked about the barriers faced by youth and parents both in the participation process and in general, in addition to questions about youth roles. Section five returned to the school setting but asked questions about the parent’s experience as a parent within the school and school district, to gather additional information about potential barriers. The sixth section asked what sources of support were available to the parent. The parent protocol, similar to the student protocol, ended with asking participants if there was anything else that they would like to share. Again, this question provided opportunities for several parents to share specific experiences, and additional stories that they told at this time.

Qualitative data analysis. Quantitative analyses preceded the qualitative analyses for purposes of developing broad categories from which the data could be explained. Qualitative analyses were used to answer research question 2, which has sub-questions focusing on barriers youth experience, boundaries, and roles. All qualitative analyses were completed using framework analysis, according to the model outlined by Pope, Ziebland, and Mays (2000). Framework analysis was selected as a method because it is best adapted to research that has specific questions and a priori constructs. In these data, the framing questions included probes relating to barriers, boundaries, and roles as experienced by students and explained by parents, students, and adult leaders. A goal in using this data analytic approach is to examine whether the data “fit” the proposed frameworks guiding the analyses. Framework analysis was considered appropriate for these data because this analysis method allowed for results that are primarily based on the observation and accounts of the participants; it was dynamic in that throughout the process changes or amendments were explained based upon data; it was systematic in its
methodical treatment of the data; it was comprehensively used to address research questions; and it maintained access to original textual data through the use of participant quotes. Five distinct stages were used in the analysis of qualitative data from the student and parent interviews.

**Stage 1: familiarizing yourself with your data.** In Phase 1, I personally transcribed each interview from its digital recording, which allowed me to thoroughly review and understand each interview. In four separate parent interviews, I had perceived the interview to be complete, but following conversation at the conclusion of the interview process, I continued to garner information relevant to the interview. In two instances, I was able to record these conversations by restarting the audio recorder. In one instance, the parents specifically waited until I had turned off the audio recorder to share more information, and requested that I not audio record that portion of the interview, although I was permitted to include the shared information as data. And finally, in one instance, the mother had begun crying, and I felt it was inappropriate to pause the conversation to turn on the audio recorder during her moment of distress. All of these experiences and conversations were documented in memos I wrote immediately following the conclusion of the parent interviews. In addition to memos which amended parent interviews, I completed memos for each student interview that related to that student’s survey answers. Prior to conducting each parent interview, I transcribed their child’s interview, so I had a better memory of their child, and after each parent interview I completed memos about my overall interview experience. I transcribed each audio memo that I had collected during the interview process, and included these memos with their relevant interviews. This process allowed me to become familiarized and fully immersed in my data. NVIVO software version 10 was used from the outset of the coding process, but much of the coding was completed using paper transcripts, with the codes later being entered into the software program.

**Stage 2: identifying a thematic framework.** Following transcription, I began the coding process doing a line-by-line coding of the student interviews, and used students’ words and phrases (in vivo terms) to create codes. I discontinued line-by-line coding for the parent interviews, instead applying codes to short, meaningful segments of data, specifically responses to individual probes, while still incorporating parents’ words and phrases as codes. In this stage I identified all the key issues, concepts, and themes by which the data can be examined and referenced, to ensure I was generating not only a descriptive picture of participation, but also a conceptualized picture of the underlying processes shaping participation. When coding, I tried to
retain some surrounding conversation to allow for placement of the data in context. In many cases, I also included interview questions within the initial codes. My codes were shaped by drawing on a priori issues and questions specifically drawn from the research questions, as well as recurring issues raised by the youth and parents themselves. Because the coding was completed manually and later entered into the software program, I used a combination of colored pens and highlighters to identify different codes on the interview transcripts. When entered into NVIVO, I tagged these segments of data and named these segments with initial codes and descriptive phrases. Sometimes I used specific phrases from the interviews as codes. I also continued memoing during this process, which was useful in highlighting overlap among codes and inconsistencies in parent/child data. At the conclusion of this stage I had outlined a detailed index of the data with manageable chunks for subsequent retrieval and exploration.

**Stage 3: indexing.** In Stage 3, I began applying the thematic framework or index systematically to all the data in textual form by annotating the transcripts with codes from the index, by highlighting short text descriptors that elaborated upon the index heading. During this process I used NVIVO, which was helpful because single passages of text were often coded with several different themes, each of which was recorded within the appropriate node.

**Stage 4: charting.** In Stage 4, I rearranging the data according to the appropriate part of the thematic framework to which they relate, and forming separate documents for each key area addressed in the data. Each key subject area, including the a priori concepts of barriers, boundaries, and roles, had an individual document listing all textual responses from each interview participant that was identified with that code. Unlike simple cut and paste methods that group text, these documents contained distilled summaries of views and experiences along with textual interview data, and were creating using NVIVO and transferred into MS Word. Thus the charting process involves a considerable amount of abstraction and synthesis, to allow for review of each subject area, to determine where overlap occurred in the data. Collapsing (and expanding) categories required more review, and more memoing to sort through the concepts. For example, I had a category related to “Perception of Self” that fit with student interviews, but didn’t work with parent interviews. After reviewing and memoing, I created a larger document titled “Visibility” that encompassed students’ perceptions and parent descriptions related to the ways in which visible perception of disability influenced
conceptualizations of self/child. In this way, I was able to determine that these identified subject areas fit the data.

**Phase 5: mapping and interpretation.** In Phase 5 I used the documents I created to define concepts, particularly those identified in my research questions. In this phase I also explained the range and nature of the data, creating typologies where appropriate, particularly as they related to family boundaries and parental roles. My ultimate goal was to find associations between themes with the purpose of providing explanations for my findings. The process of mapping and interpretation is influenced by the original research objectives, as well as by the themes that have emerged from the data themselves, which included themes of Visibility/Invisibility.

**Establishing trustworthiness.** Rigor is often referred to as trustworthiness in the qualitative research process. To ensure the research process is trustworthy, or backed by evidence and can be viewed as an accurate representation of participants’ experiences, I used several steps, as suggested by Thomas and Magilvy (2011), some of which are inherent in the data collection and analysis process. To establish credibility, the students’ and parents’ words and phrases (in vivo terms) were used in shaping the coding categories, while repetition of terms and phrases were noted and used to guide the research process. Memoing was constant and informative to the data being obtained. I also included quotes from student and parent interviews to illustrate themes and patterns identified in this study.

**Dependability,** which is similar to reliability, establishes an audit trail, and was accomplished through peer participation in the research process and by providing a detailed description of the research methods used. To ensure that consistency of coding was established, a second graduate student researcher was consulted to code passages, and discrepancies were discussed and evaluated. Immediately following the first student interview, we both coded and compared our codes. NVivo software was used to determine percentage agreement via the coding comparison feature. This was repeated again as student interviews neared completion, and again when parent interviews were begun and completed. This established that reliability was maintained throughout the data collection and coding process. Percentage agreement was 92.11% on the reasons for participation theme/node, 85.21% on the barriers theme/node, 82.49% on the boundaries theme/node, and 88.33% on the roles theme/node. Additionally, as themes were established in the multiple phases of analysis, the question was repeated: To what extent do
I observe evidence of these themes in the data? To answer this, I randomly selected interview transcriptions and compared them to the existing codes, to determine if the codes were applied similarly across passages (Harry, Sturges, & Klingner, 2005). Transferability is the way in which the findings can be applied, and was established through a thorough description of the chosen sample, the research setting, and overall theoretical application. Confirmability, or verification (Chiovitti & Piran, 2003) occurred through the iterative nature of the qualitative data collection process. I responsively listened to the data, while still working to establish reliable codes and select future participants using documented and appropriate theoretical rationale. In addition, I remained aware of my own preconceptions, and was reflective throughout the research process, as demonstrated in the interview, memoing, and coding process. Through this process, verification occurred (Morse, Barrett, Mayan, Olson, & Spiers, 2002).

**Integrating Leader and Coach Data**

For leader and coach surveys, data was imported into SPSS from the SurveyGizmo.com collection site. As the surveys were both categorical and open-ended, responses were coded to allow for analysis. For purposes of this study, focus was on the barriers that leaders perceive in the participation of students with disabilities. Each open-ended response was initially coded as it related to the theoretical concept of barriers as presented in the Social-Relational Model of Disability. Barriers as explained by leaders were easily classifiable into one of two categories: Impairments as Barriers, or Societal/Structural Barriers. Results of these analyses are integrated in Chapter 5.

**Ethical Considerations**

No study information was gathered from students until parental consent was secured. Participants were assigned a pseudonym to preserve confidentiality. Interviews have been considered confidential and data (including notes, transcripts, and memos) have been kept on a secure computer in a locked office. Only researchers have access to the data. All research procedures were approved by the University of Illinois Institutional Review Board prior to any research activities taking place, and contact with the identified schools was facilitated, when required, through the Office of School University Relations in the School of Education. See Appendix F for OSURR documentation.

There were minimal risks to the youth who participate in this study. Although they were uncomfortable at times talking about their disability or their experiences, I made every effort to
establish a friendly rapport and put them at ease. The participants in this study were never required to discuss any issue or answer any question that they were uncomfortable with or did not wish to answer. I recognized that the interactions between myself as a researcher and my youth participants were potentially unequal, where I was likely viewed as having more power in the relationship. In such situations, I was aware that ethical behavior was of special importance, in addition to the development of rapport with the participant.

Incentives for participants were provided at varying levels. Students who completed the survey were entered into a raffle to receive a $15 iTunes gift card. The probability of winning this varied by school, and averaged out to one out of every ten student participants at each school. Students who participated in an interview received a $15 gift card to a store of their choosing. Parent interview participants received a $10 gift card to Walmart. Additionally, the contact person at each school received a $15 Walmart gift card, as an indicator of appreciation for their assistance in the survey and interview process.
Chapter Four: Research Question 1

Chapter 4 presents the results of Research Question 1, which uses youth survey data to explain what participation looks like for high school students with disabilities. The first research question was designed to be descriptive, exploring what participation looks like for high school students with disabilities, as well as examining to what extent impairment type/disability label impacted student participation. Research question 1 reads as follows: What does participation look like for high school students with disabilities? Two subquestions are specifically addressed below. First, what factors predict participation for students with disabilities? And second, to what extent does impairment type (disability label) impact participation?

Analyses were completed using SPSS Statistics package 17.0. Variables were descriptive, and included students’ grade in school, disability label, gender, race/ethnicity, and participation type.

Who participates?

To begin to answer what participation looks like for students with disabilities, I administered a survey to 71 students from ten different high schools. Of those 71 students, 53.5% were male (n = 38), and 69.0% (n = 49) were white. Distribution across year in high school was relatively even, with the lowest enrollment being sophomores, at 21.1% (n = 15) of the sample. Of the 71 participants, 63.4% (n = 45) indicated they had ever participated in extracurricular activities, and 54.9% (n = 39) currently participate in at least one sport, club, or school-based activity. Of students who indicate current participation, 28.2% (n = 11) of students participate in more than one activity, with the remaining 71.8% (n = 28) reporting participation in one activity only.

Correlational analysis were conducted among demographic variables including gender, family income, parental education, parents’ marital status, number of children in the home, students’ years in the district, race, mainstream/inclusion status, and disability classification. No correlations were found to be significant. Independent samples t-tests indicated no significant differences in participation by students’ race (white/non-white) or gender. One-way ANOVAs were also conducted to examine whether there were statistically significant differences among student participation by age or grade. No significant differences were found.

Participation by disability status. Students’ disability labels were obtained via the parent demographic questionnaire or direct contact with parents via telephone if that information
had been omitted or was unclear on the questionnaire. Although some parents indicated their children had several impairments, I specifically categorized according to the impairment that was referenced on student IEPs, according to parent report. The most frequent label given by parents was learning disability (45.1%; n = 32). Autism was tied with other health impairments (which included ADD/ADHD) for second highest frequency (14.1%; n = 10). No other specific label had over 10% representation, although two parents indicated their children’s impairment was Down syndrome, which is not a separate disability category according to Illinois law. In these data, I have left them as separate, as I do not know what their specific classification is, and do not want to speculate. A one-way ANOVA found no significant difference in participation among disability groups. Had the data set been larger, it is possible that significant differences in participation experiences may have existed. Complete frequencies are found in Table 3.
<table>
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<tr>
<th>Demographic Information</th>
<th>Current No Participation</th>
<th>Current Any Participation</th>
<th>Prosocial Activities (13)</th>
<th>Performance Activities (12)</th>
<th>Team Sports (20)</th>
<th>School Involvement (8)</th>
<th>Academic Clubs (12)</th>
<th>Total Activity (65)</th>
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<td>7</td>
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<td>White (69.0%; 49)</td>
<td>46.9 (N=23)</td>
<td>53.1 (N=26)</td>
<td>7</td>
<td>6</td>
<td>13</td>
<td>5</td>
<td>7</td>
<td>38</td>
</tr>
<tr>
<td>Black (21.1%; 15)</td>
<td>40.0 (N=6)</td>
<td>60.0 (N=9)</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>3</td>
<td>3</td>
<td>21</td>
</tr>
<tr>
<td>Asian (1.4%; 1)</td>
<td>0.0 (N=0)</td>
<td>100.0 (N=1)</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Latino/Latina (2.8%; 2)</td>
<td>50.0 (N=1)</td>
<td>50.0 (N=1)</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Mixed Race (5.6%; 4)</td>
<td>50.0 (N=2)</td>
<td>50.0 (N=2)</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td><strong>Disability Type</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autism (14.1%; N=10)</td>
<td>70.0 (N=7)</td>
<td>30.0 (N=3)</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Down Syndrome (2.8%; N=2)</td>
<td>50.0 (N=1)</td>
<td>50.0 (N=1)</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Emotional Disability (5.6%; N=4)</td>
<td>25.0 (N=1)</td>
<td>75.0 (N=3)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Intellectual Disability (9.9%; N=7)</td>
<td>42.9 (N=3)</td>
<td>57.1 (N=4)</td>
<td>5</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Learning Disability (45.1%; N=32)</td>
<td>40.1 (N=13)</td>
<td>59.4 (N=19)</td>
<td>3</td>
<td>6</td>
<td>10</td>
<td>5</td>
<td>8</td>
<td>32</td>
</tr>
<tr>
<td>Multiple Disabilities (1.4%; N=1)</td>
<td>100.0 (N=1)</td>
<td>0.0 (N=0)</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Orthopedic Impairment (7.0%; N=5)</td>
<td>40.0 (N=2)</td>
<td>60.0 (N=3)</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Other Health Impairment (14.1%; N=10)</td>
<td>40.0 (N=4)</td>
<td>60.0 (N=6)</td>
<td>2</td>
<td>1</td>
<td>5</td>
<td>0</td>
<td>1</td>
<td>9</td>
</tr>
</tbody>
</table>

*For Activities Reported, the reported N is of general activity participation, NOT number of individual student participants; for example, an N=3 for team sports may mean one person who reported participation in two sports plus one person who reported participation in one sport.
Participation by activity type. Student participation was classified according to five categories as identified by Eccles and Barber (1999): prosocial activities, performance activities, team sports, school involvement, and academic clubs. Eccles and Barber (1999), in their analysis of students without disabilities, found participation differences by gender, in that males were more likely to participate in sports than females, and females were more likely to participate in all other forms of activities (see also Antshel & Anderman, 2000). An independent samples t-test was conducted to examine whether there was a significant difference between males and females in relation to their current activity participation. No statistically significant differences in participation were found between males and females in this sample ($t = .273$, $df = 66.079$, $p < .786$).

Prior to creating surveys at each school, I received a list of all available organizations available at each individual school. I categorized activities I was familiar with, and asked my school contact person about any activities I was unable to classify. Depending on the schools, student options varied. Most schools offered standard prosocial activities (for example, National Honor Society (NHS)), performance activities (e.g., chorus and drama), school sports (e.g., football, track, softball), school involvement (e.g., student council, yearbook), and academic clubs (e.g., Spanish club). Some schools offered activities offered by no other schools, for example, School 5 offered a Best Buddies program (prosocial) for its students. A list of all activities in which students currently reported participation in is attached as Table 4.
Table 4.  
*All Extracurricular Participation by Activity*

<table>
<thead>
<tr>
<th>Activity by Type</th>
<th>Participants (Total N=65)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Prosocial Activities (n=13)</strong></td>
<td></td>
</tr>
<tr>
<td>Best Buddies</td>
<td>2</td>
</tr>
<tr>
<td>FFA</td>
<td>1</td>
</tr>
<tr>
<td>FTA</td>
<td>1</td>
</tr>
<tr>
<td>Interact</td>
<td>2</td>
</tr>
<tr>
<td>Key Club</td>
<td>3</td>
</tr>
<tr>
<td>National Honor Society</td>
<td>3</td>
</tr>
<tr>
<td>TRiO</td>
<td>1</td>
</tr>
<tr>
<td><strong>Performance Activities (n=12)</strong></td>
<td></td>
</tr>
<tr>
<td>Band</td>
<td>2</td>
</tr>
<tr>
<td>Choir/Chorus</td>
<td>5</td>
</tr>
<tr>
<td>Dance Team</td>
<td>1</td>
</tr>
<tr>
<td>Drama</td>
<td>3</td>
</tr>
<tr>
<td>Musical</td>
<td>1</td>
</tr>
<tr>
<td><strong>Team Sports (n=20)</strong></td>
<td></td>
</tr>
<tr>
<td>Baseball</td>
<td>2</td>
</tr>
<tr>
<td>Basketball</td>
<td>5</td>
</tr>
<tr>
<td>Cross Country</td>
<td>1</td>
</tr>
<tr>
<td>Fishing</td>
<td>1</td>
</tr>
<tr>
<td>Football</td>
<td>4</td>
</tr>
<tr>
<td>Soccer</td>
<td>2</td>
</tr>
<tr>
<td>Softball</td>
<td>1</td>
</tr>
<tr>
<td>Track</td>
<td>3</td>
</tr>
<tr>
<td>Wrestling</td>
<td>1</td>
</tr>
<tr>
<td><strong>School Involvement (n=8)</strong></td>
<td></td>
</tr>
<tr>
<td>Journalism/Newspaper</td>
<td>1</td>
</tr>
<tr>
<td>Student Council</td>
<td>4</td>
</tr>
<tr>
<td>Yearbook</td>
<td>2</td>
</tr>
<tr>
<td>Media/AV Club</td>
<td>1</td>
</tr>
<tr>
<td><strong>Academic Clubs (n=12)</strong></td>
<td></td>
</tr>
<tr>
<td>African American Club</td>
<td>1</td>
</tr>
<tr>
<td>Art Club</td>
<td>3</td>
</tr>
<tr>
<td>Chess Club</td>
<td>2</td>
</tr>
<tr>
<td>French Club</td>
<td>1</td>
</tr>
<tr>
<td>Math Club/Math League</td>
<td>1</td>
</tr>
<tr>
<td>Reading Club/Book Club</td>
<td>2</td>
</tr>
<tr>
<td>Spanish Club</td>
<td>2</td>
</tr>
</tbody>
</table>

**Prosocial activities.** Students participated in a variety of prosocial/service activities. Available activities differed by school, with schools offering a range of two to eight prosocial activities. Some activities were directly tied into a specific career or career category, for example, FTA (Future Teachers of America). FFA was the only activity offered that was also a class offering in many schools; however, only one student reported participation. Some activities were more directly service based, such as Key Club, which was offered at eight of the
ten schools, and was tied for the highest number of student participants (n = 3). Still other activities were tied to school grades and required a minimum grade point average, such as National Honors Society, which was tied with Key Club for the highest number of participants (n = 3). In general, prosocial activities were among the most accessible activities to join, but may also have required additional commitments outside the school related to community service commitments.

**Performance activities.** The range of different performance activities offered in participating schools ranged from two to seven. According to survey data, the most frequent activity that students participated in was choir/chorus (n = 5). All schools offered some form of choral activity. Participation in performance activities at most schools was accessible for students in chorus or band, because those were also offered as classes during the school day. Some of these activities were year round, including chorus and band, and others, such as drama or the school musical, required seasonal commitments from their participants. Most of these activities required attendance at least one final performance outside of school hours.

**Team sports.** Sports were the most widely offered participation option for students, as well as the most frequent participation category for students with disabilities. Several students participated in multiple sporting activities, but most reported participation in only one activity. Participating schools offered varied sporting activities, with a range of 5-16 activities offered. Sports activities were the only activities that were often exclusive by gender, with separate activities for males and females; the exception to this was fishing, which was a co-ed sport. The most popular sport was basketball (n = 5). This was also a sport that was accessible to males and females, and was offered at every school.

In the student survey, sport participation was not delineated according to varsity, junior varsity, freshman, modified, or intermural participation, so students who reported participation were likely to be playing at various levels of competition. There was a question to allow for students to indicate their role on the team; one student selected that he was the team manager. All other students who reported participation on sports teams indicated that their role was that of a player. Because sports are seasonal activities, students were asked to report if they were now participating or if they had participated within the past year.

**School involvement.** School involvement activities included activities such as Student Council, journalism, and yearbook. School involvement was the least cited participation
category, but there were also fewer participation options in this category, with participation options across schools ranging from 3-6 activities, which were mostly consistent across schools. Student council, which was offered at all participating schools, was the most frequently reported school involvement activity (n = 4). One student reported participation in the Media Club, which was a video version of the school’s newspaper.

**Academic clubs.** Academic club options differed by school, and offered the greatest variety of activities. Larger schools offered a greater range of clubs, although student participation looked similar at larger and smaller schools, with students from smaller and larger schools participating in similar types of activities (e.g., a student at a smaller school was in Spanish club, and a student at a larger school was in French club). The range of offered academic clubs at participating schools was between three and eight options. The most popular academic club was Art Club (n = 3), which was offered at six of the ten schools where students completed surveys.

**Participation in multiple activities.** In the survey, a total of 39 students with disabilities reported current participation in a total of 65 activities. However, most students (71.8%; n = 28) participated in only one extracurricular activity. Of the 39 student participants, 28.2% (n = 11) reported participation in multiple activities. Students who reported multiple activity participation in almost all cases participated in more than one category of activities; of the 11 students who reported multiple participation, one reported multiple sporting activities only, and one reported multiple performance activities only. The remaining nine students were involved in multiple types of activities. Two students reported participating in five activities, and three students each reported participating in four, three, and two activities.

**Students’ Time Commitment**

Two questions in the survey were designed to explore the amount of time spent participating in activities. The first question asked: “How many times a week do you participate in extracurricular clubs, activities, or sports?” The second asked: “How many hours each day do you participate in extracurricular activities, clubs, or sports? (Only include Monday-Friday, NOT weekends.)” These questions yielded a variety of responses, with no discernible pattern by type of activity or quantity of activities.

The first question included answers ranging from 0 times a week to 7 times a week, with a mean of 4 times a week for all student participants. Students who participated only in sports,
or only in different types of clubs recorded similar responses. Students who participated in multiple activities also recorded similar responses. The second question, too, included a range of responses, with a range of hours from 0 to 6 hours a day spent on activities. The mean of participation for students was 3 hours, but again, this looked similar for students who participated in sporting activities and all other activity types.

It is likely that greater clarification as to type of response required for each of these questions may have yielded more informative data. It may also be the case that students participating in activities experience differing points in their activities where students participate more or less, depending on events within the activity. For example, a student in Yearbook may have long periods of infrequent participation, but intense periods of participation nearing the publication deadline. Similarly, students in drama or theater may report participation based upon time spent individually rehearsing, rather than spent in the group. Because of the range of responses, as well as responses that were difficult to explain, these questions are reported, but were not used in selecting student interview participants.

**Overall Participation**

In these data, students with disabilities report participating in extracurricular school-based activities. Independent samples t-tests indicated no significant differences in participation by students’ race (white/non-white) or gender. One-way ANOVAs were also conducted to examine whether there were statistically significant differences among student participation in by age, grade, or disability label. No significant differences were found. Students participated in a range of activities, including prosocial, performance, team sports, school involvement, and academic clubs. Of the 71 students who completed the survey, 45.1% (n = 32) do not currently participate, 39.4% (n = 28) participate in one activity, and 15.5% (n = 11) participate in multiple extracurricular activities. A subsample of these data will be explored in more detail in Chapter 5.
Chapter Five: Research Question 2

Chapter 5 presents the results of Research Question 2, which is divided into three subsections to explain concepts of barriers, boundaries, and roles, and uses data from parent and student interviews and leader surveys. In each subsection, the research questions guided the presentation of the results. Research question 2 reads as follows: In what way do barriers, boundaries, and roles impact participation for students with disabilities?

This question is explained by specific subquestions, which encompass the ideas of barriers, boundaries, and roles as experienced by youth with disabilities. Each subquestion is explained using interview data from youth with disabilities and their parents. Short answer responses from the survey of coaches and leaders is also used to explain the barriers experienced by youth. To lead into an explanation of the barriers, boundaries, and roles students with disabilities experience, I will first outline the reasons students give to participate, as well as reasons they may not participate. This is explained using data from student surveys and student interviews. Student interview participant information is found in Table 5.
### Table 5.

**Student Interview Participants**

<table>
<thead>
<tr>
<th>Participation Level</th>
<th>Pseudonym</th>
<th>Extracurricular Activities</th>
<th>Disability Type¹</th>
<th>Year in School</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>High</strong></td>
<td>Aaron³</td>
<td>Soccer Baseball Basketball Football</td>
<td>Emotional Disability Bipolar Disorder ADD/ADHD Learning Disability</td>
<td>Freshman</td>
</tr>
<tr>
<td></td>
<td>Abby</td>
<td>Key Club Interact National Honor Society Art Club</td>
<td>Intellectual Disability</td>
<td>Junior</td>
</tr>
<tr>
<td></td>
<td>Addie²</td>
<td>Basketball Best Buddies Club Interact</td>
<td>Intellectual Disability</td>
<td>Freshman</td>
</tr>
<tr>
<td></td>
<td>Aisha¹</td>
<td>Drama Chorus Track</td>
<td>Intellectual Disability</td>
<td>Senior</td>
</tr>
<tr>
<td></td>
<td>Brianna</td>
<td>Key Club Student Council</td>
<td>Learning Disability</td>
<td>Senior</td>
</tr>
<tr>
<td></td>
<td>Dolly</td>
<td>Journalism Drama Chorus Track</td>
<td>Learning Disability</td>
<td>Junior</td>
</tr>
<tr>
<td></td>
<td>Jenaia</td>
<td>Basketball Reading Club African American Club Dance Team Soccer</td>
<td>Learning Disability ADD/ADHD</td>
<td>Senior</td>
</tr>
<tr>
<td></td>
<td>Mark</td>
<td>Track Chess Club Band</td>
<td>Learning Disability Speech Impairment</td>
<td>Junior</td>
</tr>
<tr>
<td></td>
<td>Tyler</td>
<td>Football Baseball Basketball Student Council</td>
<td>Learning Disability ADHD/ADD</td>
<td>Senior</td>
</tr>
<tr>
<td><strong>Low</strong></td>
<td>Andrew</td>
<td>FFA (recently quit)</td>
<td>Learning Disability</td>
<td>Junior</td>
</tr>
<tr>
<td></td>
<td>Anna²</td>
<td>None</td>
<td>Learning Disability</td>
<td>Senior</td>
</tr>
<tr>
<td></td>
<td>Asher</td>
<td>Football</td>
<td>Learning Disability Speech Impairment</td>
<td>Sophomore</td>
</tr>
<tr>
<td></td>
<td>Caleb³</td>
<td>None</td>
<td>Autism</td>
<td>Freshman</td>
</tr>
<tr>
<td></td>
<td>Fiona²</td>
<td>TRiO</td>
<td>Learning Disability</td>
<td>Freshman</td>
</tr>
<tr>
<td></td>
<td>Jake⁴</td>
<td>NHS</td>
<td>Down Syndrome</td>
<td>Junior</td>
</tr>
<tr>
<td></td>
<td>Peter</td>
<td>Gamer’s Club (newly joined)</td>
<td>Autism</td>
<td>Junior</td>
</tr>
<tr>
<td></td>
<td>Rebecca</td>
<td>None</td>
<td>Learning Disability Physical Impairment (severe scoliosis)</td>
<td>Junior</td>
</tr>
<tr>
<td></td>
<td>Spencer</td>
<td>Art Club</td>
<td>Learning Disability</td>
<td>Sophomore</td>
</tr>
</tbody>
</table>

¹ As reported by parent
² Interviewed with director of special education in the room
³ Interviewed in storage closet
⁴ Interviewed with aide
⁵ Parents of these students were not interviewed.
Why Students Do (and Do Not) Participate

In the survey, students were given a list of nine reasons to participate in extracurricular activities and sports, and were asked to select any that made them want to participate (see Table 6). Of the nine reasons, students selected a mean of 3.88 responses ($SD = 1.34$, range: 2 - 9). Among students who had ever participated, the most frequent reason for participation was because they liked or enjoyed the activity (68.9%, $n = 31$), followed by having friends who participated in that activity (51.1%, $n = 23$). The three least chosen reasons for participation were related to adults, with parents as the third least popular reason to participate, and the final two reasons being related to leader or coach influence: “I like the leader or coach” (31.1%, $n = 14$); and “The leader or coach asked me to join” (22.2%, $n = 10$). Responses were similar among students who were currently participating and students who had ever participated.

Table 6. What makes you want to participate in current sport or activity?

<table>
<thead>
<tr>
<th>Reasons</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>I like the activity.</td>
<td>31</td>
</tr>
<tr>
<td>I have friends who participate.</td>
<td>23</td>
</tr>
<tr>
<td>It’s good for my future.</td>
<td>22</td>
</tr>
<tr>
<td>I want to make new friends.</td>
<td>21</td>
</tr>
<tr>
<td>I am good at the activity.</td>
<td>20</td>
</tr>
<tr>
<td>It helps me in school.</td>
<td>16</td>
</tr>
<tr>
<td>My parents wanted me to join.</td>
<td>15</td>
</tr>
<tr>
<td>I like the leader or coach.</td>
<td>14</td>
</tr>
<tr>
<td>The leader or coach asked me to join.</td>
<td>10</td>
</tr>
</tbody>
</table>

**Enjoyment.** Student interview responses echoed the reasons for participation that were cited in the survey. By far the most common responses when asked why students did or did not participate in activities were related to personal enjoyment of the activity. Peter, a student with autism who quit Art Club because it did not interest him, and recently joined his school’s newly established Gamer’s Club, said simply: “If it sounds fun, I’ll join it.” When asked how he picked what to be involved in, Mark, who is in track, chess club, and band, and has a learning disability and a speech impediment, said: “To see if I . . . what I like at that time being. If I liked it, and if I really wanted to commit to it, that’s how I chose.” Anna, who has a learning disability and does not participate in any activities, said, “There’s just nothing I want to do. I’m not interested in things offered at school.” Addie, a student with an intellectual disability who was in clubs and
Sports, when asked about why she decided to join basketball, grinned from ear to ear and said, “It’s the best sport. It’s the best thing! I just LOVE it.”

Availability of activities that are of interest to students became the most noticeable theme in looking at why students with disabilities chose to participate. Just like their peers without disabilities, these students wanted to have fun in their activities of choice (Fredricks & Eccles, 2006). If an activity was deemed to be unenjoyable, students were unlikely to participate, even if encouraged by others.

**Peers and friends.** Input from others, including peers, parents, and activity leaders, had varying levels of influence on students’ participation in extracurricular activities. On the student survey, friends were listed as the second most influential reason why students chose to participate. While peers were not cited as the strongest motivator of participation, for some students, experiences with their peers kept them in the activities, and in their interviews, students emphasized the role that having friends participate played in their decisions to join activities.

For example, Brianna, who has learning disabilities and participates in Key Club and student council, said, “My friends were in there from last year, and they said it was fun, so I just decided to do it this year.” For several students, being in an activity was viewed as an opportunity to establish new friendships. Abby, who has an intellectual disability and participates in a variety of service activities, explained, “I can see myself participating with my friends, but also without my friends. So then I can make more friends!”

In interviews, participating with friends was something most students discussed positively. However, when students were specifically asked if they were more likely to join an activity if their friend asks them to, or if a friend is already in it, a majority of students said no. Dolly, who has a learning disability and is many activities, said, “In soccer, one of my friends . . . tried to persuade me to join next year . . . but it didn’t sway me, it just didn’t. Several friends have asked me to join art club. But I’m not very artistic.” Most students simply were not interested in participating if they were not interested in the activity itself.

**Parents and family.** Given my application of family systems theory, I was especially interested in the role of parents in the activity participation process. In the student survey, among students who have participated in extracurricular activities, 33.3% (n = 15) selected “My parents wanted me to join” as a reason for participation. When asked why they may have stopped participating, only one student gave “My parents didn’t want me to participate anymore”
as a reason for ending participation. Finally students were asked if they ever wanted to participate in a club, activity, or sport, but did not, and why not. Of students who had wanted to join, but did not, only two students selected “My parents didn’t want me to.”

In the survey data, reasons to participate (and reasons not to participate) relating to parents were in the lowest percentages of overall reasons chosen. Student survey results appear to indicate that although parents may be supportive of the activity choices of their children, in most instances they are not the main factor students consider when making the decision to participate or not. However, in their interviews, students were more straightforward about their parents’ influence, often directly explaining the ways in which parents influenced their activity choices. For example, Jenaia, who has ADD and a learning disability, and participates in a variety of activities, cited her mother when asked why she is involved in so many activities. She said: “[My mom] said, ‘Stay active in school . . . so my grades don’t fall.’ I picked the ones that I wanted. And she just picked one. She said, go to the Reading Club.” Similarly, Fiona, who has a learning disability and is in TRiO, an activity to help encourage students plan to attend college, said: “[My parents] were the main reason I joined TRiO, because my mom said it would be a good idea, because of the whole fact they help with college. And she was right. I love TRiO.”

Other students did not put much weight on their parents’ advice. For example, Peter, who has autism, and recently joined Gamer’s Club, said, “They try to get me into [activities], try and get me to do more, but always fail. . . . Usually it’s stuff I don’t like, or I could be doing stuff I would prefer to do.” Dolly, who has learning disabilities, and participates in many activities, when asked about her parents’ influence, said: “My mom, she thought I was joking about the whole chess thing. She didn’t think I would follow through with it, but I did. She really hasn’t impacted [me] at all.”

Other members of the family, most noticeably siblings, were also cited as influential to participation. For example, Abby, who has an intellectual disability, is involved in many service activities at her school. She says:

[My parents] encourage me to get involved in stuff, and all that stuff. So, I mean, I guess I look up to them a lot, ‘cause they were . . . I mean, I have two sisters, and they did a lot of this stuff. So I mean, I’m like, maybe I’ll do that when I get in high school, so . . . they encouraged me to do stuff.
In most instances, although students indicate that their participation is influenced by family members, enjoyment or interest in the activity remains their main reason for participating. For example, Mark, a student with a learning disability who in band, chess club, and track, also mentioned his siblings. He said, “Chess? Two of my brothers played it, and I’m like, I might as well just do it, ‘cause how awesome chess club is . . . just a pretty awesome club.”

Overall, students indicated that while not the main reason they participate, parents’ support is appreciated and necessary. Aaron, who has bipolar disorder and ADHD, and who participates in multiple activities, said:

They play a big role! They’re my transportation. If I didn’t have ‘em, I wouldn’t be able to get to the sports. They encourage me. . . . I’d get down and he’d yell across, well, not yell, but like, say my name, and I’d cheer up again.

**Leaders and coaches.** It appears that the role that leaders play in the choices of youth with disabilities may be more nuanced than the role of parents. In the survey I found that for youth who currently participate, being asked by a leader or coach (22.2%, n = 10), and liking the leader or coach (31.1%, n = 14) were the two least selected participation reasons. For youth who had considered joining, but decided against it, having a coach or leader who made them feel uncomfortable was also the least chosen reason for not participating (n = 1). This seems to indicate that youth are not likely to have a negative perception of leaders prior to joining, and neither are they likely to participate based solely upon enjoying the coach or leader. It may be the case that leaders are not a strong factor in initially making the decision to join an activity. For example, when asked if she would participate when asked by a program leader or coach, Dolly, who participates in many activities, and has a learning disability, said:

I would, because if they feel like I’m right for it, then that would sway me a little. But coaches have asked me to join cross country, because I am a distance runner, but now that I think about it, I just can’t.

Although not a main factor in joining activities, coaches and leaders were a major factor in ceasing participation. When citing reasons they decided to stop participating, not liking the leader or coach was the most selected option by students who completed the survey, at 26.7% (n = 12). This ranked higher than not liking the activity (20.0%, n = 9), not fitting in (22.2%, n = 10), and not having enough time (22.2%, n = 10). In interviews, students were able to explain more fully. Aaron, who has bipolar disorder and ADHD, participates in many activities. He has
had differing experiences with leaders, and currently plays football because a coach asked him to join. In explaining why he stopped participating in a different sport, he said, “I did not like it. It was because of the coach and the stuff we had to do. I didn’t feel comfortable.” Similarly, Tyler, who has a learning disability and participates in various sports, said, “I stopped baseball two years ago because of coach reasons . . . just trying to cut me down from varsity last year.”

Jake, who has Down syndrome, used to play on his high school basketball team, but stopped when the coach, who he really enjoyed, was replaced mid-season. Jake said, “I had a good coach who has been like a friend to me. . . . He’s a nice guy. . . . I heard that he resigned.”

Jake’s mom explained further:

It was the happiest time in his life. The coach was so impressed at how well he learned the plays. He played in a game and actually scored. What a night. After that, board members were angry with the coach. Things got ugly, and he resigned. Some of Jake's peers told him he had caused it. The coach talked to Jake and tried to get him to believe that he had not caused the trouble. No one at the high school tried to ease Jake's mind, although they knew he was bearing this burden. I called the new coach to see what the plans were for Jake on the team, and he informed me he "had too much on his plate" to deal with him. We had to turn in his uniform. It was a very hard time.

**Barriers**

Barriers to participation are addressed in research question 2a, which reads: *What are the structural and societal barriers that youth with disabilities experience, and in what way do these shape participation of students with disabilities?* Current literature related to extracurricular program participation of youth with disabilities often inferentially references barriers that youth experience. I hypothesized that structural barriers related to transportation may be an issue for youth with disabilities, potentially limiting their participation. I also hypothesized that societal barriers to participating could include peer misconceptions about participation of youth with disabilities (Lippold & Burns, 2009), leading youth with disabilities to feel unwelcome or out of place (Castañeto & Willemsen, 2006), potentially leading to decreased participation, or causing youth to choose a different activity.

The influence of program leaders in creating or eliminating societal barriers was also explored in the current study. I hypothesized that program leaders and coaches have the potential to influence barriers positively or negatively, which would potentially be explained by
the experiences and training leaders have had in working with youths with disabilities (Carter et al., 2010b). The social-relational model of disability outlines structural and societal barriers that are experienced by people with disabilities. In this section, barriers to the participation of youth with disabilities in extracurricular activities are explained using youth and parent interview data, and survey data from coaches and activity leaders.

**Structural barriers.** Common requirements for joining an activity, like taking a test to be eligible for certain academic clubs, or even knowing when and where the activities meet, were occasionally cited by students with disabilities as obstacles to joining. While these may also be considered obstacles for students without disabilities, these simple procedural tasks, if not addressed, can become structural barriers for students with disabilities who may want to join. As a whole, structural barriers were not explained by students in this study as playing a significant role in their participation.

Structural barriers were outlined by parents in their interviews, however, and while students did not report such barriers as being an issue, it became evident that structural barriers, although not perceived by students with disabilities, were somewhat influential to their extracurricular participation. Structural barriers as explained by four parents generally fell into one of two categories: Barriers related to transportation, and institutional barriers at a school level.

**Transportation barriers.** I had hypothesized that transportation may be a barrier to the participation of students with disabilities, but it was not frequently cited as a barrier by parents. Two of the mothers I interviewed did indicate that transportation was a specific barrier for the participation of their children with disabilities. Abby had two older siblings who also participated, and her mother believed that once those children graduate, Abby would no longer have a ride, and would not be able to make it to and from community events sponsored by her school clubs like she does now. Abby’s mom explained:

Abby likes to do a lot of activities and really enjoys serving the community with her peers, especially in Key Club. But it’s going to be hard for her… She really needs to study to pass the license test and she hasn’t passed yet. She’s determined, but if she doesn’t pass it doesn’t look like she’s going to get there [to activities]. Although, I mean, maybe she’ll come out of her shell and ask someone else for a ride? Really, who knows, right?
While Abby lived in town, Jake lived on a farm away from school. He also was determined to get a license, but similar to Abby, had not yet been able to pass the test. Jake’s mom said:

It would be so great for him to have the freedom to go with his peers. Granted, he really doesn’t have friends, per se, but feeling like he had the ability to be able to head into town to participate would give him a sense of freedom. I think he’s frustrated that he can’t pass the test, and frustrated that he needs to take a bus, and sometimes the bus just isn’t an option, unfortunately.

One of the reasons that transportation was not often cited as a barrier to the participation of students with disabilities was that most activities were accessible during school hours, had busing options, or parents were able to provide transportation. Some students who needed to would carpool or arrange rides to their practices or activities. Overall, transportation was not a common barrier to participation for most students, likely because few participants who were interviewed had impairments related to mobility.

**Institutionalized structural barriers.** Two parents explained institutionalized structural barriers, which included specific rules related to participation, and inflexible participation standards, determined by either the administration or program, that served as barriers for students with disabilities. Such barriers were generally enacted by administrators or leaders who set general guidelines without conceptualizing the way such guidelines served to exclude students with disabilities who may be potential participants. Both parents who explained institutionalized structural barriers had children with more involved impairments.

Jake’s mom explained that coaches sometimes felt that it was inappropriate to allow students with disabilities to be managers, because it was unfair to students without disabilities who might also want to be managers. This was after Jake’s former basketball coach was fired after a disagreement with administration. The new assistant basketball coach was also Jake’s aide, and Jake’s mom said:

Really, they’re going to tell me that another kid who doesn’t have a disability is going to want to be the manager? I’ve given up fighting with the district. This new principal is better but there’s just no point anymore.

Aisha’s mom explained a somewhat unusual case, in that an incident that occurred outside of school impacted Aisha’s participation in the school. Because her daughter had a conduct violation, she was unable to participate in activities for a certain length of time. Even
though Aisha’s mother went to the school to advocate on her behalf and to explain the situation, the administration felt it was better to maintain the guidelines as they were, rather than allow that certain situations may warrant change to general policy. Aisha’s mom explained:

So, I teach my daughter if there is any problem at all, you go to the police, and they will take care of it. Now, after what happened, she’s afraid of the police . . . Pretty sure she’s not going to be running to them for help. So I say, things will be better back in school. And then, she can’t participate because she got arrested. When it was all just a huge misunderstanding! The school can’t be flexible, and it’s not benefiting anyone.

**Societal barriers.** Societal barriers were experienced by almost all students, regardless of their participation level or disability status. For students who had more visible physical or intellectual disabilities, societal barriers were experienced more frequently and in different ways. While in interviews only two of the students directly mentioned stigma from peers as a reason not to participate in activities, many of these same students, when previously asked in the survey questionnaire why they stopped participating or why they chose not to participate, selected “I felt like I didn’t belong,” “I felt like the other kids would make fun of me,” or “I felt like I didn’t fit in.” Although most students did not discuss these feelings explicitly in relation to extracurricular participation, feelings of difference and stigma were articulated by 13 of the 18 students interviewed, when discussing their school experiences in general. Most of the societal barriers experienced had to do with peer perceptions and interactions. Students were acutely aware of their classmates’ perceptions of them.

Fiona, a freshman who has a learning disability, explained that there are certain activities she would avoid due to the behaviors of some of her peers:

Some of the kids that know that you have an IEP, they see you a little different . . . Just that clique that’s always been there since grade school. Just, they just know, and they’ve never been too friendly. But everybody else is real nice about it. . . . I’ve been pushed, I’ve been tripped, I’ve had things thrown at me, I get called names. . . . Sometimes, if they’re in some of the things . . . that I want to be in, I don’t join ‘em, because I don’t want to put up with the frustration of having to deal with them.

Dolly, who participates in a variety of activities, quit soccer because she felt like an outsider. She said:
I just sat on the bus with nobody else. . . . I decided I didn’t like it as much as I thought I would. It’s like, a lot of things are cliques, like, the girls in it . . . if they had a sleepover, it’s like, I wasn’t invited. It didn’t hurt my feelings, I just didn’t want to be part of that.

Many students dealt with varying levels of social stigma and social exclusion in their overall high school experience. Caleb, a freshman with autism who did not participate in extracurricular activities, simply replied, “yeah” when asked if he felt like he was treated differently than other kids. When asked how, he began to cry. I gave him the option to end the interview, and asked if it had been a rough year. Caleb responded, “More like a rough life.”

Asher, a senior with learning disabilities and a speech impediment, played football, and said that his favorite part of school was his friends. Despite this, he still explained that he was sometimes treated differently, saying: “[They] might make like a joke or something, because I might slur a word, but nothing – I’m pretty good at taking jokes; I might make a smart remark. Usually I just get along with everybody.”

Students who had more visible physical disabilities, and students with intellectual disabilities articulated feelings of stigma more acutely than students whose impairments weren’t obviously visible. Aisha, who has an intellectual disability and participates in drama, chorus, and track, had this to say:

I never, I like, I’m always – they don’t treat me [well] here at school. Some people just treat me like crap. I just – they don’t treat me the same. They just make me so not good, I guess, so I just . . . [Banged her fist on her backpack.] Rebecca, who has a learning disability and scoliosis, was aware of being made fun of when she had to wear a brace for her scoliosis, but now that she no longer has to wear the brace, she no longer feels that students target her. She said:

A lot of people saw when I was leaning over, something sticking out of my back, and a lot of people had called me Brace Girl, and things like that. And also I still had braces [on my teeth], and they kind of made fun of me. When they found out in health class – they found out how hard it can be. They really don’t pick on me anymore. I had surgery. I’m better now.

Societal barriers as experienced by students with disabilities are not always verbalized, and do not necessarily include bullying or taunting. Looks, stares, or simply ignoring the
presence of someone with a disability also can create barriers for students with disabilities. Jake, who has Down syndrome, had this to say about his experiences with peers in his school:

I have a few friends . . . they eat lunch with me almost every day. But other kids don’t try to talk to me, or it’s like they don’t even see me. I’d like to have friends. I’d like to know why they can’t see me. [Other students] make me feel lonely.

**Students’ internalized societal barriers.** Stigmatizing experiences, both in extracurricular activities, and in school in general, are often internalized by the students who are targeted. In interviews, students were questioned about their Individualized Education Plans (IEPs) and their purposes. All but one student interviewed freely explained that their IEPs helped them in school, and were able to articulate why they had IEPs. For example, Anna, who has a learning disability said: “Not a huge IEP, just like, some work in English and that stuff. But I’m like, working on it and stuff. And I get extended time on tests, and tests read.”

Students were also asked if having an IEP affects the way they feel about themselves. Most students simply answered no, but a few students did indicate that having an IEP affected their perception of themselves. For example, Tyler, a student with a learning disability who plays multiple sports, answered, simply: “Yeah, ‘cause I feel like I fail, basically.” Dolly considers herself to have “overcome dyslexia” and feels she has a learning “difference,” rather than a disability. When asked if having an IEP affected her perception of herself, she responded:

Not at all, honestly. [Pauses.] Maybe a little bit, for the fact that I feel like I am one of the more educated, less dependent people, because you do see the people that have to have their hand held, metaphorically, and it’s not something that I would like. And I would just, much rather have my hand not held, or anything of that sort.

Students who embrace society’s negative perceptions of disability may create internalized barriers for themselves. Of the 14 students who were specifically asked if they felt they had a disability, 10 said no. The school definition of disability is closely tied to having an IEP, and these students openly discussed their IEPs. However, they rejected the association of their IEP with disability status. For example, Aaron, when asked about his IEP, explained:

IEP? Yes. I have behavioral issues and stuff. Behavioral, bipolar, and ADD. I think it helps me. I can do a lot of stuff that could, like, help me. I don’t know, [I’m] just a normal high school student that has some stuff wrong with him.
When asked if he felt he was a student with a disability, however, he said, “No, if I thought about that I would get too, like, down on myself. So I kinds think about it as like, I’m a special person, not like a disability, ‘cause that just makes it sound depressing.”

**Societal barriers as explained by parents.** Parents explained the societal barriers their children encountered, both from peers and from program leaders. While student responses were often specific to activities they were currently in, or recently had been in, parents often elaborated on barriers their children experienced in multiple settings and over longer periods of time. Questions were phrased to be specific to children’s current activities, but parents often included information about barriers experienced in multiple contexts.

**Societal barriers from students’ peers.** Students were explicit in explaining the barriers they experienced from their peers, and parents often elaborated upon their children’s experiences, telling those and similar stories. Of the 15 parents interviewed, 12 mentioned some kind of societal barrier their child had overcome or experienced. Some of these barriers discussed by parents were explained using specific disability labels, for example, the mothers of Peter and Caleb specifically mentioned their sons’ autism, and Jake’s mother discussed Down syndrome. Parents of children with learning or intellectual disabilities would sometimes specifically mention impairments, but not in every case. For example, Abby’s mother said:

I know that the kids can sometimes target her because of her, you know, disability, but she has a very tight circle of friends. Those girls take care of each other, and that helps her deal with the nasty kids who are sometimes a little hurtful.

And Andrew’s mom said:

He has some times at school where it’s just tough for him. His disability makes it hard for him to be really social sometimes, like, he might not read social cues all that well. So I think it’s made it tough for him to make friends, because he’s different, and they know he gets a little extra help, and you know, that makes him not the same. And in high school it’s so important to just, um, well, be the same!

**Societal barriers from coaches and leaders.** Parents were very aware if there were coaches or leaders that were unwilling or unable to work with their children specifically due to their children’s disabilities, but parents also had positive experiences with coaches and leaders who worked to decrease barriers experienced by participants with disabilities. Jenaia’s mother explained her experiences dealing with a leader in one high school:
I told that dance coach that my girl is capable. She can learn. She loves to dance, and she just needs a little more time to practice the steps. She can even practice at home with her sisters, and then come in the next day and she’ll have it down, right? But no, they was having none of that. If she can’t do it right away, she wasn’t even gonna get a chance.

Jenaia’s mother also explained that she specifically requested that her children attend a different school within the district because she felt that the environment for students with disabilities was better at the second school. She successfully arranged for her children to attend the new high school, and explained her daughter’s new experience with a different activity:

Same thing, right? She might need a little longer to get the plays, but I told that coach, and he was okay with it! He knew she had the talent, and he would work with her. He took her in and supported her and man did it work once he knew how to deal with her. She just took right to it. I know my girl. I know she gotta be busy, and she gotta feel like she’s accepted. And then she just thrives! And now she has the basketball scholarship. See the difference? I knew what I was doing, all right. I knew the difference between a good and a bad coach.

Similarly, Jake’s mother detailed multiple experiences where her son experienced barriers and stigma when attempting to participate in activities, but also an experience with a coach that was positive:

Well, it’s been going on as long as I remember. His track coach in junior high gave him a little trophy, and gave all the quote “normal” kids large letter trophies. He was so embarrassed he asked to go home right away. And then, he finally was a part of the basketball team. I mean, the coach just took him in! He let him play, and Jake, wow, you know he just felt like a team member and it was just so very happy for him, for everyone. But well, like I said, then parents in the community were mad and he got fired. And now we’re back to there not being, well, space for him to participate. Which means they don’t want to be bothered.

**Societal barriers as explained in coach/leader data.** Coach and leader data were collected via a survey that included forced choice and open-ended questions to allow for responses explaining student roles in activities, and potential barriers for student participation. (Survey can be found in Appendix 4.) Two-fifths of those who completed the survey were
coaches (43.1%, n = 69), and almost two-thirds (61.3%, n = 92) indicated at least some sort of training related to disabilities. In this section I will discuss the ways in which coaches and leaders explained the barriers they perceive for students with disabilities who may choose to participate. Descriptives of the coach and leader participants are found in Table 7.

Table 7.
Demographics of Extracurricular Program Leaders

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>86</td>
</tr>
<tr>
<td>Female</td>
<td>64</td>
</tr>
<tr>
<td>Age</td>
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</tr>
<tr>
<td>20-29</td>
<td>38</td>
</tr>
<tr>
<td>30-39</td>
<td>56</td>
</tr>
<tr>
<td>40-49</td>
<td>38</td>
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<td>50-59</td>
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<tr>
<td>60+</td>
<td>4</td>
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<tr>
<td>Education</td>
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<tr>
<td>Some college</td>
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</tr>
<tr>
<td>Bachelor’s</td>
<td>104</td>
</tr>
<tr>
<td>Graduate Degree</td>
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</tr>
<tr>
<td>Amount of training (disability)</td>
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<tr>
<td>None</td>
<td>58</td>
</tr>
<tr>
<td>School Professional Development</td>
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<tr>
<td>Specific Coursework</td>
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<tr>
<td>Degree in Special Education</td>
<td>13</td>
</tr>
<tr>
<td>Activity type†</td>
<td></td>
</tr>
<tr>
<td>Prosocial (Service)</td>
<td>18</td>
</tr>
<tr>
<td>Performance</td>
<td>16</td>
</tr>
<tr>
<td>Team Sports</td>
<td>69</td>
</tr>
<tr>
<td>School Involvement</td>
<td>22</td>
</tr>
<tr>
<td>Academic Clubs</td>
<td>35</td>
</tr>
</tbody>
</table>

†A few participants were leaders in multiple activities; therefore, N=160 for this category

Coaches and program leaders were straightforward in their descriptions of who they felt were capable of participating in their activities. The way in which the survey questions were phrased, by not defining disability, purposely left the meaning of disability open to individual interpretation. When asked if students with disabilities were currently participating in their sport, 22 percent (n = 33) of coaches and leaders selected “yes,” or “yes, previously,” 14 percent (n = 21) selected “I don’t know/I’m not sure,” and 64 percent (n = 96) responded “no.”

There was an interesting dichotomy in the responses of coaches and program leaders when they were asked: *What barriers do you see for students with disabilities participating in school activities, clubs and sports?* Of coaches and program leaders who completed the survey,
68 percent (n = 102) listed barriers that were directly related to individual student impairments and how those student impairments may affect the activity. For example, a coach of track and football said that his sports had students with disabilities currently participating, and when asked about barriers, responded, “Sometimes they have issues knowing where to be and what they need to do.” Another football coach explained, “Football is a very physical sport so there could be several barriers depending on the students [sic] disabilities.” One teacher was the leader of a social skills club specifically for special education students. In responding to the open-ended question about barriers to the participation of students with disabilities, she wrote, “Critical thinking skills is hard for students with intellectual disabilities, and some of them lack the social skills as well.”

While most coaches perceived barriers to be related to the students’ disabilities, 32% (n = 48) of coaches and leaders listed barriers that were directly related to societal or structural factors. A coach of a varsity softball team said:

They play the same role as any other player. I currently have a varsity pitcher who has autism and she works along side [sic] the rest of the team perfectly. The biggest barrier is not being understood by OTHER teams. On our team everyone is accepted, however other teams may look at my players as odd and my girls take offense to that.

A coach of a girls track team currently had students with disabilities on his team. He explained:

I think a large barrier is the social stigma of not being very good at a sport. I think the potential for "failure" can be a big deterrent for school aged children. The emphasis on winning that has permeated athletics is another aspect. When coaches are concerned with talent over character often times students with disabilities get cut from teams.

A baseball coach explained, “I think it can be difficult for students with disabilities to break some social barriers as far as ‘fitting in’ with other students.”

Coaches and leaders, in explaining barriers to participation, also occasionally wrote about ways in which those barriers could be overcome, or ways in which their activity may allow for participation despite barriers. A coach of boys tennis, who does not currently have students with disabilities on his team, explained that he may have to change his coaching: “Logistics, I could see it taking a lot of time and planning to adequately include kids depending on their disability.”

An assistant football coach explained:
As long as the disability allows them to [participate] then they do so fully. In my sport they are limited only by their own ability. [Students with disabilities] participate the same as any other student athlete as long as the disability does not interfere with what is expected of any player. If it does, then modifications have to be made.

A school play director who is not sure if students with disabilities are in her activity, said:

Theater reflects the real world, so anyone who is part of the real world can be in a play. It depends on the disability and accommodations [sic]. As a director, I have so many duties, that I could not be in charge of the accommodations [sic], but I could help implement them.

Although coaches and leaders indicated that participation may be possible, most believed that changes to the activity may be necessary to incorporate students with disabilities. The coach of a high school track team felt that her sport was varied enough to allow participation, indicating that she was not sure if students with disabilities currently participated, but she felt that track:

Offers a lot of variety…any student has the ability to go out and compete as they are physically able. There would be some physical barriers for certain students depending on their own disabilities. I do believe that this is the type of sport though that offers many options that can overcome some of these barriers.

By phrasing the survey questions to incorporate disability in general, and then providing leaders a space in which they could explain their initial response, we learn that many coaches view disability as a physical or medical impairment, and fail to realize the way in which their definition of disability creates barriers due to a lack of understanding about difference and disability in general, or the way in which their responses to participation by students with disabilities may perpetuate stereotypes and stigma. Other coaches were aware of societal stigma, and explained it as the major barrier to participation. Consistent societal barriers enacted by coaches and leaders on a program level can become program boundaries, leading to an activity system that is closed to the participation of certain types of students with disabilities.

**Boundaries**

System boundaries as they work to include and exclude are addressed in research question 2b, which reads: *In what way do family and program boundaries affect participation of students with disabilities?*
Family boundaries. Researchers hypothesize that the effect of family boundaries will vary for youth with disabilities, depending on the context and the family’s level of support. Research by Turnbull and Turnbull (1996) described the loosening of boundaries as families became more comfortable with the presence of outside support, including supports available within a school setting. Conversely, Smith et al. (2010) found that family boundaries would tighten as parents felt the need to take care of and support youth with disabilities. Such fluidity of boundaries is logical. If youth are encountering barriers to participation within an afterschool program, it may be the case that family boundaries would contract as a protective measure to prevent harm to the child with a disability. Similarly, if youth are comfortable and supported in an extracurricular program, it is likely that family boundaries would become more flexible, encouraging youth to experience positive participation opportunities. See Table 8 for an overview of parent interview participants.

Table 8. Basic Family Demographic Information

<table>
<thead>
<tr>
<th>Parent Participants</th>
<th>Child’s Pseudonym</th>
<th>Marital Status</th>
<th>Total Household Income (in dollars)</th>
<th>Children Currently Living in Home</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother</td>
<td>Abby</td>
<td>Married</td>
<td>70-79,999</td>
<td>2</td>
</tr>
<tr>
<td>Mother</td>
<td>Addie</td>
<td>Married</td>
<td>20-29,999</td>
<td>2</td>
</tr>
<tr>
<td>Mother</td>
<td>Aisha</td>
<td>Married</td>
<td>80-89,999</td>
<td>1</td>
</tr>
<tr>
<td>Mother</td>
<td>Brianna</td>
<td>Divorced</td>
<td>Under 20,000</td>
<td>3</td>
</tr>
<tr>
<td>Mother</td>
<td>Dolly</td>
<td>Divorced/Remarried</td>
<td>60-69,999</td>
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<tr>
<td>Mother</td>
<td>Jennaia</td>
<td>Married</td>
<td>20-29,999</td>
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</tr>
<tr>
<td>Mother</td>
<td>Mark</td>
<td>Married</td>
<td>60-69,999</td>
<td>3</td>
</tr>
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<td>Father</td>
<td>Tyler</td>
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<td>2</td>
</tr>
<tr>
<td>Mother</td>
<td>Andrew</td>
<td>Divorced</td>
<td>80-89,999</td>
<td>1</td>
</tr>
<tr>
<td>Mother</td>
<td>Asher</td>
<td>Divorced</td>
<td>20-29,999</td>
<td>2</td>
</tr>
<tr>
<td>Mother</td>
<td>Caleb</td>
<td>Married</td>
<td>Under 20,000</td>
<td>2</td>
</tr>
<tr>
<td>Mother</td>
<td>Jake</td>
<td>Married</td>
<td>40-49,999</td>
<td>1</td>
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<tr>
<td>Mother</td>
<td>Peter</td>
<td>Married</td>
<td>100,000+</td>
<td>2</td>
</tr>
<tr>
<td>Mother</td>
<td>Rebecca</td>
<td>Divorced</td>
<td>Under 20,000</td>
<td>2</td>
</tr>
<tr>
<td>Mother</td>
<td>Spencer</td>
<td>Divorced/Remarried</td>
<td>20-29,999</td>
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While parents weren’t the main reason why youth indicated they choose participate in extracurricular activities, parents still encouraged their children to participate. All of the parents I interviewed indicated they felt their children should participate in something, and that extracurricular participation, when experienced positively, had value. While students principally viewed participation in extracurricular activities as opportunities to have fun, most parents perceived extracurricular activities to be opportunities for their children to interact with peers
and develop stronger friendships. For example, Mark’s father said, “I don’t think that my son would have any friendships in school if it weren’t for the sports and activities he has participated in.” In examining the ways in which family boundaries worked to enable or restrict the participation of students with disabilities, data analysis revealed three types of boundaries.

**Open family boundaries.** Open boundaries, which generally allowed for students to explore participation, while at the same time offered support and encouragement from parents, was the most frequently explained family boundary pattern, with open boundaries being identified in nine of the fifteen interviews I conducted with parents. In these types of boundaries, parents and children felt comfortable in their roles, and were able to articulate the ways in which they worked together in relation to participation. For example, Dolly’s mother explains:

She decides what she wants to do, and then I will encourage her to do it. She wanted to do soccer for a year, and I encouraged her. I didn’t know how much she would like it; she ended up not liking it very much, but she also knew she had to stick out the whole season, and so this year she wanted to do track. You don’t like one thing, try something new! So, I don’t push, but once she says she wants to do something, I’m all behind her.

Dolly echoed this sentiment in her interview, saying, “They are supportive. [My mom] goes to my plays, and she actually... They needed a chaperone, and they chaperoned. I appreciate her for that.”

**Closed family boundaries.** While in nine families boundaries appeared to be open for both parents and children, there were three families in which boundaries were closed, and were more protective of their teens due to their disabilities. In the case of Spencer’s mom, family boundaries had been established from early on, due to Spencer’s impairment, and had not changed. Spencer’s mom was acutely aware of her son’s heart problems, going so far as to explain that when Spencer was an infant, she would watch him when he slept, because she was worried he would have an attack and she would not be able to get to him in time. She still sleeps during the day and stays up all night, and while she realizes she needs to allow him to do things, such as get a license, she wishes he wouldn’t so she could continue to “protect him.” Spencer was also acutely aware of his mother’s influence when selecting extracurricular activities, and knew that family influence was “BIG, cuz they want me to be careful not to get hurt.” Spencer’s mom purposefully maintained closed family boundaries as a result of his impairment.
This closed, more enmeshed family boundary was also explained by Rebecca’s mom. Rebecca, her younger brother, and her mother were relatively new to town, and Rebecca’s health problem and learning disability were referenced frequently throughout her mother’s interview. However, Rebecca’s mother was protective as a result of disabling societal barriers, rather than a specific impairment. Rebecca’s mom said:

I tried at first to see if the kids would do stuff, you know, participate and make, like, connections. But after Rebecca told me how she got called “Bracey” and after I planned her Dairy Queen birthday and only one kid came, I said, you know what, you don’t need ‘em. I’m fun and we can do stuff, you know, like, I remember what it’s like to be a kid! So I’ll kind of act the fool so to speak and be goofy and crazy, and we stick together. It’s just us against the world. . . . But you know what, it’s okay. It’s us against the world and we’re all we need.

Jake’s mom, too, explained closed family boundaries, although she explained that she wished that it did not have to be the case. After years of trying, and fighting, and working to facilitate Jake’s participation, she felt resigned to limiting Jake’s participation and keep a strong central family unit. She explained:

Jake’s extracurriculars are a whole other story. After the old basketball coach that played him was fired, I called the new coach to see what the plans were for Jake on the team, and he informed me he "had too much on his plate" to deal with Jake. We had to turn in his uniform. It was a very hard time. Jake’s sophomore year, the new junior varsity coach became his aid. I had hoped that he would offer Jake the manager position and encourage Jake to take an interest with the team. That didn't happen. At the end of the sophomore year, I asked Jake’s aid if it would be possible for Jake to be a manager his junior year. He said that would be great. He told me how busy Jake would be the month of June with summer basketball. They would be going to an away game and spending the night in a motel. Jake was so pumped. OK, summer ball came, Jake managed the home games, then when he showed up to go to an away game, he was told there was no room for him on the bus. He was left standing all alone in the parking lot as they drove away. No one ever apologized to him or assured him that he was needed and to please continue managing. The overnight game came and went, Jake was never invited. Other extracurricular activities such as FFA and drama don't work well, because, while Jake is
welcomed to be there, once he is there, no one encourages interaction. Jake stands alone. Kids for the most part have not abused Jake, but they don't include him either. It's as if he's invisible. That makes him feel very lonely. He was bullied terribly in 8th grade, but you know, I think he preferred the bullying to being ignored. He withstand the bullying for a long time, and didn't want anyone to take action. He at least felt that he was included when he was being bullied. Now I just try to make him feel included at home. I think he values that, and feels like he is an important and central part of our family.

Although parents made the decisions to establish closed participation boundaries, these parents did not feel they had a choice. Both mothers of Rebecca and Jake set their family boundaries because they wanted to protect their children from experiencing painful stigma, while Spencer’s mom wants to protect him from physical pain. All three parents were worried their children would get hurt, and thus established boundaries because of the children’s disabilities, although in only one case were the boundaries established due to a youth’s specific impairment. In the cases of Rebecca and Jake, these are instances in which societal barriers become “barriers to being.”

**Fluid family boundaries.** The remaining three families articulated more varied boundaries dependent upon context, and explained how these boundaries changed over time and as a result of specific experiences. For example, Mark’s family explained that their family boundaries had previously been open, but became more restrictive as a result of experiences Mark had when he was 13, when he was molested by some of his male peers. Mark’s father believed it was likely that Mark’s disability had something to do with Mark being targeted, because he has a difficult time processing and being able to express himself, and Mark’s father felt that at the time Mark may not have been able to understand what to say, or what was going on. As a result of this incident, family boundaries were tightened, and only recently, as time has passed, and Mark has gone through therapy, have they opened, with Mark beginning to participate in extracurricular activities again.

**Roles**

Roles of students and parents are addressed in research question 2c: In what way do acted and expected roles play a part in youth program participation for students with disabilities? To answer this question, I examined roles as performed by students with disabilities within the
activity setting, as well as within their family systems. I also examine the types of roles that parents play in their children’s activity participation.

**Roles of students with disabilities.** Use of the word role in student interviews proved to be a tricky concept. In the interview protocol, I asked about roles in various ways. For students who were participants in activities and sports, I asked students what they believed their role was in the activity, club, or sport. I asked all the students I interviewed what their role was in the family, and I also asked some students whether they felt their roles changed or were different depending on what their activity or setting was. Many of the students were not sure what to make of the concept of “role”. It became apparent that many students had not considered their exact role in certain activities, while in some activities the answer was immediate.

**Roles in extracurricular activity settings.** Students responded most decisively about their roles when they participated in an activity or sport that had a very defined role. For example, for Mark, who ran track, he was able to specify that his role was to run the 100 meters, and the 200 meter hurdles. Because he knew his specific task, responding to the prompt was simple. When the type of activity has a specific assigned task, students’ responses were quick and decisive. “I sing soprano”; “I run the 100 meters”; “I am the secretary of the club”. Such systems operate in a very structured, methodical way, and allow those who participate to know exactly how their role functions to make the sport, activity, or club run. However, because these systems are structured in a precise and defined way, it can be difficult for students who do not fit the specified role to be included. Roles that are defined in such structured activities are expected to be acted in a consistent manner. Everyone who runs the 100-meters will perform the same task. Everyone who sings soprano will sing the same part. Such expectations can be positive, for students who need structure and are capable of playing the specified role. The students who continued participating in such activities were able to feel successful and were able to define their role precisely. Students who attempted those roles and were unable to fulfill the expectations of those roles often left the club or activity, and were left feeling unsuccessful. For example, Andrew had previously been in FFA, and explained all the different options for FFA participation:

They have like, they have a welding class, which I’m not a real big fan of welding, they have ag science, which is like a chem class also, they had a greenhouse management . . . and they dropped the class, and that’s when I decided to drop.
For Andrew, when the activity he enjoyed, greenhouse management, was dropped from the FFA options, he felt like he was unable to participate any longer. He did not enjoy other roles, and he did not feel successful attempting them.

While students in activities with defined roles responded quickly when prompted about their roles, students who were in more group oriented activities and sports often took longer and were less decisive when explaining their roles. Mark, who was able to quickly answer about his role in track, was also asked about his role in chess club. It was apparent he had not considered this before, and after a pause, he responded, “To be a teammate, I guess? Maybe to win?” This type of response was usual for students who were in activities with less defined roles. For example, Abby had to pause and think about her role in her service activities. Finally, she responded, “I help people. I do stuff to help other people in our community. It’s a great job to do and that is my role. I am happy to be in helping groups.”

While most students were able to define their roles as being a specific type of action within the organizational system, some students when interviewed explained that their role was simply to show up. Students’ conceptualizations of roles were often explicitly defined by what was expected within the activity system. In general, students who participated in activities were performing their expected roles, which ranged from simply showing up for Gamer’s Club, to being a forward on the Basketball Team. Students who felt uncomfortable or incapable of performing the assigned roles within the activity either left the activity, or if possible, attempted to change their role within the system.

**Roles in the family system.** Students were also asked about their role within their family. While sometimes students in extracurricular activities would pause before describing their role in those activities, all the students interviewed paused when asked about their role in the family. Several students even asked me to rephrase or restate the question. It became apparent that the majority of the students I interviewed had not previously considered their role within their family systems.

Most student responses were strikingly similar across the board, with the exception of three students. All but two students indicated they acted one of two roles: that of “a helper” or that of “a family member.” Students who indicated their role in the family was that of a helper included responses related to household tasks, such as mowing the lawn, vacuuming, and other common household chores. These type of role responses were rattled off after a moment to
pause and think of their specific action. For example, Brianna said, “I, um, help around the house with laundry and dishes.” Students who indicated their role was to be a family member said they were sisters, daughters, brothers, and sons. When students responded to a question of their role in their family in this way, it was a relatively quick and dismissive response. For example, Tyler, who had a learning disability, responded: “I’m a son, a brother, a kid, I guess?” The exception to this was Jake, who was very thoughtful and paused repeatedly when discussing his role in his family. It was apparent that Jake had previously thought at great length about his role, and had considered how his disability impacted his family. Jake said:

They are like, perfect family. See, they do things for me, and I do things for them. . . . I WANT to, because, this is kind of hard for me to say, because I haven’t said it for a long time. My family are always important for me, because I know what they feel, when they have a son like me [specifically referencing his Down syndrome]. . . . See, I want to be a man by myself and do things for them. It’s very important.

Jake’s response alluded to the efforts his family made to advocate on his behalf, and although he felt that his role was that of a son, he indicated that he would like to take a more active role. Jake was the only participant to reference his disability when asked about the role he plays in his family.

Only two student responses fell outside of the general role descriptions of “helper” and “family member”, and both were older teen boys whose families were currently in transitional states. Spencer indicated that his role was that of the “man of the house.” When asked to elaborate, Spencer said, “Cause my dad’s not always there…and my grandma, I’ve always lived with her.” In her interview, Spencer’s mom also explained that she was very protective of him, and then he in turn “feels the need to look out for me.” Similarly, Andrew stated that he was “very close to my mom these days.” Andrew then explained his current situation:

Like, my mom and dad’s gone through a divorce . . . and my mom has been stressed for a while, and plus with everything she’s been doing, she works with the school district. . . . She’s the assistant director and she does everything. She’s busy. She’s always busy, especially in the summer time, wrapping up stuff going on, and plus with my dad. That thing . . . [sighs]

Overall, students with disabilities did not perceive their familial roles to be in any way shaped by their disability status, with the exception of Jake, explained above. The students
Spencer and Andrew also explained roles that were more contextually specific, based upon larger events happening within their family systems. These roles were echoed by their mothers in their interviews, when I asked parents about roles in both the family system and the student participation process.

**Parent roles.** Early on in the parent interview, parents were asked what role they as parents played in their children’s participation in activities. In looking at the roles in which parents self-identify, I was able to delineate five main types of parental roles, as related specifically to the participation of their children with disabilities. These five categories are: protectors, activists, motivators, supporters, and parents who “facilitate the accomplishment of natural growth” (Lareau, 2003). While the first three role categories were directly shaped by the presence of the child’s disability, the final two role categories had little to do with a child’s disability status.

**Parents as “activists” (n = 2).** These parents were mothers of children with intellectual disabilities, and the influence of barriers resulting from those labels was prevalent in these parents’ interviews. Their role of “parent as activist” was a role that acted in many systems. Although Jenaia’s classification was learning disabilities, her sister had intellectual disabilities, and Jenaia’s mother explained that her activism skills were useful for all her children. Each mother explained experiences where she went to bat for her child, so to speak, and not just in the contexts of extracurricular participation, although that was included in the activist role played by these mothers. Jenaia’s mother created activity experiences for her children, when other participatory activities weren’t available in school or other social contexts. She explains:

> You know, I tried and tried to have the school allow them to participate. It got to the point where I made my own touring dance team for my girls. And they loved it! And parents of kids who didn’t have no disabilities were asking if they girls could join. Sure, of course! So I was always pushing. And Jenaia knows it. I think that’s why she’s so feisty. I wasn’t afraid to take them out of one school and switch ‘em when they wasn’t getting’ the services they needed. I wasn’t joking around with my girls.

Aisha’s mother took action for her daughter in the public realm, serving as a social advocate when Aisha was arrested after an incident while waiting at the bus stop. She explained:
I’m okay doing small things, like, I had written a letter to them [choral teachers] when she first started, and explained. And they were excellent. But when everything happened with the school bus stop thing, I had to really step up. I mean, I had registered her as having a disability, but they didn’t believe me. They told me that she must be drugged, or drunk. After everything that happened, I made sure that everyone knew to check their computers. There is no way a little girl who is mentally impaired who gets mad that she is called a retard needs to be dragged away handcuffed in a cop car. I am not afraid to be an activist when times call for it.

Children of parents who fall in the activist category were not more likely to be participating in activities, but they did have parents who were very aware of their children’s experiences in and out of school, and were vocal advocates and activists for their children’s inclusion and social participation.

Parents as “protectors” (n = 3). Parents who act as protectors have taken roles that remove their children from or intentionally limit the activities their children participate in, specifically due to experiences they have had as a result of their children’s disabilities. Playing the role of protector does not necessarily mean that their children had never participated, it simply means that now, they do not allow child to participate, or severely limit the activities of their children. In his interview, Caleb said of his parents, when talking about his participation, “Well, there aren’t many activities my mom and dad will allow me.” Caleb’s mom explained this in more detail in her interview, explaining that in the clubs he had been in:

He’s had a couple bullies that, I just stopped it up real quick. . . . I just talked to the teachers, straightforward, and told them if they didn’t want to take care of it, since the kids were in their class, I was gonna go above their head and go to the school board.

Jake’s mother told stories of continuously challenging the schools and coaches to allow her son to participate, and constantly failing. While at one point, Jake’s mother would have been considered an activist, at the time of the interview, she was tired of fighting, and specifically tired of watching her son get hurt when he tried to participate. She explained,

At this point, I don’t want him to keep putting himself out there. He’s a young man, but he’s still a kid. And if they can’t accept him, include him, value him? Then he’s not participating. It’s just not right for me to watch him over and over get his hopes up, and
then watch him be disappointed. Unless something changes, I’m just not comfortable with him being involved.

Parents as “motivators” (n = 3). Some parents felt that their role involved motivating their child to participate and be involved. These parents were very involved in the choices made by their children, and would often suggest potential activities for participation, or promote activities they felt their child may enjoy. Parents who were motivators often felt that their child’s disability could be a limiting factor for their child, and went above simple support and encouragement. These parents were likely to indicate that they played a part in their child’s current activities, and were explicit in discussing the reasons they played such a “motivating” role. These parents explained their reasoning behind high levels of involvement in their children’s activity choices in one of two ways: their children’s disabilities had either already resulted in barriers, or, alternately, these parents felt that the presence of their children’s disabilities could result in future barriers. Peter explained in his interview, “They try to get me into [activities], try and get me to do more, but always fail . . . Usually it’s stuff I don’t like, or I could be doing stuff I would prefer to do.” In her interview, his mother elaborated:

I am aware of the challenges he faces. He’s not super thrilled with social activities, and I am just trying to help him find his niche, find friends, and get involved! It’s very tough for him because of the autism, and I want him to find a hobby, or something! I just need to get him involved in something. So we do a lot together; I’ve taken him scuba diving, we do things related to animal welfare. I just make sure to find things that he can be involved in, so he doesn’t sink into himself.

Addie’s mom used her own personal experience, as she articulated her experiences growing up with an intellectual disability. She said:

I know from experience, right, how hard it is, and I just want to make my girl know it’s okay to do things. Especially, you know, if those things will help her. So I try and figure out what she likes, and encourage her. She’s a smart kid and has lots of abilities, you know. . . . So I try to make sure to motivate her to find things she can be successful at. And she’s good at basketball, so that’s great. ‘Cause, I mean, I know what it’s like not to be, you know?

Parents as “supporters” (n = 4). Parents who fall into the “supporter” category envision their role as a support for their children. While motivators and activists were more likely to seek
out and pursue activities for their children to participate in, parents who are supporters take a secondary role in the involvement process, and are seen as supporters once their child makes the decision to participate. Parents as supporters do not see their children’s disabilities as central elements of their children’s participation. These are parents who show up at games, drive their children back and forth to practices and events, and will serve as chaperones or coordinators of activities. Although they don’t play a part in the selection of their children’s activities, they make an effort to be actively involved as a supportive bystander and encourage their children’s engagement. Parents who fall into the “supporter” category may indicate that their children’s disabilities impact their choices of participation, or they may not, but their children’s disabilities are not central to the parents’ role formation.

For example, Brianna’s mom explained that she supported her daughter’s participation in Key Club: “Um, yeah, I mean, I go to special events, and I pick her up when they go to volunteer activities. It’s important for her to know I care and support her.”

Parents as “facilitators of the accomplishment of natural growth” (n = 2). In her book Unequal Childhoods, Lareau (2003) coined the phrase “facilitators of the accomplishment of natural growth.” This phrase maps well onto this fifth group of parents, who articulate their roles being those simply of parents, engaged in the time-consuming work of feeding, clothing, and taking care of children. According to Lareau, parents who fall into this category take a more hands-off approach to their children’s activities. While not actively discouraging their children’s participation, these parents are more concerned with day-to-day necessary activities, and place less value on their children’s extracurricular choices. Lareau uses the phrase specifically to refer to working class parents, as in her study, these parents often prioritized concerns related to issues of transportation, employment, and daily tasks, while leisure activities took a backseat to more pressing matters including income and household maintenance. Additionally, Lareau contextualizes “facilitating the accomplishment of natural growth” in parents who were working class. This proved to be the case in this sample, as well.

For example, Asher’s mother was a single parent who worked as a hairdresser, and had several other children besides Asher. She knew he loved playing football, and talked about the support he received from his coaches: “They really know what he needs and just…they just help him out and make it so he can play.” When asked about her role in supporting Asher’s involvement, she said:
Well, he does what he needs to, so I know he can play. I think, ya know, he gets what he needs to done, and so my role is just, ya know, be the mom and those kinds of things. He sorta has his own plan, and I let him do it. My role is just mom, I guess?

Similarly, Rebecca’s mother struggled to make ends meet. She was recently divorced, and working the second shift. She had Rebecca and a younger son at home, and her husband lived in California. Although she felt that extracurricular activities would be a good thing for Rebecca to do, she said:

She would really just need to do it, and I don’t see that happening right now. I’m not saying I don’t want to do more, because maybe that would help her. I’m just saying that my role is more to make sure that all the things going on stay going on, and sometimes even though it sounds nice, sports and those kinds of things just aren’t happening. And I’m not in a position to fight right now, I just can’t. It’s not that I haven’t tried, because I have a little, but it’s not something I can deal with right now.

The distinct parent role categories highlight the different ways in which parents prioritize extracurricular activities, along with the ways in which students’ disability status may or may not influence parental involvement in participation. For students with more involved disabilities, or for parents who had more resources or time, parental roles are those of activists or motivators. Some parents, who were concerned with their child’s disability, or were aware of the barriers to participation their children experienced, acted as protectors. And other parents, who didn’t specifically attach roles related to their children’s disability, acted as supporters or bystanders to their children’s participation in extracurricular activities.

In sum, participation of students with disabilities in school-based extracurricular activities looks very similar among students who are high activity participators and students who are low activity participators. Most students chose to participate based on interest in the particular activities, but most also experienced some form of barriers to their participation. In their interviews, student participants discussed societal participation barriers enacted by their school peers. Parents who were interviewed explained both societal and structural barriers, although more emphasis was placed on societal barriers, enacted not just by peers, but also coaches and activity leaders. The coach and leader data indicated that coaches are aware that students with disabilities encounter barriers to their participation. Over two-thirds of coaches and leaders cited the student’s impairment as the main reason students with disabilities may not
participate, while one-third of the coaches and leaders explained elements of societal stigma experienced by students with disabilities. In some instances, student participation was affected by family boundaries, particularly relate to students’ disabilities. Both impairments and societal barriers were cited by parents as they established their boundaries. Students’ reported roles in both extracurricular activities and within their families were relatively straightforward. Almost all students explained their roles without perceiving disability to be a major influence. This was not the case for parents, however, and many parents, specifically parents of children with more involved or visible disabilities, defined their roles in their children’s participation as being affected either by their children’s impairments or societal barriers, or both.
Chapter Six: Discussion and Conclusions

In answering the research questions, I focused on three important considerations. First, it was essential to determine what the participation of students with disabilities looked like in general. Although there were not as many student survey participants as I would have liked, there are still solid conclusions to be taken away from these data. While the students I surveyed and interviewed do have impairments, they also had personal desires, interests, and abilities that explained why they chose to participate in programs. For many students, their choice to participate was often just that, a personal choice. But students with disabilities were making the choice to participate while at the same time living at home and negotiating structural and societal barriers.

Second, because the students I interviewed were still living at home and were part of a functioning family system, I hypothesized family boundaries and parental roles would impact the choices these youth made and the level of independence they had to make those individual choices. For the students I interviewed, parent involvement was often a secondary consideration when discussing their activity participation. However, in parent interviews, it was apparent that parents were often highly aware of their roles in encouraging, facilitating, or even limiting student participation.

Finally, it was essential to understand the ways in which the school and society (in this case, peers of students with disabilities, their coaches/leaders, and school structures in general) impacted participation, either through the absence or presence of structural and societal barriers. While these three steps don't explicitly define the youth's presence in the greater society as a whole, the societal barriers that youth, parents, and program peers and staff experience are, by definition, presumed to be shaped by larger societal structures, allowing us to understand that the participation of students with disabilities in extracurricular activities can best be described as a situational experience.

Although interview participants were selected based upon their level and range of participation, findings suggest that there are not substantive differences in the barriers experienced by students who are high participators, or students who are low participators. In general, students participate based upon their interests, and are facilitated in or discouraged from participating by parents based on established boundaries and roles. Although there were differences among students with disabilities in their experiences of barriers, establishment of
family boundaries, and acting of roles related to participation, distinctive patterns among students who were high participators, and students who were low participators did not emerge. In this sense, participation was a situational experience for students with disabilities, with each student negotiating his or her disability identity as participation occurred. The following discussion will include an explanation of the situational experience of individual students, and the concepts of disability as a visible/invisible negotiated identity.

**Participation as a situational experience.** The conceptual image from chapter two, in which three circles overlap to create a central participation layer, is useful as a visual illustration, but doesn’t appear to map onto the data. Although each student’s participatory opportunities and experiences were shaped by the presence of impairment as well as barriers, family boundaries, and expected roles, it is important to note that such a model of overlap looks different for each student with disabilities who participates in extracurricular activities in a school setting. In addition, using the word Impairment as the entire process by which students with disabilities negotiate their participation in extracurricular activities is reductive, and fails to be inclusive of the ways in which students with disabilities make choices similar to their peers without disabilities. In fact, I would argue that students with disabilities in this study were more like their peers without disabilities than different. Bagatell (2004), in his study of students with autism and their negotiation of identity, suggests that identities are constructed through engaging in social worlds. In explaining the participation of students with disabilities, each student’s unique engagement yields a different arrangement of barriers, boundaries, and roles depending on the participant, the participant’s impairment, the participant’s family, and other external forces, including school peers and program leaders.

While structural barriers were not explicitly realized by students, larger institutional practices limited the participation of some students. Conversely, institutional practices that valued the participation of students with disabilities were evident in one school in particular, which had created a specific afterschool club for students with and without disabilities to interact. However, although the club existed, students at the school still reported incidents of stigma and othering, which may indicate that although institutional barriers weren’t enforced, societal barriers were still present for students with disabilities.

In selecting for interviews students who were highly participatory and students who participated very little, to not at all, I intended to explain the ways in which participation differed
for students; however, it quickly became apparent that both high and low participating students had varying levels of support and input into how they were making participation selections. In short, there were not common participation experiences that emerged exclusively among high participators or exclusively among low participators. However, there was a common theme among all student participants, regardless of participation level: that of visibility/invisibility.

**Visible/Invisible impairments.** While the most immediate finding in this research is that there is no one model that maps on to all students with disabilities, there was a common experience for all students who participated in interviews, specifically the idea of visibility/invisibility in negotiating disability. In discussing the concept of hidden or invisible disabilities, Gere (2009) writes, “The visible is not an accurate measure of the reality of another’s body.” While Gere applied this concept specifically to people who aren’t visually outside the norm, the application of this phrase fits, in some way, every student participant in this study.

**Invisible impairments.** The students with invisible impairments who were interviewed had labels that ranged from learning disabilities to intellectual disabilities to other health diagnoses. These were students who visually looked the same as their peers, and for many, looking the same as their peers allowed them the freedom to “just be kids”, as Abby’s mother declared. For these students, who lacked physical and conversational markers of difference, disclosure became a factor to consider when deciding to participate. I had hypothesized that lack of appropriate training or inexperience in dealing with youth with intellectual disabilities may cause program leaders to adopt misconceptions about the participation of youth with disabilities, especially for those youth whose disabilities do not have accompanying physical or conversational markers (Lippold & Burns, 2009). Such misconceptions and a lack of awareness may cause youth with disabilities to feel unwelcome or out of place (Castañeto & Willemsen, 2006). For students like Dolly, who was acutely aware of her learning disability, but felt she had mostly overcome it, the decision if and when to disclose the presence of her learning disability was something she weighed cautiously. Additionally, she was aware of the social stigma that she experienced in her classroom when her name appeared on a special list for students with IEPs, and this made Dolly hesitant to again be singled out as a result of her disability label. For students such as Dolly, participating in extracurricular activities served as an opportunity to be valued for skills outside the classroom, rather than being seen as a student with a label, while at
the same time, fear of potential stigmatization often meant not disclosing disability status. This is in line with Baines’ (2012) examination of the ways in which students with autism negotiate identity. She found that perceptions of ability were emergent through social interactions and that students negotiated their identity based upon context and prior experiences. It may also be the case that parental roles influence students’ decisions to disclose. For example, Dolly’s mother was supportive, but didn’t make Dolly’s disability a priority. Dolly’s mother told Dolly that she would have to “work harder to do the same things as everyone else” and Dolly consciously took that to heart when selecting and participating in activities.

Baines’ (2012) findings contextualizing the negotiation of disability also map onto the actions of Aaron, another student with invisible disabilities. Unlike Dolly, Aaron believed that disclosing the presence of his impairment was important, and allowed him to feel like his coaches, leaders, and teachers would be able to better understand him and his behaviors. While Aaron personally didn’t feel like he had a disability, and “just needed help sometimes” he felt that his impairments would impact his participation in such a way that it was important to disclose his disability status. Aaron also indicated that his mom told him that being in many activities helped him “get some energy out” and that she had initially disclosed his ADD/ADHD to coaches when he started playing sports at an early age. Such complex negotiation of identity by not just the student with the disability, but other major actors, including parents, was common among students as they made the decision to disclose, or not to disclose.

The concept of invisible disability takes on another dimension when students look like their peers without disabilities on the outside, but have disabilities that became apparent once they speak. For these students, disclosure was less of an option. For example, Mark had learning disabilities and a slight speech impediment, and so his impairment became obvious when he was carrying out a conversation. While his speech impediment made his enunciation less pronounced, his ability to carry on a conversation was not in any way hindered by his disability, and his vocabulary was expansive. That Mark was a student with a disability became apparent to his peers, but for the most part, Mark’s peers in track and chess were his friends. As Erevelles (2009) writes, in her discussion of the disability experience, “what is at issue is how the social world has ‘read’ these differences.” In Mark’s case, he looked the same as his peers, and his impairments allowed him to participate similarly. While previously Mark’s disability
had been an issue for him, negotiating his identity in his current activities did not involve negotiating the disclosure of his disability status.

Like Mark, Aisha had an invisible impairment, but it became apparent when she spoke. Aisha had an intellectual disability, and her speech often was delayed as she took time to formulate words and ideas. While she looked similar to her non-disabled peers, her speech was somewhat slurred, and her interactions were slower than those of her peers. The barriers Aisha had experienced as a result of her of invisible disability affected her very directly. While Aisha touched on her experiences in her interview, her mother elaborated, to explain the ways in which public perception of disability impacted Aisha’s participation at school. While waiting for the bus one morning, Aisha had gotten angry with a fellow student who called her retarded, and threatened to hit him with a branch that had fallen from a tree. The police were called, and instead of believing that Aisha had a disability that affected her speech and language, they insisted that she must be drugged and took her away in the back of their police car. While this experience wasn’t something that happened in an extracurricular activity, the residual effects of it impacted her time in school, her perceptions of authority figures, and her ability to participate in her activities once she returned to school following the incident. This experience also directly affected Aisha’s trust in adults and peers. While those who regularly interacted with Aisha were familiar with her communication mannerisms, and understood the ways in which her impairment affected her. However, in the situation described above, the fact that Aisha didn’t outwardly appear to have a disability caused confusion and miscommunication in an already tense situation. For students like Aisha, who have impairments that aren’t immediately obvious, disclosure, even if it is not an option, can have unforeseen consequences.

**Visible impairments.** While Gere (2009) discussed the concepts of disclosure in situations where invisible disabilities are present, the idea that “the visible is not an accurate measure of the reality of another’s body” can also be applied for students who have visible differences as a result of their impairments. For Rebecca, who had scoliosis and used to wear a brace, the visibility of her difference was apparent to her peers. She was teased and taunted because she didn’t look the same, and because her brace made her stand out and move awkwardly. Rebecca also explained that those experiences changed after she had surgery to correct her scoliosis. She said, “It’s not a big deal now. The brace is gone, and I’m the same as everyone else on the outside!” For Rebecca, who continued to receive help in school for her
For Jake, who felt unseen, the visible differences he had as a result of having Down syndrome resulted in his peers and others making assumptions about him because of the way he looked, and he didn’t have the option of surgery to eliminate markers of physical difference. While those physical markers indicated the presence of Down syndrome, they were unable to accurately disclose the personality, intelligence, or humor of the person inside his physical body. In this case, the social preconceptions about what Down syndrome is affected the ways in which Jake was perceived by his peers and by some adults in his school. While Jake wanted to be accepted by his peers and be included in extracurricular activities, many of his peers failed to get to know Jake beyond what they saw on the surface. Because of the societal barriers Jake experienced in school and in his extracurricular choices, Jake felt isolated and alienated from his peers, both with and without disabilities, which was in line with Baines’ (2011) findings that others’ perceptions of ability constrained Jake’s participation. Jake spoke about the ways in which he tried to encourage other students with Down syndrome in his school, but explained that he was already “doing algebra, and they are only knowing numbers.” As Jake tried to negotiate his identity, the visibility of his impairment constantly reminded him and his peers of his differences. While his peers with invisible disabilities had the opportunity to negotiate their “coming out”, Jake had no such option. As Gere (2009) explains: “When we, for example, assume that the visible impairment assigns an individual to the category of the disabled, we assume a resemblance to the actual student before us with the community we define as ‘the disabled’” (p.61). Such societal barriers were at play in the activity process for Jake, who was present, but never “there” to his peers, despite supportive involvement from his family.

**Family and its impact on student participation.** Although in the student survey participants didn’t place much weight on family as a factor in why they wanted to participate, student and parent interviews were able to tease out much more information about the ways in which parents were influential in the participation of their children.

Parents established family boundaries related to the participation of their children with disabilities, in line with children’s participation experiences or disability status (Canary, 2008). Parents who established optimal, open boundaries encouraged participation for their children, and often cited the establishment of positive peer relationships as an outcome (Schall &
McDonough, 2010). In developing family boundaries related to their children’s participation, parents who had closed family boundaries were explicit in discussing disability as it affected their decision to encourage their children to participate, or not. Prior research on families with disabilities has found that closed family boundaries are the result of a desire to “protect” and care for family members with disabilities (Hall, 2004). Sanders (2006) explains that overprotection by parents is often intended to shield their children with disabilities from difficult challenges, discrimination, or hurtful attitudes in society. In interviews, the parents who established closed boundaries were explicit about their desire to protect their children, and two of the parents who had previously allowed their children to participate had seen their children be affected by social stigmas related to their disability. While Sanders presents these closed boundaries as being more harmful than good, explaining that overprotection can lead to passive, dependent behavior in youth who are capable of learning responsibility and acceptable behavior, the families in this study who established closed boundaries were more in line with the findings of Lippold and Burns (2009), who argued that in families of youth with more severe intellectual disabilities, more closed family boundaries were in fact protective and created a stronger, albeit smaller, network of caring supporters.

Results from the current study do suggest that parents in many ways are doing all they can to enable their children to choose to participate, as well as to support them in the participation process. Parents’ role selection indicates that most parents are supporting, encouraging, or at the very least, acknowledging the participation of their children in extracurricular activities. In labeling one of the parental roles as “Parents as ‘facilitators of the accomplishment of natural growth,’” I was aware of the way in which Lareau (2003) established these parents roles within working class families.

In this study, although parents who enacted this role were in working class families, parents who demonstrated greater levels of involvement in other roles were not always middle class or above. Several of the parents who were motivators and activists were in working class families, which doesn’t necessarily map onto Lareau’s (2003) involvement patterns. In this study, the larger survey sample had a higher percentage of families who reported incomes that would indicate working class families. However, my survey sample also included schools situated in more rural areas, including smaller towns and villages. It could be the case that in these families, establishing community social capital became more important than income or
social class. In studies that look at social capital related to families with disabilities (Hale, 2011; Ong-Dean, 2009), social capital relates strongly to income and class; however, these studies are situated in urban environments where there is likely to be a different way of establishing social capital. In smaller, more rural areas, where families may have lived for generations, relationships may have been established over time, making income level less relevant in establishing social capital. As an example, in Jake’s case, the basketball coach who was fired was new to the town, and although he was a prominent businessman in the area, he was not part of the established social hierarchy, and thus was perceived to be an outsider.

However, even parents who acted as activists and motivators may not have established strong social support networks. Although for students, having parental support appears to be a motivating factor that enables the participation of youth with disabilities, it also was apparent that the parents who were not offering direct support for their children’s participation appeared to lack direct supports of their own. Parents repeatedly reported that they experienced a lack of personal support, although most parents continued to offer support for their child to participate, and support for their families in general. In examining the importance of support for parents, Ong-Dean (2009) found that parents with greater social and cultural capital were more able to get their voices heard in IEP and due process hearings. Nachshen and Minnes (2005), in their study of families of children with intellectual disabilities, found that a combination of perceived social support and family-centered support practices led to greater empowerment for parents. Having strong support networks allows parents to serve as better advocates for their children in school settings, and it is likely that having strong social support and social capital would also enable parents to be more involved in promoting the extracurricular activity of their children with disabilities.

Implications and Future Directions

In the current study, I used mixed methods research to integrate the social-relational model of disability with family systems theory, using the interactions of barriers, boundaries, and roles to explain the ways in which students with disabilities participate in extracurricular activities in high school settings. The results of this integration have important implications for future research, theory, and practice.

**Implications for program leaders.** The ways in which program leaders and coaches impact the participation of students with disabilities is profound. While in their surveys students
didn’t cite leaders as a main reason for participating, they did report that coaches and leaders were often a major influence in why they didn’t participate. In interviews, students and parents elaborated on this, reporting instances where coaches/leaders were strongly positive influences for participation, but also instances where such leaders were negatively influencing students’ desire to participate, and/or stay participating.

For program leaders and coaches, additional training and experience working with children with disabilities is crucial. Some leaders and coaches report that they have experience working with children with disabilities, or have training in special education, but most do not. Additionally, although some report to have had training related to disabilities and special education, such training often targets at specific labels and the ways in which students with those labels can achieve success in schools. For all leaders and coaches, an understanding of the social-relational model of disability, and the barriers that students with disabilities may encounter, would be beneficial. Carter et al. (2010a, 2010b) propose that educators and leaders need to play a role in developing the supports necessary for inclusion of youth with disability. As youth with disabilities become more fully integrated into program activities, it is possible that the role of the leader could evolve into one of supervisor, rather than providing special support. And training would also need to incorporate an understanding of visible/invisible disabilities, and the ways in which students choose to disclose their disability status. Murphy et al. (2008) propose a scaffolding effect, in which leaders are trained in modification to accommodate impairment, while also being trained to understand and be aware of the barriers faced by youth with disability.

It wasn’t clear in surveys or interviews if classroom teachers or resource teachers were interacting with coaches and leaders, but based upon the response received, it can be assumed that such communication was limited. In some activities, students’ impairments would not be expected to affect their participation, while in other activities, students’ impairments could directly affect participation, so encouraging communication between coaches and teachers could be a positive step in facilitating participation of students with disabilities, particularly in activities where a student’s impairment may be relevant to participation. Such communication between leaders and teachers could also allow program leaders and coaches to understand if a student has decided to disclose an invisible disability, allowing for them to monitor participation for students with disabilities. However, for other students, who may choose not to disclose their
disability status while they participate, the extracurricular activity may be a setting where they feel separated from social stigma related to their disability status. Although I believe that communication between classroom teachers and coaches and leaders is useful, it should be up to the student participant to disclose their disability status. For students with disabilities to feel comfortable disclosing to an activity leader, the activity should ideally be a place in which stigma is not tolerated. For coaches and leaders to understand this conceptualization of disability, they need to understand the implications of the social-relational model of disability as it applies in their activity setting.

**The social-relational model and its implications.** From a conceptual standpoint, the findings of this study represent a contribution to the continuing search for ways to operationalize the dimensions of disability. A key feature of the social-relational model of disability is its recognition of the fact that disability is not simply a medical phenomenon, but is multidimensional in nature, specifically impacted by social and structural factors. The environment is a central element of the social model with the recognition that the experience of disability is defined by the interaction of the person with the environment (Davis & Watson, 2001). For students who were experiencing barriers, we can see that those barriers were mostly perceived to be as a result of societal interactions with their peers within the school and the activity or sport. For such social interactions to be perceived as barriers, those students felt that their peers were disabling them through misconceptions or attitudes related to disability, and not valuing the student with disability for their positive contributions to the activity or sport.

While such stigmatizing attitudes can be a result of an individual judgment about disability, it is also the case that most of the misperceptions and stigma that are perpetuated are societal in nature, meaning that it is not just the one-to-one interaction that is enacting barriers, but the greater social circle that is enacting such “barriers to being.” Experiences of stigma are perpetuated at multiple levels. McMaugh (2011), who interviewed students with disabilities in Australia and their experiences with bullying and harassment by peers, suggests that peer harassment may be the result of structural disabling practices in the school community, such that children’s behaviors are simply perpetuating exclusion on a social level by making sense of exclusion on a structural level. While the students interviewed in this study weren’t explicitly explaining structural barriers, parents explained structural practices that accounted for student barriers, including rigid policies that limited students’ participation.
Application of the social-relational model to these data allow for an understanding of the barriers that students and their families experienced, and how such barriers influence family boundaries and parental roles that also impact student participation. The social-relational model of disability is most useful when the players involved understand the ways in which barriers are established, perpetuated, and overcome. All students in this study were included in classes with their peers in some way, and all parents believed that their children were in inclusion classes. Heshusius (2004) explains that the conceptualization of inclusion allows for social integration, but often the enactment of it does not, and she argues for special education to move away from a “prevention/treatment/remediation/measurement” to a “social/cultural/political” understanding of disability. While inclusion classes allow for students with disabilities to physically be in the same environmental setting as their peers without disabilities, inclusion as a concept needs to be embraced by those who are in charge of including. If the classroom teachers, and in turn, extracurricular activity leaders, fail to see the value in the social aspect of inclusion, it is unlikely that students will perceive the value of inclusion, and will instead continue to perpetuate the social stigma that leads to barriers for students with disabilities. Similarly, understanding the perceptions of students without disabilities who are participating in activities as peers with students with disabilities would provide a way to understand how their participation experiences may be similar and different to the students with disabilities in their activities. Do students without disabilities perceive these students to be their peers? Do they perceive them to be different? And do these students without disabilities enact inclusion as a social integration or merely a side-by-side environment?

As a way of creating an understanding of the “social/cultural/political,” Ware (2010) explained a lecture series implemented with university faculty and secondary teachers that presented disability studies ideas framed by the social model of disability. The humanities aspect of understanding disability allowed those who completed the lecture series to develop an understanding of disability through a cultural lens, rather than the traditional model that highlights “cure, care, and compliance” (Ware, 2009). Implementing similar training for school faculty, program leaders/coaches, and even parents could initiate dialogue, promote inclusion as an action, rather than an environmental setting, and facilitate an understanding of the barriers faced by youth who choose to participate in activities.
Implications for parents. In their interviews, several parents stated they didn’t know other parents who had children similar to theirs, and thought that it might be useful to have connections with families going through the same kinds of experiences. Abby’s mother indicated that the special education team at their high school specifically offered a parent group for parents of students with disabilities, and through it she had made strong connections with other parents in the community. The parent support group met monthly, and addressed issues specifically related to the special education process, including IEPs and transition planning. However, an additional benefit of this group was that parents had the ability to make direct contact with other parents in the community who may have similar experiences with the school system and the faculty and staff at their students’ schools. Wilgosh, Nota, Scorgie, and Soresi (2004) found that being in contact with other parents of children with disabilities was perceived as an important source of support for the family system in general. Providing an opportunity for parents of children with disabilities to make connections and build a social support network with other parents could provide supports for parents who need them. Guralnick, Neville, Connor, and Hammond (2003) found that the availability of social support and parents’ satisfaction with such support was significant in affecting social competencies for children with learning disabilities.

A monthly parent support meeting may not be as effective for parents who don’t have available resources to make it to a group meeting, however. Another option for parents who live in rural areas, or who work unusual hours, would be to connect with other parents online. In their grounded theory study, Huws, Jones, and Ingledew (2001) found that parents of children with autism perceived that email conversations with other parents on an autism specific listserv caused them to experience connection and to decrease their sense of being socially isolated. In this study, one mother explained that her strongest source of information and support was the social connection she had via the Autism Speaks Facebook page; she communicated regularly with other parents on the site to learn about developmental challenges and what she could expect now that her son was in high school.

Limitations

The current study contributes to the literature on participation of students with disabilities by integrating the social-relational model of disability with family systems theory, and shedding more light on the ways in which youth with disability are participating in school-based
extracurricular programs. The study does have some limitations that future research can address. Quantitative and qualitative data were collected, but the sample was restricted in terms of size and diversity. A larger and a more diverse sample would provide a wider distribution of experiences, and allow for more detailed examinations of the participation experiences of students with disabilities. While over 1100 letters were sent out to parents, there were only 71 final student survey participants. Therefore, this study may have omitted a potentially large population of students and parents with unique participation experiences, thus responses have the potential to be biased since such a large segment of the voices were not included in this study. Future research will need to address this self-selection issue to allow for a greater range of responses. Additionally, the data only includes schools in the east central Illinois region. While I identified schools with some varied demographic characteristics, experiences of participants may differ depending on the geographies of particular places, and a large urban population is simply unavailable in the local area.

A second limitation is that parent data included almost exclusively mothers. It would be ideal to examine fathers’ perceptions of their children’s participation, specifically as it relates to their children’s disability status. In outlining family boundaries and the ways in which those boundaries influence family roles, experiences of fathers may be helpful in understanding family dynamics, particularly in families where mothers indicated they had little support. Students with disabilities and their mothers often referenced the influence of fathers and additional family members, including siblings and grandparents. In the future, it will be important to gather data from other relevant family members.

A third major limitation is that program leaders’ experiences were collected via an online survey, instead of interviews. While the survey offered opportunity to gather basic demographic data and allowed for some open ended responses without using up valuable time and resources, clarification related to the survey responses would have been beneficial. It was also the case that coach and leader participants were contacted via the school contact person, thus potentially omitting some leaders and coaches at some schools. It would be beneficial to use in-depth interviews to further probe leaders’ experiences with students with disabilities participating in their programs.
Implications for Future Research

The current study points to a gap in the research literature on the extracurricular participation of students with disabilities and concludes that while participation experiences vary according to situation, there are common similarities that students with disabilities experience separate from those of their non-disabled peers. Students in general choose to participate in extracurricular activities because they enjoy them, although some students do indicate that they may experience societal barriers or stigma that may cause them not to join or to leave an activity. In addition, the ways in which students participate are often shaped by parent influence, namely, through the application of family boundaries and the influence of parent roles. Further examination of this concept, specifically focusing on students with invisible and visible disabilities, may provide a more complete picture about the ways in which different groups encounter barriers in extracurricular settings. Although I anticipated that level of participation may be related to various demographic factors or specific impairment type, the ways in which barriers were experienced and negotiated by youth with invisible and visible disabilities became more relevant than demographics or disability label. These findings underscore the need for future research that examines the role of disability visibility in impacting program participation by youth. Similarly, barriers reported by students all were in the form of social stigma related to disability, both external and internal. Additional research should be done with various age groups to see if social stigma looks the same at different ages, and how it changes over time. At what point do children begin to perceive the presence of visible disabilities, and how are these stigma experiences different for students with invisible disabilities? Such research considerations are a natural follow-up to the findings presented in this paper.

Along similar lines, it is also important to consider in future research how to ensure that participation is measured beyond attendance. In her interviews of adolescents with varied disabilities, Murray (2006) found a theme of “being present, but not belonging” (p.36), which was occasionally the case with some of the participants in this study, particularly students who felt they experienced barriers as a result of their disability status. While participation is the goal emphasized in this research, participation without a sense of belonging is unlikely to be a beneficial experience for any of the participants involved.

This study offers several ways to inform coaches, leaders, and even school administrators who work with students with disabilities and their families. Coaches and youth leaders should be
aware that students with disabilities will likely be interested in participating in their activities. To allow for students to participate, program leaders and coaches should receive training to understand that disabilities come in all forms, and affect every student differently. Leaders and coaches should also be aware that students can have extracurricular activities in their IEPs, and that students with disabilities are able to receive additional supports, if necessary.

Additionally, utilization of the social-relational model of disability does not perfectly map onto schools’ definitions of disability, which generally tend to follow the deficit approach of the medical model. IEP goals for participation that follow rigidly structured framework may not be easy to implement, or provide for meaningful activity by students with disabilities. Therefore, training for teachers, coaches, and leaders should also include information about barriers that students with disabilities experience, and ways those barriers could be diminished in activities. Special education teachers and administrators, on the other hand, should strive to provide students with disabilities and their families resources and support in selection of activities, and then support once students chose to be involved. In addition, administrators, leaders, and coaches who work with students with disabilities should partner with parents when necessary to provide support for parents, and to encourage optimal participation experiences, to allow students with disabilities become fully-functioning participants within their chosen activities.

Lastly, there needs to be more research examining relations between student participation and family dynamics. While certain parental roles were tied to the disability status of children, very few of the student roles explained were related to disability status in any way. This may have been because the student interviews focused less on disability status and more on participation and participation related topics, while parent interviews tended to explicitly mention disability in multiple areas. However, it may also be the case that students with disabilities are less focused on their impairments because the impairment has always been a part of who they are, and is all they know. Some parents were very aware of the othering that their children experienced as a result of these impairments, and worked to “normalize” their children’s perceptions of self, telling their children, “Normal is a setting on a drier” or, “Everybody has a disability, just some are in school and some are other places”. Such attempts by parents to normalize the experiences of their children with disabilities may have helped answer their children’s questions about differences, but may also have served to minimize the conversations about how to self-advocate, and how to own those differences. Most students wanted to distance
themselves from their “disability” label, but it is possible that the act of distancing oneself from the disability also disempowers the ability to self-advocate. Future research should examine the ways in which parents work to empower their children with disabilities to self-advocate.

Contributions

This study adds to the sparse literature relating to the participation of youth with disabilities in extracurricular activities. It makes several contributions to the current body of research. First, the study provides insight into the extracurricular participation choices youth with disabilities make, and how barriers, boundaries, and roles influence their choices. While barriers are a part of the way in which disability is created and experienced for the youth I interviewed, the barriers youth experienced affected not just their extracurricular activity participation, but the ways in which parents encouraged or discouraged the participation of their children with disabilities. Although most students with and without disabilities choose to participate in activities because they enjoy them, some students with disabilities explain barriers they encounter as a result of their impairments. In turn, the barriers that students encounter may lead parents to react through altering family boundaries or taking a more direct role in the participation process.

Second, the mixed methods approach for this study is a unique contribution, as most studies of the participation of youth with disabilities are strictly qualitative or quantitative, and mixed methods research exploring the experiences of youth with disabilities has been quite limited. Currently, there are studies that focus on the quantitative statistics of involvement for youth with disabilities (Kang et al., 2010; Wagner et al., 2004) but do not explain what participation involves for program participants; and there are studies that give youth voice in explaining their feelings about participation (Cavet, 1998; Moses, 2010), but do not provide the opportunity to generalize experiences, or integrate the voices of parents and program leaders.

Third, multiple voices were referenced, with parent and leader data augmenting youths’ participatory reports. Incorporating multiple data sources, including parents, coaches, activity leaders, and most importantly, students with disabilities, adds confidence to the research findings. Being able to expand upon survey findings in student and then parent interviews allowed for a richness in the data, and the development of a thorough explanation of the ways in which barriers, boundaries, and roles influence the participation of students with disabilities.

Finally, this study will be the first known application of an integrated approach using a social-
relational approach to disability with the family systems model. By using the social-relational model of disability, this research goes beyond a deficit explanation of the ways in which families of children with disabilities interact and develop. While in some families, disability is a major factor in family functioning, in others, a student’s impairment is less central to the establishment of family roles and boundaries.

In summary, the current study documents the complexity of the participation experiences of students with disabilities, and the ways in which participation influences family relationships. This study demonstrates that students with disabilities choose extracurricular activities for personal reasons, but may rely on the support of others (parents, friends, leaders) to maintain their participation. Most importantly, this study also explains the presence of barriers to participation for students with disability, while detailing the ways in which such barriers shape the choices of students with disabilities, as well as influence ways in which families encourage or discourage participation experiences. Since students with disabilities are participating in activities with their non-disabled peers, the well-being of these young individuals should be the priority of scholars and practitioners. Additional research is needed to better understand the diverse participation experiences of students with disabilities and their families, and to address the unique challenges these students and families face.
References


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Appendix A: IRB Approval

UNIVERSITY OF ILLINOIS
AT URBANA-CHAMPAIGN

Office of the Vice Chancellor for Research
Institutional Review Board
528 East Green Street
Suite 203
Champaign, IL 61820

August 12, 2011

Brent McBride
Human & Community Development
2013 Christopher Hall
904 W Nevada Street
M/C 081

RE: School-based Extracurricular Activity Participation of High School Youth with Disabilities
IRB Protocol Number: 11660

Dear Brent:

This letter authorizes the use of human subjects in your project entitled School-based Extracurricular Activity Participation of High School Youth with Disabilities. The University of Illinois at Urbana-Champaign Institutional Review Board (IRB) approved, by expedited review, the protocol as described in your IRB-1 application. The expiration date for IRB Protocol Number 11660, is 07/24/2012. The risk designation applied to your project is no more than minimal risk. Certification of approval is available upon request.

Copies of the enclosed date-stamped consent forms must be used in obtaining informed consent. If there is a need to revise or alter the consent form(s), please submit the revised form(s) for IRB review, approval, and date-stamping prior to use.

Under applicable regulations, no changes to procedures involving human subjects may be made without prior IRB review and approval. The regulations also require that you promptly notify the IRB of any problems involving human subjects, including unanticipated side effects, adverse reactions, and any injuries or complications that arise during the project.

If you have any questions about the IRB process, or if you need assistance at any time, please feel free to contact me or the IRB Office, or visit our Web site at http://www.irb.illinois.edu.

Sincerely,

[Signature]

Sue Keehn, Director, Institutional Review Board

Enclosures

c: Colleen Gibbons
Appendix B: Recruitment Materials

September 28, 2011

Dear Parent or Guardian,

In the next few days, you will be receiving an informational consent form in the mail inviting you and your child to participate in a project to better understand the needs of all students at XXX High School. The project is specifically focused on how all students make decisions to participate in extracurricular activities, clubs, and school sports. Your child is eligible to participate even if he or she doesn’t belong to clubs or participate in other activities or sports at this time.

This project would involve your child completing a brief, ten minute survey to explain his or her participation in afterschool activities. The survey would be administered while your child is in a classroom setting. Your child will be entered into a raffle for a $15 iTunes gift card if he or she completes the survey. Additionally, there is potential that you and your child may be contacted for interviews at a later date, to further explain his or her participation. If you are selected for a follow-up interview, you will receive a $10 Walmart gift card, and your child will receive a $15 iTunes gift card.

Your participation is completely voluntary, and more detailed information will be supplied in the mailing. We will also be happy to provide more information if you have questions. Please feel free to contact us. If you have questions, you can call Colleen Gibbons at (217)778-7780 or email her at cgibbon2@illinois.edu, or call Brent McBride at (217) 333-0971 or email him at brentmcb@illinois.edu.

Thank you!

Colleen Gibbons, M.S.
Doctoral Candidate
Department of Human and Community Development
University of Illinois at Urbana-Champaign
(217) 778-7780
cgibbon2@illinois.edu
Dear Parent/Guardian:

We invite you and your son/daughter to take part in a new and exciting project. The project will focus on the participation in extracurricular activities and sports of students with disabilities at XXX High School. This project is sponsored by the University of Illinois at Urbana-Champaign.

Here are some highlights of the project:

- All student participants will complete a survey about their previous and current experiences in extracurricular activities and sports at XXX High School.

- Some students will be selected as interview participants to talk about why they do and do not choose to be involved in extracurricular activities.

- Parents may be selected to explain their role in the participation of their child in school activities.

- Club leaders and coaches will give input about their goals for the participation of students with disabilities in the activities they lead.

The consent form that follows this letter tells more about the project and your rights. There is a space where you can sign if you would like your son/daughter to participate or where you can mark if you do not want your child to participate. Please return the three attached pages in the enclosed envelope no later than 12/31/11. The other page is a copy is for you to keep for your records.

As a “Thank you” to participants, Walmart and iTunes gift cards will be provided as explained below. Student survey participants will be entered in a drawing to receive a $15 gift card. All parents who are selected will receive a $10 gift card, and student interview participants will receive a $15 gift card. In addition, XXX High School will receive a $10 gift card.

If you have any questions, feel free to contact me at (217)778-7780 or cgibbon2@illinois.edu.

Sincerely,

Colleen Gibbons
Doctoral Candidate
PARENT CONSENT LETTER

November 8, 2011

Dear Parent or Guardian:

My name is Colleen Gibbons and I am a doctoral student from the Department of Human and Community Development at the University of Illinois at Urbana-Champaign. My advisor, Dr. Brent McBride and I would like to include your child, along with his or her classmates, in a research project on extracurricular activity participation for high school students with disabilities. We are interested in learning how students currently participate, and we anticipate that this project will help inform schools about future extracurricular services including youth with disabilities. You and your child are invited to participate in this research study as outlined below.

Participation: There are two steps in this project. If you consent for your child to take part in this project, your child will first complete a brief, 15 minute survey about his or her current and past participation in extracurricular activities. We also ask that you complete and return the family information sheet attached to this form. The second part of the project consists of two individual interviews, one with you and another with your child. These interview sessions will take place separately, with your child's interview being completed at school, and your interview being scheduled at a time and place convenient to you. If at any time you or your child prefer not to answer an interview or survey question, you can skip it. Interviews will be recorded using a digital recording device. Not all who have agreed to participate will be asked to complete interviews.

Confidentiality: Your child's responses will be entirely confidential. To ensure maximum privacy, your child will be assigned an identification number, and only these numbers will be associated with your child's survey and interviews. The audio recordings, surveys, and all other information that is obtained during this research project will be kept strictly secure and will not become a part of your child's school record. All materials will be kept in a locked office in a secure file cabinet, and will be accessible only to project personnel. The audio recordings will be transcribed and coded to remove children’s names and will be deleted following the completion of this project.

Risks and Benefits: We do not anticipate any risk greater than normal life. Your child's participation in this project is completely voluntary. In addition to your permission, the project will be explained to your child, and he/she will be asked if he/she would like to participate. Any child may stop taking part at any time. The choice to participate or not will not impact your child’s grades or status at school. We cannot claim any direct benefits to your child for participation, but the general study will serve to inform your child's school about patterns of participation of youth with disabilities.

Appreciation: If your child completes the first step of this project, the survey, he or she will be entered to win a raffle of a $15 iTunes gift card. Odds of winning are 1 in 25. If you and your
child are selected to complete interviews, your child will receive a $15 iTunes gift card, and you will receive a $10 Walmart gift card.

Results: The results of this study may be used for a dissertation, an educational report, journal article and presentation. Pseudonyms will be substituted for the names of children and the school. This helps protect confidentiality.

In the space at the bottom of this letter, please indicate whether you consent to have your child participate in this project. Participation is strictly voluntary for both you and your child. Please complete one copy and return in the enclosed stamped envelope by December 31. The second copy is to keep for your records. If you have any questions about this research project, please feel free to contact us either by mail, e-mail, or telephone.

Sincerely,

Colleen Gibbons, Research Assistant
217-778-7780
cgibbon2@illinois.edu

Brent McBride, Professor
217-333-0971
brentmcb@illinois.edu

g___Yes _ g___ No    I agree to allow my child to complete a survey about his/her extracurricular activities.

g___Yes _ g___ No    I agree to allow my child to be interviewed, if selected.

g___Yes _ g___ No    I agree to be interviewed, if selected. (Please provide contact information below.)

g___Yes _ g___ No    I give permission for audio recording of interviews, as explained above.

Parent’s signature ________________________________
Date__________________

If you have any questions about your or your child’s rights as a participant in this study or any concerns or complaints, please contact the University of Illinois Institutional Review Board at 217-333-2670 (collect calls will be accepted if you identify yourself as a research participant) or via email at irb@illinois.edu.
If you consent for your child or yourself to participate, please complete the following information:

Child’s name: ____________________________________________

Your Contact information:

Name:____________________________________________________

Phone:__________________________________________________

E-mail:__________________________________________________

Best way to contact:______________________________________
Family Information Sheet

Information about your child:

For how long has your child attended schools in the XXX school district?

____ years attended

Your child has been identified as a possible participant. Can you tell us why you believe he/she qualifies?

_____________________________________________________________________________________________

Does your child have an IEP or a 504 plan?

☐ Yes
☐ No

For how long has your child had an IEP or 504 plan?

☐ Since birth
☐ Since preschool
☐ Since elementary school (K-5)
☐ Since middle school (6-8)
☐ Starting in high school (9-12)

What kinds of services or accommodations is he/she receiving as a result?

_____________________________________________________________________________________________

Is your child mainstreamed (or in an inclusion classroom) with his/her peers?

☐ Yes, my child attends only classes with his/her peers without disabilities
☐ Yes, my child attends most classes with his/her peers without disabilities
☐ Yes, my child attends at least one class with his/her peers without disabilities
☐ No, my child attends only special education classes

Does your child identify as Hispanic or Latino?

☐ Yes
☐ No

What is your child's race? (Please check all that apply.)

☐ White
☐ Black or African American
☐ Native Hawaiian or Other Pacific Islander
☐ Asian
☐ American Indian or Alaska Native
☐ Two or More Races

Family information:

How many children do you have?

____ children
How many children currently live in your home?

____ children

What is your gender?

☐ Male
☐ Female

What is your relationship to the student? (Please check all that apply.)

☐ Mother    ☐ Biologically related
☐ Father    ☐ Non-biologically related
☐ Grandmother
☐ Grandfather
☐ Legal Guardian

What is your marital status? Are you:

☐ Now married
☐ Widowed
☐ Divorced
☐ Separated
☐ Never married

What is your total household income?

☐ Under 20,000
☐ 20,000-29,999
☐ 30,000-39,999
☐ 40,000-49,999
☐ 50,000-59,999
☐ 60,000-69,999
☐ 70,000-79,999
☐ 80,000-89,999
☐ 90,000-99,999
☐ 100,000 and over

What is the highest number of years of school you have completed?

____ years completed

What is the highest number of years of school your spouse (if applicable) has completed?

____ years completed

Please indicate the highest degree achieved by both you and your spouse.

<table>
<thead>
<tr>
<th>Degree Earned</th>
<th>You</th>
<th>Your Spouse</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Elementary School</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High School Diploma/GED</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Associate Degree</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bachelor's Degree</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Master's Degree</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Professional Degree (MD, DDS, DVM, LLB, JD)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doctorate Degree (Ph.D. or Ed.D.)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix C: Sample Student Survey

XXX High School Student Survey

ID Code: ______________

Please answer the following questions to the best of your ability. An extracurricular activity is a club or sport that you choose that is not a required school subject.

Please select one:

- Male
- Female

What grade are you in?

- 9 - Freshman
- 10 - Sophomore
- 11 – Junior
- 12 - Senior

How old are you? _____________ years old

How long have you been in the XXX School District? _____________ years

1. Do you now participate in after-school or extracurricular activities or sports?

- Yes
- No

2. Have you ever participated in after-school or extracurricular activities or sports?

- Yes
- No (If no, skip to question 10 on page 5.)
3. What sports did you participate in last year, participate in right now, or plan to participate in later this year?

- I do not and have not participated in any sports teams. (Skip to page 3.)
- I participate in sports teams. (Please indicate which sports teams below.)

Please select any sports that you are in, and if you participate in something that isn’t listed, please write it in the blank spaces at the bottom.

<table>
<thead>
<tr>
<th>Sport</th>
<th>I participated LAST year</th>
<th>I participate NOW</th>
<th>I will participate LATER this year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseball</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Basketball</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bowling</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cheerleading</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cross-Country</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fishing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Football</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Golf</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lacrosse</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Soccer</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Softball</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Swimming/Diving</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tennis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Track and Field</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Volleyball</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wrestling</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4. If you marked a sports team above, what is (or was) your role on the team?

- I play the sport/ I played the sport
- I help manage/ I helped manage the team
- Other ..........................
5. What clubs or activities did you participate in last year, do you participate in right now, or plan to participate in later this year?

☐ I do not and have not participated in any clubs or activities. (Skip to page 4.)
☐ I participate in clubs or activities. (Please indicate which activities below.)

Please select any clubs or activities that you are in, and if you participate in something that is not listed, please write it in the blank spaces at the bottom.

<table>
<thead>
<tr>
<th>Club/Activity</th>
<th>I participated LAST year</th>
<th>I participate NOW</th>
<th>I will participate LATER this year</th>
</tr>
</thead>
<tbody>
<tr>
<td>African American Culture Club</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anime</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Art Club</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asian American Culture Club</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Board Games</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brother’s Inc.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Centinal Newspaper</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Children’s Miracle Network</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dance Marathon</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Choir</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Club About Nothing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Color Guard</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fiction Addiction: Book Club</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>French Club</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Future Teachers (FTA)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gay-Straight Alliance</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>German Club/German Honor Society</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>G.I.F.T.S.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interact Club</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Key Club</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Math Honor Society</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Math Team</td>
<td></td>
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<td></td>
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<tr>
<td>MECC</td>
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<td></td>
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<tr>
<td>Melody 4U</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>National Honor Society</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Operation COOL</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pep Band</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Scholastic Bowl</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Speech</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Student Council</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thespians</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>WYSE (Worldwide Youth in Science and Engineering)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
6. How many times a week do you participate in extracurricular activities, clubs, or sports?  
___________ times a week

7. How many hours each day do you participate in extracurricular activities, clubs, or sports? (Only include Monday-Friday, NOT weekends.)  
___________ hours a day

8. For sports, clubs, or activities you are in NOW, what makes you want to participate? (Please pick all that apply.)

☐ I like the activity.  
☐ I have friends who participate.  
☐ The leader or coach asked me to join.  
☐ I like the leader or coach.  
☐ My parents wanted me to join.  
☐ It’s good for my future.  
☐ I am good at the activity.  
☐ I want to make new friends.  
☐ It helps me in school.

9. For sports, clubs, or activities you used to be in, but aren’t anymore, why did you stop participating? (Please pick all that apply.)

☐ I didn’t like the activity.  
☐ I didn’t have friends who participated.  
☐ I didn’t like the leader or coach.  
☐ I felt like I didn’t fit in.  
☐ My parents didn’t want me to participate anymore.  
☐ I didn’t have transportation.  
☐ It conflicted with other activities.  
☐ I wasn’t good at the activity.  
☐ I didn’t have enough time.  
☐ I wanted to join again, but didn’t make the team, or wasn’t chosen to participate.

10. Are there sports, clubs, or activities that you would like to participate in, but have not joined?
11. If so, what activities, clubs, activities, and/or sports do you want to participate in?

__________________________________
__________________________________
__________________________________

12. Have you ever wanted to join an activity, club, or sport, but then you didn’t join?

☐ Yes
☐ No

13. Why not? (Please pick all that apply.)

☐ I didn’t make the team, or I wasn’t chosen for the activity.
☐ I felt like I didn’t belong.
☐ I didn’t have transportation.
☐ I thought it would take up too much time.
☐ It interfered with other activities.
☐ My parents didn’t want me to.
☐ I felt like the other kids would make fun of me.
☐ I wasn’t able to do the same things as the other kids.
☐ The other participants made me feel uncomfortable.
☐ The leader or coach made me feel uncomfortable.
Appendix D: Leader Survey

Leader Survey

Please answer the following questions to the best of your ability. In some places the blanket term "activity" is used in place of the more specific terms "club" and "sport".

Do you currently work at ___________ High School?
   If yes: How long have you been at the high school?
   If no: What is your current occupation?
   For how long?

What activities, clubs and/or sports do you lead?

How long have you been a leader of clubs, sports, and other school activities?

Do students with disabilities participate in your sport, club, or activity?

☐ Yes, this year
☐ Yes, previously
☐ No
☐ I don't know/I'm not sure

   If yes: How fully do youths with disabilities participate in your activity?

      1 The same as youths without disabilities
      2 Very similar, with some modifications
      3 They have their own individual roles to play

(Include space for additional comments)

If no/don’t know: Do you think your activity is appropriate for students with disabilities?

      1 No, this is not an appropriate activity for them
      2 It could work depending on the disability of the student
      3 Yes, it is appropriate for students with disabilities

(Include space for additional comments)

What role do you see students with disabilities playing in your sport or club?

What barriers do you see for students with disabilities participating in school activities, clubs, and sports?
How do you feel your school prioritizes the inclusion of youth with disabilities in extracurricular activities?

1 - Not a priority
2 - Occasionally a priority
3 - Very often a priority
4 – Always a priority

Do you have a background or training in special education?

Basic demographics:

Please select one:

- male
- female

Please check your age:

- Under 20
- 20-29
- 30-39
- 40-49
- 50-59
- 60-69
- 70 and over

Please indicate the highest degree you have completed.

- None
- Elementary School
- High School Diploma/GED
- Associate Degree
- Bachelor's Degree
- Master's Degree
- Professional Degree (MD, DDS, DVM, LLB, JD)
- Doctorate Degree (Ph.D. or Ed.D.)
Appendix E: Interview Protocols
Student Interview Protocol (Active Participant)
Hi! My name is Colleen, and I'm very interested in learning about your experiences at _______. Today I'm going to be asking you to tell me your story. I will ask you a few specific questions, but mostly I want to know about what your likes and dislikes are, and how you like to spend your time. You can choose to end the interview at any time if you want. You can also choose not to answer certain questions if you don’t feel comfortable. I will keep your name confidential and everything that we will talk about will be kept private and confidential. Do you have any questions before we begin?

I. General Overview Questions
1. How long have you been at _______ High School?
2. Do you like school? Why or why not?
3. What is your favorite class? Why?
4. What is your least favorite class? Why?
5. What is your typical school day like?
6. How do you get to and from school?
7. What kinds of things do you like to do in your free time?
8. Tell me about the other kids in your school.
9. How do you feel about your friends?

II. Organization Specific Questions (repeated for each activity)
Now I'm going to ask about extracurricular activities that you do at school.
1. Do you feel like it’s easy to find an activity that fits you?
2. What leads you to be involved in so many different activities?
3. What got you started participating in ____________?
4. How long have you been participating?
5. What kind of activities do you do in ____________?
   a. Have the kinds of activities you do changed since you joined?
   b. What do you think your role is in the club/team?
6. How often do you participate?
7. How do you get to and from activities?
8. Do you have friends that participate with you?
   a. If yes, have friends that participate:
      i. Were you friends before you joined?
         (a) If yes: Did he/she influence your choice to join?
         (b) If no: How did you become friends?
   b. If no, friends don’t participate:
      i. Do you think you'll make friends as you continue to participate? Why/why not?

III. Organization Interests
1. Has anyone ever asked you specifically to join in a club or activity?
2. Do you think you would be more likely to join if the program leader or coach asked you? What about a friend?
3. What role do you see your friends playing in your participation?
4. Do you feel comfortable participating with other students who aren’t your friends?
5. Do you ever feel uncomfortable when participating in sports or activities? Why/why not?
6. Do your parents ever impact your thoughts about programs? Would you join if your parent wanted you to?
7. What role does your family play in your participation?
8. How do you pick what activities/sports to be involved in?
9. Have you ever started to participate in an activity but then stopped?
   a. If yes: Why?
10. If a new student were to come to _______ High School and asked you if he/she should participate in extracurricular activities, what would you recommend to him/her? Why?

IV. Impact of Disability/Impairment
1. Does having a disability influence your choice to participate in activities? (This would be modified depending on the parental response on the info form – I may use language to indicate what the youth’s disability is, for example, “does having a learning disability...”, or “does having autism...”)
   a. If yes: How so?
   b. If no: Why do you think it hasn't affected your participation?
2. Do you think that you are treated any differently because you have a disability?
3. How does having a disability affect the way you feel about yourself?
4. Tell me about what it means for you to be a high school student with a disability.

V. Family
1. Do you spend a lot of time with your family?
   a. If yes:
      i. Do you spend time with your family by choice, or because it's something you have to do?
      ii. Do you like spending time with your family?
      iii. What kinds of things do you do?
   b. If no:
      i. Why not?
      ii. Who do you usually spend your time with? (I know it's not grammatically correct)
      iii. Would you like to spend more time with your family?
2. Do you think your parents support your decisions?
   a. If yes: How? What kinds of things do they support you with?
   b. If no: Why not? Do you wish they did?
3. What do you think your role in the family is?

VI. Support
1. If you're having a bad day, who do you talk to?
2. Who do you think are your best sources of support?
And finally, what else do you want me to know about you before we end this interview? Are there other experiences that you'd like to share?

Student Interview Protocol (Non-Active Participant)

Hi! My name is Colleen, and I'm very interested in learning about your experiences at ______ High School. Today I'm going to be asking you to tell me your story. I will ask you a few specific questions, but mostly I want to know about what your likes and dislikes are, and how you like to spend your time. You can choose to end the interview at any time if you want. You can also choose not to answer certain questions if you don't feel comfortable. I will keep your name confidential and everything that we will talk about will be kept private and confidential. Do you have any questions before we begin?

I. General Overview Questions
1. How long have you been at ______ High School?
2. Do you like school? Why or why not?
3. What is your favorite class? Why?
4. What is your least favorite class? Why?
5. What is your typical school day like?
6. How do you get to and from school?
7. What kinds of things do you like to do in your free time?
8. Tell me about the other kids in your school.
9. How do you feel about your friends?

II. Organization History
1. Have you ever participated in clubs, activities or sports at your school?
   a.) If yes, have participated before:
      i.) Why were you first interested in ____________?
      ii.) What was your experience as a participant like?
      iii.) What made you stop doing/playing ____________?
      iv.) If it was a positive experience:
           Have you ever thought about joining again?
      v.) If it was a negative experience:
           What kind of things would have to be different for you to want to think about participating again?
   b.) If no, haven't participated before:
      i.) Have you ever wanted to join a club, activity or sport at your school?
          aa.) If yes, wanted to join:
               What stopped you from joining?

2. If a new student were to come to ______ High School and asked you if he/she should participate in extracurricular activities, what would you say to him/her? Why?

III. Organization Interests
1. Do any of the activities listed here interest you? (Share generated list of school activities.) (Carter et al., 2010)
2. What keeps you from being involved in school activities? (e.g., don’t know anyone in the group, unaware of available opportunities, no time)? (Carter et al., 2010)
3. Has anyone ever asked you specifically to join in a club or activity?
4. Do you think you would be more likely to join if the program leader or coach asked you? What about a friend?
5. What role do you see your friends playing in your participation?
6. Would you feel comfortable participating with other students who aren’t your friends?
7. Do you think you would feel comfortable participating in sports or activities? Why/why not?
8. Do your parents ever impact your thoughts about programs? Would you join if your parent wanted you to?
9. What role does your family play in your decision to participate or not?
10. What things would make you more likely to want to join in with clubs, sports, or other school activities now?

IV. Impact of Disability
1. Does having a disability influence your choice to participate in activities? (This would be modified depending on the parental response on the info form – I may use language to indicate what the youth’s disability is, for example, “does having a learning disability...”, or “does having autism...”)
   a. If yes: How so?
   b. If no: Why do you think it hasn't affected your participation?
2. Do you think that you are treated any differently because you have a disability?
3. How does having a disability affect the way you feel about yourself?
4. Tell me about what it means for you to be a high school student with a disability.

V. Family
1. Do you spend a lot of time with your family?
   a. If yes:
      i. Do you spend time with your family by choice, or because it's something you have to do?
      ii. Do you like spending time with your family?
      iii. What kinds of things do you do?
   b. If no:
      i. Why not?
      ii. Who do you usually spend your time with? (I know it's not grammatically correct)
      iii. Would you like to spend more time with your family?
2. Do you think your parents support your decisions?
   a. If yes: How? What kinds of things do they support you with?
   b. If no: Why not? Do you wish they did?
3. What do you think your role in the family is?

VI. Support
1. If you're having a bad day, who do you talk to?
2. Who do you think are your best sources of support?

And finally, what else do you want me to know about you before we end this interview?
Are there other experiences that you'd like to share?

Parent Interview Protocol (Non-Active Participant)

Hi! My name is Colleen, and I'm looking forward to learning about your experiences as a parent of a child at _______ High School. Specifically, I'm interested in learning about extracurricular activity participation of high school students with disabilities, but most of all I want to know about your personal experiences as a parent. Today I'm going to be asking you to tell me your story. I will be asking you questions I have arranged in advance, but mostly the questions are to make sure I hear the most I can about your experiences. Finally, I need to emphasize that I will judge you based on any of your responses. I'm very interested in what you have to say and value your experiences. You can choose to end the interview at any time if you so choose. You can also choose not to answer certain questions if you don’t feel comfortable. I will keep your name confidential and everything that we will talk about will be kept private and confidential.
Do you have any questions before we begin?

I. General Overview Questions
1. How many children do you have?
2. Where does __________ fall in the birth order?
3. What kind of a relationship does __________ have with his/her siblings?
4. Tell me about __________'s experience in school so far. What has school been like for him/her?
5. Does __________ like school? Why or why not?
6. Do you think it's important for __________ to like school?

II. Participatory Experiences
1. When you were in school, were you active in extracurricular activities?
   a. If yes: Tell me about your experiences.
   b. If no: Why not?
2. Do you think it is important for your children to participate in extracurricular activities? Why/why not?
3. Has __________ ever expressed interest in participating in a school activity?
   a. If yes:
      i. Did __________ participate?
      ii. What was the outcome?
   b. If no:
      i. Why do you think __________ hasn't been interested in participating in school extracurricular activities?
4. What have __________’s experiences in extracurricular activities been like?
5. What role have you played in ________’s selecting and participating in activities?

6. Are there activities that _________ participates in outside of the school setting?
   a. **If yes:** What factors have led to participation in these activities?

7. Are there activities outside of school that you participate in as a family?
   a. **If yes:** What things do you like to do together?

8. **If there are siblings:** What kind of role do you think _________’s brothers/sisters have played in _________’s participation?
   a. Do _________’s siblings participate in activities?
   b. Are there differences in the way you approach parenting for _________ in comparison to your other children?

### III. Friendships/Peers

1. Tell me about _________’s friendships at school.
2. Has _________ had steady friendships over the years?
3. Does _________ get together with friends from school?
   a. **If yes:** How frequently?
      How often does ______ use Facebook, talk on the phone, text...?
   b. **If no:** What is _________’s main source of social interaction with friends and peers? (Talking on the phone, texting, Facebook...)
4. Does _________’s disability affect the types or quality of his/her relationships? In what ways?

### IV. Additional Impacts of Disability

1. Do you think that _________’s disability has impacted his/her participation?
   a. **If yes:** In what way?
   b. **If no:** What other factors have influenced participation?
2. Are there barriers that _________ has experienced as a result of his/her disability?
3. Are there barriers that you have experienced as a result of _______’s disability?
4. What do you think _________’s role in the family is?
   a. **If there are siblings:** Is the role different than that of his/her siblings?
5. Has this role changed over time?
   a. **If yes:** In what ways?
6. Do you think that _________’s disability has impacted your family? How so?

### V. School

1. Tell me about your experience as a parent of a student with a disability at ____________ High School.
2. How have your experiences with teachers, administrators, coaches and program leaders impacted decisions about ____________’s participation?

### VI. Support

1. Are you familiar with other parents and families who have similar experiences to yours?
2. Do you feel like you have support from others in your daily life?

And finally, what else do you want me to know about __________ before we end this interview? Are there other experiences that you'd like to share?
Parent Interview Protocol (Active Participant)

Hi! My name is Colleen, and I'm looking forward to learning about your experiences as a parent of a child at _______ High School. Specifically, I'm interested in learning about extracurricular activity participation of high school students with disabilities, but most of all I want to know about your personal experiences as a parent. Today I'm going to be asking you to tell me your story. I will be asking you questions I have arranged in advance, but mostly the questions are to make sure I hear the most I can about your experiences. Finally, I need to emphasize that I will judge you based on any of your responses. I'm very interested in what you have to say and value your experiences. You can choose to end the interview at any time if you so choose. You can also choose not to answer certain questions if you don’t feel comfortable. I will keep your name confidential and everything that we will talk about will be kept private and confidential. Do you have any questions before we begin?

I. General Overview Questions
   1. How many children do you have?
   2. Where does ________ fall in the birth order?
   3. Tell me about ________’s experience in school so far. What has school been like for him/her?
   4. Does ________ like school? Why or why not?
   5. Do you think it's important for ________ to like school?

II. School Participatory Experiences
   1. When you were in school, were you active in extracurricular activities?
      a. If yes: Tell me about your experiences.
      b. If no: Why not?
   2. Do you think it is important for your children to participate in extracurricular activities? Why/why not?
   3. What have ________’s experiences in extracurricular activities been like?
   4. What role have you played in ________’s selecting and participating in activities?
   5. What factors do you think have influenced ________ as he/she has decided to participate in activities?
   6. If there are siblings: What kind of role do you think ________’s brothers/sisters have played in ________’s participation in school activities?
      a. Do ________’s siblings participate in activities?
      b. Are there differences in the way you approach parenting for ________ in comparison to your other children?
   7. What do you think makes ________ choose to continue to participate?
   8. Are there activities that ________ participates in outside of the school setting?
      a. If yes: What factors have led to participation in these activities?
   9. Are there activities outside of school that you participate in as a family?
      a. If yes: What things do you like to do together?

III. Friendships/Peers
   1. Tell me about ________’s friendships at school.
2. Has ____________ had steady friendships over the years?
3. Does ____________ get together with friends from school?
   a. If yes: How frequently?
      How often does ________ use Facebook, talk on the phone, text...?
   b. If no: What is ________’s main source of social interaction with friends
      and peers? (Talking on the phone, texting, Facebook...)
4. Does ____________’s disability affect the types or quality of his/her relationships?
   In what ways?

IV. Additional Impacts of Disability
1. Do you think that ____________’s disability has impacted his/her participation?
   a. If yes: In what way?
   b. If no: What other factors have influenced participation?
2. What supports (if any) have been influential in your child's participation?
3. Are there barriers that ____________ has experienced as a result of his/her
disability?
4. Are there barriers that you have experienced as a result of ________’s disability?
5. What do you think ____________’s role in the family is?
   a. If there are siblings: Is the role different than that of his/her siblings?
6. Has this role changed over time?
   a. If yes: In what ways?
7. Do you think that ____________’s disability has impacted your family? How so?

V. School
1. Tell me about your experience as a parent of a student with a disability at
   ____________ High School.
2. How have your experiences with teachers, administrators, coaches and program
   leaders impacted decisions about ____________’s participation?

VI. Support
1. Are you familiar with other parents and families who have similar experiences to
   yours?
2. Do you feel like you have support from others in your daily life?

And finally, what else do you want me to know about ________ before we end this interview?
Are there other experiences that you'd like to share?
Appendix F: OSURR Documentation

SCHOOL RESEARCH FORM
OFFICE OF SCHOOL-UNIVERSITY RESEARCH RELATIONS

Researcher’s name, college affiliation, and contact information:

Colleen Gibbons
College of ACES, Department of Human and Community Development
147 Early Child Development Laboratory
1005 W. Nevada
Urbana, IL 61801
(217) 778-7780
cgibbon2@illinois.edu

Title of project:
School-based Extracurricular Activity Participation of High School Youth with Disabilities

Brief summary of project and abstract of procedure:

The objective of this research is to examine the participation of high school students with disabilities in extracurricular school-based activities. While there is a large body of literature examining school-based youth program participation of non-disabled youth, very little is known about the participation habits of youth with disabilities, particularly youth with disabilities who are often in classes with their non-disabled peers.

This study will be the first known application of an integrated model incorporating the social-relational approach to disability with family systems theory. This model allows us to examine youth participation not only from a school and social perspective, but through the perspective of parents and family. Exploring the participation of high school youth with disabilities will provide greater insight into their lives and contribute to the sparse literature on after school participation for youth in this population.

Results from this study will inform researchers, administrators, youth leaders, and policy makers on the participation and experiences of high school youth with disabilities. It will provide insight into their relationships and support, potentially providing for new avenues of participation or ways to reach this often overlooked population.

Students with disabilities at fifteen Central and East Illinois high schools will complete a survey explaining their choice of participation, and what their participation desires and needs look like. Some of these same students will then participate in in-depth interviews, to further expand upon and clarify what they want as far as participation, options they already have, and how they feel about participation. Parents (one parent for each child interviewed) will also be interviewed, to help elaborate on the family role in participation, as well as explain parent experiences.

Additionally, at each of the fifteen high schools, youth program leaders and coaches will complete a survey, explaining their background with youth programs, their training with youth with disabilities, and their comfort levels with integrated youth programs.

Anticipated duration of school’s involvement in project:

from: September 2011 to: May 2012
If research involves students:

grade levels needed: high school (9-12)

total number of students needed at each grade level: students with IEPs/504 plans - no specific number

time needed (per subject/respondent): 15 minutes per student for the survey, if interviewed, one additional hour

If research involves teachers, administrators, parents, or other non-students:

number of subjects/respondents needed: all teachers who are current coaches or program leaders, also, parents of children with IEPs/504 plans

time needed (per subject/respondent): 15 minutes per teacher for the survey; 15 minutes for parent surveys, one hour for parents participating in interviews

Special considerations (kinds of students, classrooms, etc.):
I am specifically interested in youth with intellectual disabilities, learning disabilities, autism, and other non-physical disabilities. I will only recruit students who are currently mainstreamed/included with their non-disabled peers in at least one class.

Information needed from the cooperating teacher, school, or district:
The schools will create a list of potential participants, and distribute consent forms to parents (either by hand or via the USPS).

Schools will provide space to conduct student interviews.

Schools will provide a contact list (e-mail addresses) for coaches/youth program leaders.

Potential benefits to participating school(s):

By understanding how and why youth with disabilities do and do not participate, we may be better able to outline pathways to improve extracurricular youth programming within school districts of varying sizes and socioeconomic levels. Historically, youths with disabilities haven't been given the opportunity to share their experiences with program participation; this research gives such youth, and their parents, a voice.

Additionally, program leaders and coaches are given the opportunity to share their experiences and perspectives.

Questions? Contact OSURR at 217-333-3023 or Anne S. Robertson at arobritsn@illinois.edu